Older adolescents valuing the EQ-5D-Y-5L and EQ-5D-5L: a feasibility and acceptability study

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OBJECTIVES

Exploring appropriate ways for young people to value their own health, including anchoring preference values on the 0-1 scale to estimate quality-adjusted life years (QALYs), is increasingly gaining attention. The objectives of this study were to explore the feasibility and acceptability of older adolescents valuing their health-related quality of life, including health states considered to be worse than dead, using an adapted version of the tool used in the New Zealand (NZ) EQ-5D-5L study[1] and to compare their preference weights across the youth and adult versions of the EQ-5D.

METHODS

An online valuation tool was created using 1000minds software[2] to value the EQ-5D-Y-5L and EQ-5D-5L respectively. The tool comprises an adaptive discrete choice experiment (DCE) based on the Potentially All Pairwise RanKings of all Possible Alternatives (PAPRIKA) method[3] and a binary search algorithm to locate 'dead' within each adolescent's full ranking of health states. Convenience sampling was used to recruit 24 NZ adolescents aged 16-19 years (13 female, 50% Māori). Each adolescent individually attended two think-aloud sessions (about a fortnight apart) where they completed two online DCE surveys in the presence of two researchers. One survey comprised the EQ-5D-Y-5L and the other, the EQ-5D-5L (Fig. 1), in random order. Both surveys included questions relating to health states worse than dead (Fig. 2). Paired t-tests were used to compare each participant's rankings of dimensions for each instrument. Individual EQ-5D-Y-5L and EQ-5D-5L weights (anchored at full health=1 and dead=0) were reported and Bland-Altman Plots used to graphically compare agreement between the measures.

RESULTS

There was no evidence of a difference ($p > 0.57$) in mean differences in preference weights (by dimension) across the youth and adult instruments, with observed mean differences small (diff ≤ 0.01) (Table 1). The overall ranking of dimensions was similar between the two instruments with Feeling worried, sad or unhappy/ Anxiety/depression 1st, Pain/discomfort and Usual activities 2nd or 3rd, Mobility 4th and Looking after myself/Self-care, 5th (Table 2). The mean value for dead (i.e. before rescaling for dead=0) was 0.410 for the EQ-5D-Y-5L and 0.417 for the EQ-5D-5L, 17.8% of the values were negative for the EQ-5D-Y-5L and 21.2% for the EQ-5D-5L, and the lowest values were –0.796 and –0.884 respectively. Adolescents were capable of trading-off health states, including states worse than dead.

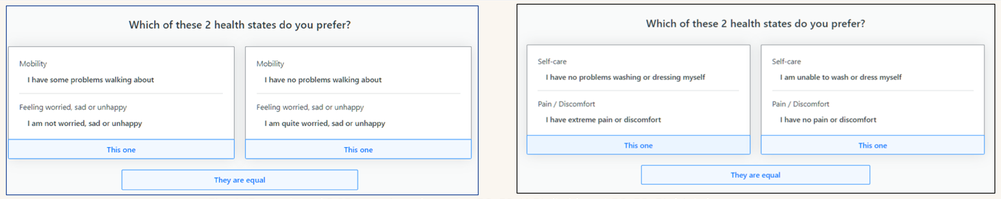

Fig. 1. Examples of DCE questions from the EQ-5D-Y-5L (left) and EQ-5D-5L (right) surveys

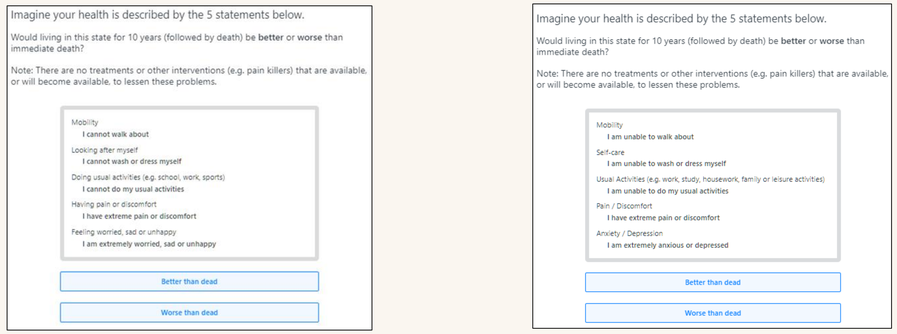

Fig. 2. Examples of binary-search questions for the EQ-5D-Y-5L (left) and EQ-5D-5L (right) to identify states worse than dead

EQ-5D dimension	(Youth – Adult)	p-value
Mobility (MO1)	-0.005 (-0.028, 0.017)	0.642
Looking after myself / Self-care (SC1)	-0.007 (-0.032, 0.018)	0.577
Pain/discomfort (PD1)	0.010 (-0.030, 0.050)	0.614
Usual activities (UA1)	0.001 (-0.031, 0.033)	0.958
Feeling worried sad or unhappy / Anxiety/depression (AD1)	0.001 (-0.032, 0.034)	0.938

Table 1. Paired t-tests showing the mean differences (95% confidence intervals) between dimensions on the EQ-5D-Y-5L and EQ-5D-5L

EQ-5D dimension	Mean DCE weights	
	EQ-5D-Y-5L	EQ-5D-5L
Mobility	0.174	0.179
Looking after myself / Self-care	0.157	0.164
Usual activities	0.214	0.213
Pain/discomfort	0.220	0.210
Feeling worried, sad or unhappy / Anxiety/depression	0.236	0.234

Table 2. Mean DCE weights for the EQ-5D-Y-5L and EQ-5D-5L

References

1. Sullivan T, Hansen P, Ombler F, Derrett S, Devlin N. A new tool for creating personal and social EQ-5D-5L value sets, including valuing 'dead'. *Social Science and Medicine* 2020;246:112707
2. Ombler F, Moller J, Paton K, Sherepa V, Hansen P, 2022. 1000minds [software]. https://www.1000minds.com.
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DISCUSSION The adolescents' value sets were compared with the NZ EQ-5D-5L value set to see how well their preferences align with the general population. The only difference in the overall ranking of dimensions is the switching in order of Usual activities (2nd or 3rd for adolescents; 5th for adults) and Self-care (5th for adolescents; 3rd for adults). Though ranked the same, adolescents place more weight on Anxiety/depression and Pain/depression. The mean (unscaled) value for dead is higher in both adolescent surveys (0.410 (Y), 0.417 (5L)) compared to the adult survey (0.338). The percentage of health states worse than dead is lower in the adolescent surveys (17.8% (Y); 21.2% (5L)) compared to the adult survey (25%), and closer to those reported in other EQ-5D-5L studies[1]. Determining the extent to which the adolescents' HRQoL preferences differ between the EQ-5D-Y-5L and the EQ-5D-5L can provide some insight into how well the instruments transition in measurement terms, something to consider when using the EQ-5D across childhood into adulthood. In this study, the differences in mean preference weights for the EQ-5D-Y-5L and EQ-5D-5L were small and the ranking of dimensions similar – which is promising – though further research is required.

CONCLUSION It is both feasible and acceptable to elicit health state preferences of older adolescents anchored at 1 and 0 as required for QALY estimation. There was no evidence of a difference in preferences (by dimension) across the two surveys. Completing the survey in a supportive environment likely enhances data quality, an aspect that is being investigated in ongoing research.

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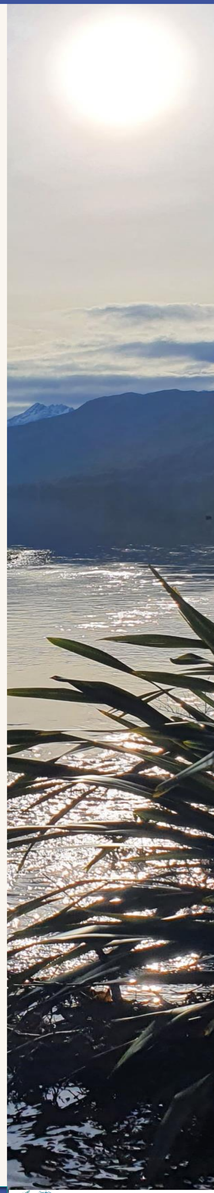

EQ-5D