A new approach for creating personal and social EQ-5D-5L value sets: provisional results from development and pilot-testing in New Zealand

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OBJECTIVES

The EQ-5D has been expanded to include a version with five levels of severity on the dimensions. We describe here a new approach for creating EQ-5D-5L value sets based on the PAPRIKA method[1] and two methods for valuing dead, implemented using 1000minds software.[2] A social value set, and personal value sets for each participant were produced.

METHODS

An online survey with four parts was developed, mostly implemented using 1000minds software. The main part comprised a discrete choice experiment (DCE) based on the PAPRIKA method where participants were presented with a series of pairwise comparisons based on two dimensions of the EQ-5D described on two levels involving a trade-off (Fig. 1). The first, third and fifth levels of each dimension were presented in the DCE; the weights for the second and fourth levels were calculated using Bézier interpolation. To test the reliability of each participant's responses, two questions were repeated at the end of the DCE. Participants were also asked questions to identify health states worse than dead, using two methods (Figs. 2-3). Finally, participants were asked about their demographic characteristics and for feedback on the survey, including the DCE and dead-valuation methods.

To test the feasibility and acceptability of the DCE and dead-valuation methods, and to explore the factors people consider when making their choices, a 'think aloud' approach was used.[3] A convenience sample of 12 participants individually attended a one-hour session where, in the presence of two interviewers, they completed the survey and verbalised their thoughts as they did so. The interviewers then clarified any issues raised, and asked follow-up questions.

To pilot-test the survey, emails were sent to a non-representative sample of participants with an invitation to complete the survey and forward the survey link to others.

PARTICIPANT FEEDBACK FROM THINK-ALOUD SESSIONS

Fig. 1: Screenshot of a pairwise-ranking question from the DCE

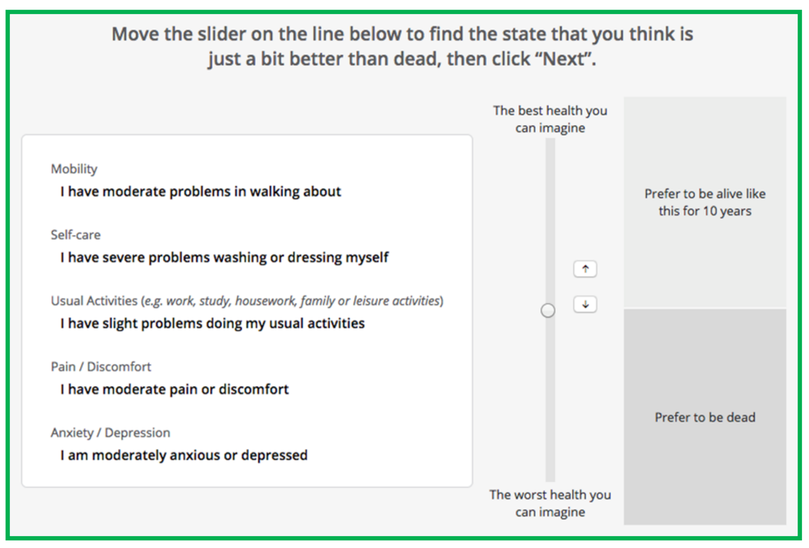

Fig. 2: Screenshot of a question to value dead using a visual analogue scale (VAS)

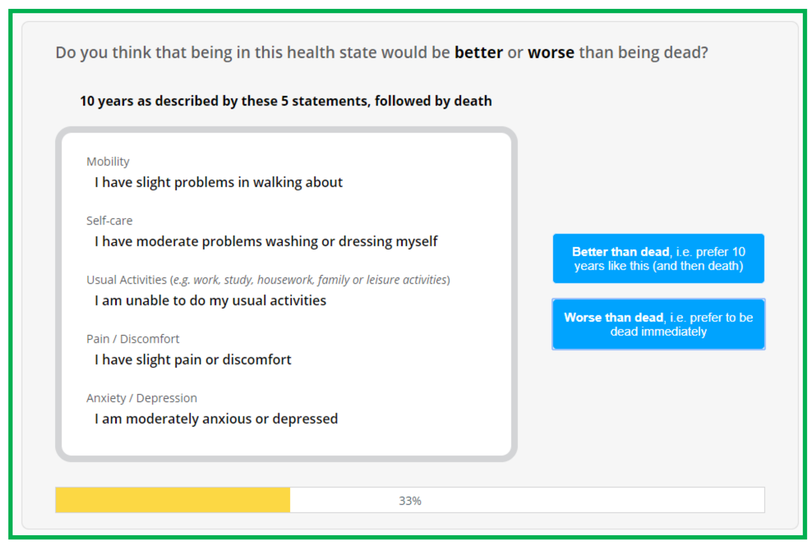

Fig. 3: Screenshot of a question used to value dead

1. Comparing health states / PAPRIKA

- Easily understood layout / instructions
- Repetition, not noticing change of question
- Implausible health states
- When making decisions, considered possible treatments to alleviate condition, e.g. pain relief

2. Using VAS to find the value for dead

- Very challenging for some participants to understand
- Some responses contradicted verbally-stated preferences
- Confronting / difficult to think about

3. Locating dead in the descriptive system

- Easily understood
- Confronting / difficult to think about

SNOWBALL SAMPLE

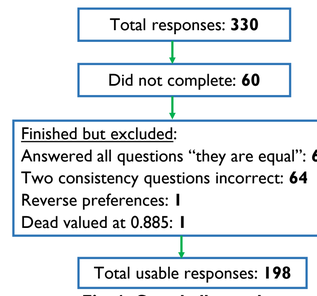

Fig. 4: Snowball sample

Characteristic	Number (%)
Age	
18-34	110 (55.5)
35-54	45 (22.7)
55+	43 (21.8)
Gender	
Male	62 (31.3)
Female	135 (68.2)
Gender Diverse	1 (0.5)
Ethnicity*	
New Zealand European	165 (83.3)
Māori	12 (6.0)
Pacific	2 (1.0)
Asian	10 (5.0)
Other	27 (13.6)
Education	
No quals/sec school	23 (11.6)
University degree or equiv	152 (76.8)
Other post-secondary qual	23 (11.6)
Individual income	
$30,000 or less	67 (33.9)
$30,001 to $70,000	81 (40.9)
$70,001 to $100,000	30 (15.2)
$100,000 or more	16 (8.0)
Did not answer	4 (2.0)
Long-term disability	
Yes	27 (13.6)
No	171 (86.4)
Self-rated EQ-5D-5L	
11111	57 (28.8)
Slight probs in 1 dimension	55 (27.8)
Slight probs in 2 dimensions	28 (14.1)
Mod probs in 1 dimension	8 (4.0)
Any other state	50 (25.3)
Self-rated EQ-VAS	
<69	18 (9.1)
70-89	111 (56.1)
90-100	69 (34.8)

* Adds to >100% as can identify with more than one ethnicity

Table 1: Demographic characteristics of participants

VALUE SET RESULTS FROM THE PILOT STUDY

EQ-5D-5L dimension	Mean weight
MOBILITY	
I have no problems in walking about	0.14
I have slight problems in waking about	0.09
I have moderate problems in walking about	0.02
I have moderate problems in walking about	–0.07
I am unable to walk about	–0.18
SELF-CARE	
I have no problems washing or dressing myself	0.16
I have slight problems washing or dressing myself	0.11
I have moderate problems washing or dressing myself	0.04
I have severe problems washing or dressing myself	–0.06
I am unable to wash or dress myself	–0.18
USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*	
I have no problems doing my usual activities	0.21
I have slight problems doing my usual activities	0.16
I have moderate problems doing my usual activities	0.08
I have moderate problems doing my usual activities	–0.03
I am unable doing my usual activities	–0.18
PAIN / DISCOMFORT	
I have no pain or discomfort	0.23
I have slight pain or discomfort	0.17
I have moderate pain or discomfort	0.09
I have severe pain or discomfort	–0.03
I have extreme pain or discomfort	–0.18
ANXIETY / DEPRESSION	
I am not anxious or depressed	0.26
I am slightly anxious or depressed	0.19
I am moderately anxious or depressed	0.09
I am severely anxious or depressed	–0.03
I am extremely anxious or depressed	–0.18

Examples of value calculations:

11111:
0.14+0.16+0.21+0.23+0.26=1

33333:
0.02+0.04+0.08+0.09+0.09=0.32

55555:
–0.18–0.18–0.18–0.18–0.18=–0.9

Fig. 5: Value set for snowball sample (N=198)

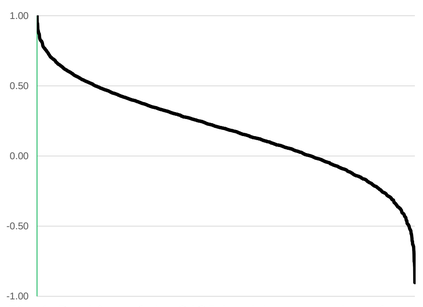

Fig. 6: Ranking of the 3125 health state values (means)

Survey aspect	Snowball sample (N=198)
Understanding instructions /survey design	n/(%)
Very Easy/Easy	151 (76.2)
Neutral	34 (17.2)
Very Difficult/Difficult	13 (6.6)
Choosing between two health states	
Very Easy/Easy	46 (23.2)
Neutral	40 (20.2)
Very Difficult/Difficult	112 (56.6)
Rank order of EQ-5D dimensions	
Correct	169 (85.4)
Incorrect	29 (14.6)

Table 2: Feedback on survey

PROVISIONAL FINDINGS

Feedback from the think-aloud sessions (1-3 above) related to the survey process rather than content, though most participants found the task of valuing dead confronting. As a result of the feedback, aspects of the survey (i.e. instructions, numbering, etc) were refined and a warning added about the sensitive nature of some of the questions, in particular valuing dead.

Of the 270 participants who completed the online pilot survey (Fig. 4 and Table 1), 200 answered the two repeated questions identically (consistently). The average number of trade-off questions answered was 22, with an average completion time for the entire survey of 14 mins (median 12 mins). Anxiety/depression was the most important dimension to participants on average, with mobility the least important dimension (Fig. 5). The unadjusted mean value for dead was 0.404 (median 0.465), with a mean adjusted value for 55555 of –0.903 (median –0.869) (Figs. 5 & 6).

More than 75% of participants found the survey instructions and design easy or very easy to follow, with 56% finding the choice questions difficult. More than 85% reported that the ranking obtained from the weighted dimensions was as they expected (Table 2).

NEXT STEPS ...

A representative sample of the New Zealand general public is currently being surveyed. In addition to creating EQ-5D-5L value sets (personal and social), the preferences of sub-groups will be explored, e.g. weights will be analysed according to characteristics such as age, gender, ethnicity, and health status.

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1. Hansen, P., Ombler, F. (2008), A new method for scoring additive multi-attribute value models using pairwise rankings of alternatives, *Journal of Multi-Criteria Decision Analysis*, 15, 87-107.
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3. Green, C., Gilhooly, K. (1996), Protocol analysis: Practical implementation, *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, 55-74.

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