

Developing a Dutch PROPr value set: study design and lessons learned

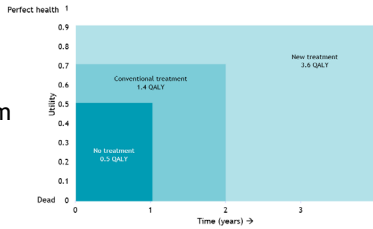
Ellen BM Elsman¹, Michiel AJ Luijten¹, Judith E Bosmans², Caroline B Terwee¹, Janel Hanmer³ & Benjamin D Schalet¹

¹Epidemiology & Data Science, Amsterdam UMC, Amsterdam, the Netherlands; ²Department of Health Sciences, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands; ³Division of General Internal Medicine, University of Pittsburgh, Pittsburgh, PA, USA

✉ Ellen Elsman: e.elsman@amsterdamumc.nl

Introduction

- Preference-based instruments can be used to estimate Quality-Adjusted Life-Years (QALYs)
- The PROMIS Preference scoring system (PROPr) was developed in 2018¹
- To date, only a US value set exists



We aimed to develop a **Dutch PROPr value set** to address the unique health utility values reflective of the Dutch population, **following and improving the US blueprint**

Methods

PROPr was developed using online preference elicitations through standard gamble methods, and is based on multi-attribute utility theory (MAUT)²

1. Replicating the US blueprint:

- Reviewing PROPr technical report and publications
- Consulting US-based PROPr developers
- Translating the standard gamble valuation survey

2. Improving the US blueprint:

- Pre-testing with three Amsterdam UMC research groups
- Pilot testing with our network using think-aloud methods

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Cognition					
I have been able to concentrate...	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have been able to remember to do things, like take medicine or buy something I needed...	Not at all	A little bit	Somewhat	Quite a bit	Very much
Depression					
I felt unhappy...	Always	Often	Sometimes	Rarely	Never
I felt that nothing was interesting...	Always	Often	Sometimes	Rarely	Never
Fatigue					
How often were you too tired to take a bath or shower?...	Always	Often	Sometimes	Rarely	Never
How often did you feel tired?	Always	Often	Sometimes	Rarely	Never
Pain					
How often was your pain so severe you could think of nothing else?...	Always	Often	Sometimes	Rarely	Never
How often was pain distressing to you?...	Always	Often	Sometimes	Rarely	Never
Physical					
Are you able to dress yourself, including tying shoelaces and buttoning up your clothes?...	Unable to do	With much difficulty	With some difficulty	With a little difficulty	Without any difficulty
Are you able to run 100 yards (100 m)?...	Unable to do	With much difficulty	With some difficulty	With a little difficulty	Without any difficulty
Sleep					
I got enough sleep...	Never	Rarely	Sometimes	Often	Always
I woke up too early and could not fall back to sleep...	Always	Often	Sometimes	Rarely	Never
Social Roles					
I have trouble taking care of my regular personal responsibilities...	Always	Usually	Sometimes	Rarely	Never
I have trouble participating in recreational activities with others.	Always	Usually	Sometimes	Rarely	Never

← DIF item³ replaced with the item "I felt sad..."

Results

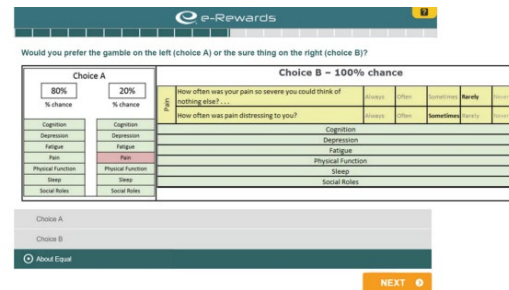
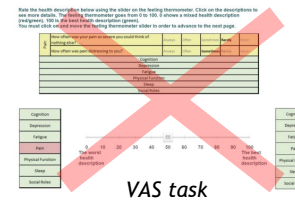
- Pretesting (n=27 researchers) resulted in improvements in instructions and visual presentation
- Based on the results of pilot testing (n=21) we:

Rewrote the instructions to make them clearer

Further refined the visual presentation of the standard gamble task

Deleted the VAS task as warm-up exercise because they were not helpful for understanding the standard gamble task

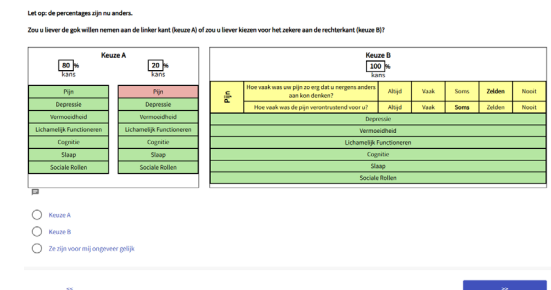
Moved the PROMIS questionnaire items to the end of the survey



Original US standard gamble task

Pilot study participant characteristics (n=21)

Male sex, n (%)	9 (42.9)
Age, mean (SD) [range]	45.6 (14.9) [25-71]
Dutch nationality, n (%)	20 (95.2)
Educational level, n (%)	
Low	3 (14.3)
Middle	6 (28.6)
High	12 (57.1)
Health conditions, n (%)	
Asthma/bronchitis/emphysema/COPD	1 (4.8)
Osteoarthritis	1 (4.8)
Rheumatic disease or complaints	2 (9.5)
Cancer	1 (4.8)
Mental or psychiatric disorder	2 (9.5)
Other	4 (19.0)
No health problems	11 (52.4)
EQ-5D index, mean (SD) [range]	0.93 (0.09) [0.74-1.00]
ED-VAS score, mean (SD) [range]	85.6 (9.2) [65-100]
PROMIS T-scores, mean (SD) [range]	
Physical Function	54.5 (6.7) [39.2 - 60.6]
Pain Interference	46.7 (7.0) [40.6 - 59.3]
Fatigue	42.8 (6.4) [31.0 - 51.2]
Anxiety	48.9 (7.8) [40.3 - 61.7]
Depression	45.7 (8.9) [38.4 - 59.7]
Cognitive Function - Abilities	56.0 (7.7) [42.0 - 66.6]
Sleep Disturbance	44.2 (6.4) [33.6 - 59.7]
Ability to Participate	58.1 (7.2) [45.1 - 65.1]
Inadequate health literacy (SBSQ), n (%)	0 (0.0)
Inadequate health numeracy (NVS-D), n (%)	2 (9.5%)



Improved Dutch standard gamble task

Conclusion

Pre- and pilot testing resulted in **improvements in the standard gamble instructions and visualization**, yet the task remains **complex**.

Following the US blueprint we will conduct the Dutch valuation study in a representative sample (n=1300) recruited via an internet panel.

References:

- DeWitt et al. Estimation of a Preference-Based Summary Score for the Patient-Reported Outcomes Measurement Information System: The PROMIS-Preference (PROPr) Scoring System. Medical Decision Making (2018).
- Keeney & Raiffa. Decisions with Multiple Objectives: Preferences and Value Tradeoffs. New York: Wiley (2003)
- Elsman et al. Towards standardization of measuring anxiety and depression: Differential item functioning for language and Dutch reference values of PROMIS item banks. PLOS ONE (2022).