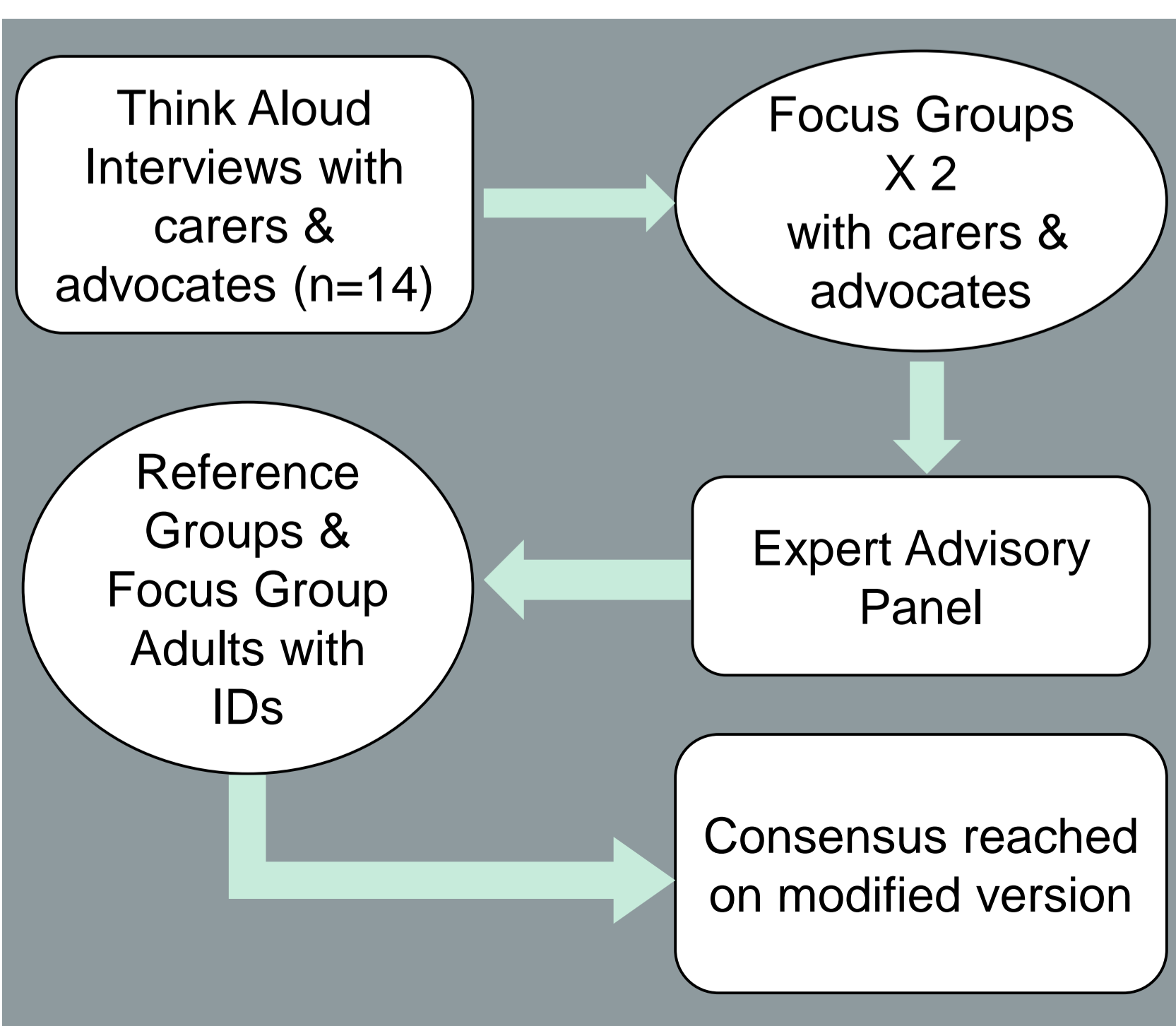


OBJECTIVE

Approximately 7.4 million people in the USA have an intellectual disability (ID). (1) This population experience some of the greatest health inequalities, losing almost 20 years of life compared to the general population. (2) People with IDs are often excluded from research by design or lack of reasonable adjustments, and self-reported health status/quality of life (QoL) questionnaires such as the EQ-5D are often not appropriate for this population. (3) We systematically examined the EQ-5D-3L (its wording, content, and format) using qualitative methods to inform the adaption of the measure for use with adults with IDs. A modified EQ-5D-3L was developed for adults with mild to moderate IDs and then tested with the target population to examine the measure's acceptability, validity and reliability.

DEVELOPMENT: Methods

Development took place over five stages. (i) Think Aloud interviews were undertaken to explore the difficulties with completing the EQ-5D-3L; (ii) Focus groups validated the interpretation of interview data; (iii) A workshop was held with a project advisory panel consisting of stakeholders and academics researching in the area of ID and measuring QoL; (iv) An iterative process of discussion and image design with an NHS intellectual disability information designer and reference groups of adults with ID; (v) Consensus on any final amendments to the proposed modification was reached with all co-authors.



DEVELOPMENT: Results

The dimensions and levels within the EQ-5D-3L were deemed appropriate for adults with mild to moderate IDs. Through an iterative process, consensus on wording, structure and images was reached and the modified version of the EQ-5D-3L was finalised. **The Modified EQ-5D-3L:**

Walking about

Which one describes you best?
Thinking about TODAY

Looking after myself

Looking after myself?
Thinking about TODAY

Doing things I want to do

Doing things I want to do
Because of how I am TODAY ...

Pain

Pain
Thinking about TODAY

Feeling worried, sad or unhappy

Feeling worried, sad or unhappy
Thinking about TODAY

Adapted EQ-VAS

We would like to know how you are TODAY.
If 10 is the BEST you could be and 0 is the WORST (bad) you could be, which number shows how you are TODAY?

This is a modified EQ-5D.
© EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation. Reproduced by permission of EuroQol Research Foundation. Reproduction of this version is not allowed. For reproduction, use or modification of the EQ-5D (any version), please register your study by using the online EQ registration page: www.euroqol.org

TESTING: Methods for assessing reliability and validity

Staff from third-sector advocacy groups identified clients with IDs as potential participants for referral. Participants completed the EQ-5D-3L and the modified EQ-5D-3L twice within a four-week period, with the order of completion randomised.

The level of support required was systematically recorded, and an interviewer-completed ease-of-completion form captured the face validity of the modified version, thus reflecting the level of comprehension. Participants also completed a single self-rated health question (5-point category rating).

Acceptability was assessed by examining levels of missing data and participants' version preferences. Statistical analyses were conducted to assess the validity and reliability of the different outcome measure.

TESTING: Results

Between September 2020 and June 2021, 64 adults with IDs from across England consented to participate. All participants were interviewed twice, online, using Zoom. Each second interview took place within four weeks.

Table 1: Preferred EQ-5D-3L

Preferred	MODIFIED EQ-5D-3L	STANDARD EQ-5D-3L	BOTH	NONE
T1	82%	9%	9%	-
T2	84%	6%	6%	4%

VALIDITY

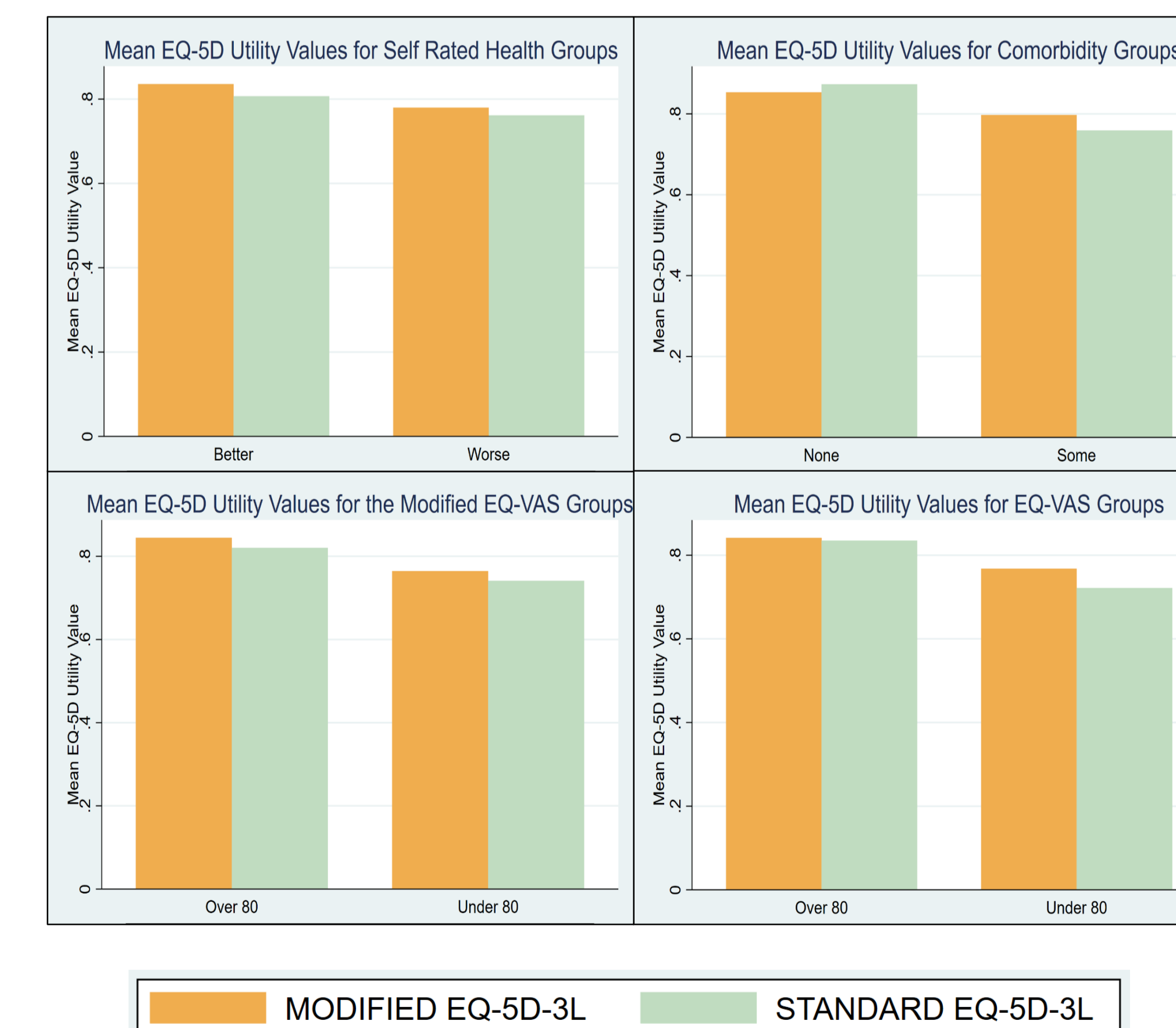
A logistic regression model was used to test the construct validity of the modified EQ-5D-3L by examining its ability to differentiate between known groups, i.e. the likelihood of choosing a worse response option in that domain. Table 2 shows which domains were predictive of being in better or worse health. Table 3 shows the differences in utility values obtained from these different EQ-5D-3L versions.

Table 2: Known-groups analysis per domain, by version of EQ-5D-3L

DOMAINS	MODIFIED EQ-5D-3L					STANDARD EQ-5D-3L				
	MO	SC	UA	PD	AD	MO	SC	UA	PD	AD
SELF-RATED HEALTH: Better or Worse	✓	✗	✓	✓*	✓*	✓*	✗	✗	✓*	✓
COMORBIDITIES Some or None	✓	✗	✓	✓*	✓*	✓	✓	✓	✓*	✓*
EQ-VAS <80 or >80	✓	✓	✓*	✓*	✓*	✓*	✓	✓*	✓*	✓*
Modified EQ-VAS <8 or >8	✓	✓	✓	✓*	✓*	✓*	✗	✓	✓*	✓*

✓ Positive association; ✗ Negative association ; *p< 0.05

Table 3: Comparative bar graphs of EQ-5D utility values using two versions of EQ-5D-3L for known groups



RELIABILITY

Test-retest reliability was estimated using Kendall's tau. Table 4 shows the strength of the agreement between domains at timepoint 1 and timepoint 2. Each domain had statistically significant results; however, three domains in the modified version showed stronger test-retest reliability than the standard EQ-5D-3L.

Table 4: Test re-test reliability at domain level using Kendall's tau: Timepoint 1 vs Timepoint 2

Domains	MODIFIED EQ-5D-3L	STANDARD EQ-5D-3L
Mobility	0.81*	0.54*
Self Care	0.70*	0.70*
Usual Activities	0.46*	0.28*
Pain/Discomfort	0.59*	0.43*
Anxiety/Depression	0.34*	0.64*

* Correlation is significant at the 0.05 level

CONCLUSIONS

- Adults with IDs and their carers/supporters have assisted in designing this modified EQ-5D-3L.
- The modified EQ-5D-3L was well-accepted by participants and easier to administer and understand.
- The suitability of this modified EQ-5D-3L for use by the target population has been demonstrated in terms of its validity, reliability, and acceptability.
- EuroQol has approved the content of this adaptation, classifying it as a "Modified EQ-5D".
- Assessing the extent to which valuations of health states using a modified EQ-5D-3L correspond to the previously established measure is necessary.
- Research is underway to assess the potential use of this modified version for economic evaluation.

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