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Research highlights

- Health state valuation relies on one-off interviews that do not give participants time to reflect on their preferences. Research has shown that deliberation can affect health state values but this has not been conducted using the Time Trade Off and the EQ-5D. We examined the effect of reflection and deliberation on health state preferences
- Large changes in individual level values cancelled out at the aggregate level and deliberation focused on personal beliefs and not objective knowledge exchange
- Participants were uncertain about the relevance of their experience and values
- The mixed methods design used is promising to help elucidate research findings

Concise summary

- Reflection and deliberation exercise did not change aggregate level health state values but participants were uncertain about the relevance of their experience and their values

Abstract:

Background: Health economists ask members of the general public to value health states, but it is recognised that individuals construct their preferences during the valuation tasks. Conventional methods rely on one-off interviews that do not give participants time to reflect and deliberate on their preferences.

Methods: This study investigates the effect of reflection and deliberation on health state preferences using the EQ-5D questionnaire and Time Trade Off valuation method. A novel concurrent explanatory mixed methods design is used to investigate the explanation for the quantitative findings.

Results: A total of 57 participants in the UK valued health states before and after a group-based deliberation exercise. There were large changes in health state values at the individual level but the changes cancel out at the aggregate level. The mixed methods findings suggest deliberation did not reveal new information or reduce inconsistencies in reasoning, but rather focused on an exchange of personal subjective beliefs. In cases of disagreement, the participants accepted but did not adopt other participants' opinions. Participants remained uncertain about the relevance of their experiences and about their values.

Conclusions: The evidence suggests that reflection and deliberation, as designed in this study, is unlikely to result in large systematic changes of health state values. The uncertainties expressed by participants means future research should investigate whether preferences are informed or whether providing participants with more information helps them construct their preferences with more certainty. The mixed methods design used is a promising design to help elucidate the reasons for quantitative findings.

Keywords: mixed methods, reflection, deliberation, MCDA, health state valuation

1 Introduction

Debates remain about preference-elicitation methods used to value the benefits of health care. In the economic evaluation implemented by NICE and other agencies the benefits of health care are measured in QALYs (1). One QALY represents one year of full health and various methods can be used to determine 'quality weights' for health states less than full health (2). To determine these weights NICE recommends the use of preference elicitation tasks (3).

The literature on preference construction has raised questions about preference-elicitation tasks (4). Economists tended to assume that participants have a set of preferences that can be elicited (4-6), but increasingly accept that preferences over some domains may be constructed during the process of elicitation (7, 8). Preference elicitation tasks are likely to contain preference construction in domains that are complex and unfamiliar (4, 7).

Health state valuation is a complex and unfamiliar task. The task is complex because participants are asked to consider many aspects of health in addition to survival durations (2). The task is unfamiliar because individuals do not generally face these choices in their daily lives (4, 9). This has previously led into investigating the completeness and reliability of preferences (10). Despite early concerns based on findings of potentially incomplete preferences health states are still conventionally valued using one-off interviews (2), which may not give participants enough time to reflect on the process of valuing health, nor any opportunity to discuss their views with others (2). Such preferences may not be well-constructed and not adequate to be used for public resource allocation.

One method advocated to help participants construct their preferences is the use of reflection and deliberation (4, 11-13). Two reasons for why deliberation may be useful are to reveal novel information not known to all participants and to reduce mistakes in reasoning (14). The use of deliberative methods has been advocated in health policy as decisions

become increasingly more complex and involve multiple stakeholders(15). Qualitative research has shown that various factors, such as an individual's beliefs on the effect of ill health on their family and an individual's experience of ill health are relevant when valuing health (16-18). Reflection allows the public to think about the relevant factors when valuing health and deliberation allows the public to make use of the experience and knowledge of other people.

Previous studies on reflection and deliberation have shown mixed results. After a review of the literature the authors are aware of four studies that have shown that some health state values change after reflection and deliberation (19-22), but one study reported the opposite result (23). None of the five studies used a prominent health state valuation technique, the Time Trade Off (TTO), alongside a prominent method of describing health, the EQ-5D (24).

To interpret the quantitative effect of reflection and deliberation correctly requires understanding the reason for that effect. For example, no change in preferences after reflection and deliberation could be because important aspects of participants' preferences were not discussed or because participants were certain of their preferences prior to deliberation. Explaining the quantitative findings will require the use of qualitative data and therefore mixed methods is an ideal design for this study (25).

The aim of this paper is to assess and to explain the effect of providing members of the public with an opportunity to engage in reflection and deliberation on their health state preferences measured using the TTO and EQ-5D. In explaining the quantitative findings, this paper will also be a demonstration of mixed methods in health economics.

2 Methods

Reflection and deliberation were conducted in several group meetings and were implemented using a Multi Criteria Decision Analysis (MCDA) task. The effect of reflection and

deliberation was measured by comparing the TTO valuations of the participants before and after the group meetings (26). An explanatory concurrent mixed design was used, meaning that quantitative and qualitative data were collected at the same time and the qualitative data was collected to help interpret the quantitative findings (27). The triangulation protocol was used to integrate the qualitative and quantitative component where both components are analysed separately and two sets of findings are developed (25). The two findings are then compared to "consider where findings from each method agree (convergence), offer complementary information on the same issue (complementarity), or appear to contradict each other (discrepancy)" (25).

Participants

Members of the general public were recruited from the University of Sheffield staff and students; from an online directory of voluntary, community, faith sector, and health or social care organisations in Sheffield (28); and by using the snowball method (29). Recruiting was conducted using email and newsletter advertisements. Participants received £15 for participating in the group meeting. The ScHARR Ethics Committee approved the study. A priori there was no reason to prefer a homogenous or a heterogeneous group composition, because homogenous background characteristics facilitate discussion but reduce range of experiences (30)) and thus participants were assigned to the groups based on their availability and not recruitment method.

The design of the group meeting

Each group meeting contained several stages: the introduction, the first TTO booklet, reflection implemented using the Multi Criteria Decision Analysis (MCDA) booklet, a rest break, deliberation using the MCDA booklet, and the second TTO. All participants

individually completed the TTO and MCDA booklets. Before the TTO, participants completed the EQ-5D-5L for their own health and a ranking exercise to familiarise the participants with the health states. The TTO was implemented using the self-completion method using pen and paper (31, 32). Participants valued six health states and a practice health state, which were hand-picked to cover a range of severities. During the second TTO exercise participants were not provided with their initial answers.

MCDA is a systematic process that assists individuals in choosing between options when there are conflicting criteria (32). MCDA was used to structure the group meeting with the intention of making the group meeting more productive than an unstructured group meeting (33). MCDA attempts to guide participants to develop their preferences over health states from more general values, which is recommended in the preference construction literature (4). MCDA was implemented as a self-complete booklet and focused on assessing six consequences of ill health. A previous study identified that individuals find six consequences important when valuing health (enjoyment, relationships, independence, dignity, avoiding being a burden, and activities) (18). These consequences describe what life would be like in ill health, and are thus closer to quality of life domains than health domains (34). Participants scored six health states, 'Dead', and '11111' on six consequences on a scale of 0 to 100, with the best and worst imaginable options as anchors. This step encouraged participants to reflect on how life with ill health would be like. Participants weighed the consequences by selecting the most important consequence and giving it a score of 100, and scoring all other consequences relatively to that consequence (35). This step encouraged participants to reflect on how important the consequences are for them.

After the scoring and weighing exercises there was a period of deliberation where participants discussed their responses to the MCDA booklet. The TTO values of the participants were not shared with the participants. The deliberation allowed participant to

explore other participants' beliefs about the consequences of ill health and to learn from other participants' experiences with ill health. The facilitator emphasised that participants did not have to reach consensus.

Quantitative analysis

The aggregate level analysis assessed the effect size and statistical significance of the difference between the pre and post valuations (36). Cohen's d was used to measure the effect size (small: 0.2, medium: 0.5, and large: 0.8) (37).

The number of changes at the individual level and the number of changes that were more than an absolute value of 0.1 were calculated. The proportions of participants who considered a state better or worse than dead before and after were compared (36). The proportion may be important because methods for valuing health states better or worse than dead are different (31). Participant's tendency to consider adaptation may change (2, 38). This tendency was measured by calculating whether all of a participant's health state values increased or decreased. Data analysis was conducted in R (39).

Explanatory qualitative analysis

The qualitative data consists of the audio recordings of the group meetings that were transcribed verbatim. Four steps were followed. At each stage, the lead author proposed the initial analysis but discussed and revised the analysis jointly with other authors. First, Framework analysis was used for qualitative data analysis of the transcripts (40). The transcripts were reviewed and each idea was coded, these codes were organised into themes, and the themes were applied to all transcripts.

Second, for most themes narrative summaries were conducted. The theme of 'participants view on the health states' was summarised by quantifying all the qualitative data to be able to

determine the degree of favourable discussion of a health state. Each mention of a health state was classified as positive or negative. The total number of negative mentions was subtracted from positive mentions and this number was ranked from highest to lowest.

Third, a quantitative hypothesis for each theme was proposed. Each summary of each theme was reviewed and a hypothesis was developed about what the likely quantitative changes to preferences would be and this hypothesis was tested. Testing these hypotheses integrates the qualitative and quantitative components by providing quantitative predictions based on qualitative findings, and can indicate the convergence, complementarity, or discrepancy between the two components (25).

3 Results

Sample description

A total of 62 participants took part in this study. The participants' background characteristics are described in Table 1. A total of 13 group meetings were held in 2014 (group size ranged from 2 to 7 with a mode of 6), with each meeting lasting about two hours. Out of the 62 participants, 57 fully completed the entire process. Five participants did not complete the TTO booklets correctly and the TTO data for these five participants were entirely removed.

[Table 1 approximately here]

Quantitative results

Most participants changed their health state values after the group meeting (on average, 75% of participants changed their values and 72% of the changes were greater than an absolute value of 0.1, see Table 2). The changes in health states values after the group meeting range from -0.058 to 0.04 with a mean absolute value of 0.03 (Table 2). After the

group meeting the ordinal ranking of the health states 44535 and 44553 reversed. The effect sizes of the changes for the health states are considered below 'small'.

[Table 2 approximately here]

Overall, the individual level results indicate little systematic change in the health state values. For most health states the number of participants who increased or decreased their valuation after the group meeting are similar. Participants who initially valued a state better or worse than dead also tended to do so after. The hypothesis that the proportion of states better or worse than dead is equal after group discussion cannot be rejected. Overall participants also did not change willingness to trade between the quality and quantity of life because for 8 of 57 participants changes in valuation were all in a positive and for 10 participants all in a negative direction.

Explanatory qualitative results

Five themes were found in the qualitative data. In all quotes the words 'ED', 'YM', 'IR', 'YC', 'GY', 'AU', 'NA', and 'UI' refer to arbitrary chosen labels for the health states.

Theme 1: agreement or disagreement

This theme covered all mentions of participants agreeing or disagreeing with each other. The disagreements amongst participants could be categorised as 'reaching agreement', 'agree to disagree', or 'ignored'. Sometimes participants reached agreement so that at least one participant changed their mind:

> *I didn't really think about the anxious and depressed really… I was thinking, dignity didn't really have a big role in anxious and depressed, but now they said it, I kind of agree with what they said. (Group 6, P3)*

Sometimes participants agreed to disagree, and participants acknowledged but maintained their disagreement:

P3: See I have a total different experience a couple years back when I was ill and....uhh you didn't see anybody for dust. Both friends and family. (Group 2)

Disagreements could also be ignored. In the following dialogue the third participant to speaker moves away from the disagreement over the effect of anxiety and depression on being a burden to the definition of burden and whether it includes wider society:

P1: I didn't really think about being anxious and depressed as being a burden on other people.

P4: I think sometimes if you're anxious or depressed you can't, you can't make any decision at all, you can't think straight

P5: I think I was thinking as well about being a burden on society sort of thing (...) (Group 3)

Of all instances of disagreements during the group meetings 19 (58%) were classified as 'agree to disagree', 9 (27%) as 'ignored', and 5 as 'reaching agreement' (15%). There is thus little evidence that deliberation encouraged participants to re-solve contradictory beliefs, rather participants maintained their own opinions.

Disagreements were sometimes explained away due to personal circumstances (such as personality, family support, or age), or past experience with ill health:

P3: I've never been in the situation, so maybe if I was I change my mind, but I think I disagree with you because …I'd rather get someone else and be presentable and dressed when I met people I know.

P1: You might think different when you get married. (Group 5)

Theme 2: personal aspect of valuation

Participants emphasised the personal aspect of the valuation process. Participants indicated that they had to consider previous experiences and personal circumstances to value a health state:

I actually ranked extreme pain uhm as being the worst of uhm conditions. I think partly because one of my sisters suffered from a particularly chronic condition and just watching her suffer was pretty bad. I haven't really experienced myself or through friends uhm mental health problems (Group 7, P3)

Theme 3: comments about own opinion

There was little explicitly stated indications that participants changed their minds or were surprised about what they heard from other participants during the deliberation period. In total, there were only 11 mentions of participants changing their mind. The following quote illustrates a participant indicating a change of mind:

P2: I think if we all did this again, took this off and gave it to us again tomorrow we'd probably all put different numbers, we'd be going over in our heads subconsciously and if we came back and looked at these again in a day or two we'd we'd have all this discussion going around in our head and it would change our views probably. (Group 1)

There were three occurrences of participants being surprised or not having considered something, for example:

P1: I find it worrying when you say about people screaming in the extreme pain, because out of ignorance I tend to think pain is controlled.

P5: Unfortunately no.

P1: Oh dear! (Group 2)

Participants indicated uncertainty in their valuation due to an abstract health state, lack of experience, uncertainty about values or judgements, and difficulty of completing a TTO. Overall, there were 47 instances, at least one in each group, where a participant mentioned uncertainty. In this quote a judgement about the health state is followed by a declaration of uncertainty:

(...) but you are more mobile...and therefore your personal, other aspects of you and your personal relationships are better. To some extent. I think. I don't know. (Group 6, P5)

Theme 4: comments about grouping of health states

The participants grouped similar health states together, dividing health states in a group of 'good' and 'bad' health states. Within the higher valued group, the two health states 11331 (labelled YM) and 31131 (labelled YC) were often valued similarly and the health states of 44553 (labelled NA) and 44535 (labelled GY) were also valued similarly:

But what I found, is the polarisation, which is some them I would put very near to the top and some that I would put very near the very bottom of the scale. But it's difficult to pick things that I would put near the middle. (Group 2, P1)

Theme 5: comments about relative desirability of the six health states

This theme describes how favourably participants described the health states. All comments about health states were categorised as positive, neutral, or negative mentions. An example of a positive mention is the following quote:

My second one was YM (...) because I'm quite happy, I mean I'm quite happy to put up with a bit of pain and uhm I'm sure I can overcome my moderate problems, with the usual activities, so it's not gonna make all that much difference to the lifestyle. (Group 11, P2)

An example of a negative quote is the following:

I just felt that everything else was you know, you have...problems within each of these domains and I felt that would probably build up and impact on how you perceive your dignity (Group 1, P5)

The ranking of the health states in order of most positively discussed was: 11331, 31131, 32322, 11334, 44553, and 44535.

Developing quantitative hypotheses

The above five themes suggest three main quantitative hypotheses. First, theme one to three would suggest a lack of large systematic changes to health state values. Second, theme three suggests that there may be changes at the individual level because participants were uncertain about their valuations. Third, theme four would suggest that the TTO values for

health states 11331 and 31131 (i.e. the 'good' states) as well as the TTO values for health states 44553 and 44535 should be closer together in the second than first TTO. Theme five shows that there is a difference between the ranking of the health states in the first TTO and in the deliberation period (44553 and 44535 were reversed and 11331 and 31131 were also reversed).

Testing hypotheses using the quantitative data

The results of the hypotheses are shown in Table 3. Both at the individual and aggregate level the evidence from the two components show concordance for hypothesis one. The findings show discordance for hypothesis two because about half of the participants had similar values for both pairs and about half the participants had larger differences between the states. The qualitative and quantitative findings for hypothesis three shows concordance for 44535 and 44553 and discordance for 11331 and 31131 and therefore the overall results are mixed. The views expressed during deliberation did predict changes in the second TTO, but only in one of the two pairs of states.

[Table 3 approximately here]

4 Discussion

The findings of this study indicate that mean health state values do not statistically significantly change after a structured reflection and deliberation exercise. The largest aggregate change for a health state was -0.06. There were large and frequent changes at the individual level. Two possible reasons for why deliberation may be useful are to reveal novel information not known to all participants and to reduce mistakes in reasoning (14). The qualitative analysis suggests that information revealed by participants was generally not noted as being novel. Deliberation could not be characterised as reducing error because rather

than focusing on objective knowledge exchange it focused on exchange of personal subjective beliefs. Participants focused on personal values, circumstances, and experiences (as previously reported in the literature, e.g. see (16, 41)) and not on whether their view was correct or incorrect. In cases of disagreement the participants generally accepted but did not adopt others' opinions. At the same time participants were uncertain about their experience and beliefs. Together this suggests that large systematic changes are unlikely, though changes may occur at the individual level because of uncertainties.

The results of this study are similar to the that of Stein et al. (23) but dissimilar to four studies that showed statistically significant changes of health state values. Krabbe et al. (20) and Akunne et al. (19) used consensus-based method. . McIntosh et al. (21) gave participants a chance to change their values rather than re-value the states. Robinson et al. (22) used the person trade off method (PTO), which has lower test-retest reliability than the TTO (42) and involves equity considerations (43). It is thus possible that the results from the other studies are not generalizable to health state valuation using the TTO, EQ-5D, and mean-based aggregate valuations.

Two of the studies in the reflection and deliberation literature conducted a qualitative analysis. Stein et al. (23) commented that their "participants discussed their personal attitude to the scenarios and presented little new information to the rest of the group." This resembles the qualitative finding in this study. Similarly, Robinson et al. (22) noted that two factors may have prompted change: (a) implications the PTO for preferring to treat different group of patients and (b) deliberation about specific diseases. These reasons are not relevant to this study.

The use of utility values without reflection and deliberation in cost-effectiveness modelling appear to be justified, although it is difficult to judge when health state values changes are practically significant. In patient decision-making the number of changes suggest

that the individual preferences may be unreliable. The qualitative evidence suggests that the quantitative findings are not due to the design of the reflection and deliberation task, but because preferences are considered personal and participants make limited use of other people's experiences.

A limitation of this study is the lack of probability based recruiting, which resulted in a unrepresentative sample (44) compared to the UK population (45). Furthermore, some groups were small due to practical recruitment issues and this may have limited the amount of deliberation in those groups. Most studies cited in the literature do not use representative samples, as this remains an exploratory area of research. The qualitative data analysis had limitation that several stages of analysis were required to integrate the qualitative and quantitative data components and this required interpretation on behalf of the researcher team. For example, participants' comments were taken as reflections of their thoughts, but participants may not act in accordance to what they say and may not express all their thoughts. Furthermore, some themes were summarised by quantifying qualitative data and each comment was weighed equally.

The presence of uncertainty in both qualitative and quantitative data suggest further research is required. First, given that participants remained uncertain it may be important to investigate whether preferences are informed. Second, a lack of novel information or accepted information was noted in the group meetings, which suggest that more focus on reflection may be useful. An area for future research could be to provide external information to the participants McTaggart-Cowan et al. (38), for example, information on the six consequences for different health states. Lastly, although this study used one particular instrument and one valuation method the issue of reflection and deliberation applies to all preference elicitation exercises and further research is needed with other instruments and valuation methods.

5 Conclusion

The reflection and deliberation exercise examined in this study did not change health state values and the mixed method evidence does not indicate that reflection and deliberation served as tools of error reduction or new information sharing. Future research is required to assess whether participants are informed and to investigate the effect of providing information to participants before they value health states. The use of conventional methods that do not incorporate reflection and deliberation was not invalidated by this study for the purpose of aggregate level cost-effectiveness analysis.

Tables

	Sample	UK population[1]
Number of participants	62	-
Number of participants with incomplete TTO valuations	5	-
Mean age	45	39
Female, n (%)	37 (60%)	50.8%
Degree, n (%)	41 (66%)	27%[2]
Employed, n (%)	21 (34%)	59%
Student, n (%)	21 (34%)	8.8%
Retired (%)	17 (27%)	13%
Median EQ-5D (1st and 3rd Quartile)	1 (0.77, 1)[3]	-
Range EQ-5D	0.55 to 1	-
Has child, n (%)	21 (34%)	-
Age bracket 18 to 19	2 (3%)	3%
Age bracket 20 to 29	22 (35%)	17%
Age bracket 30 to 49	11 (18%)	36%
Age bracket 50 to 59	5 (8%)	15%
Age bracket 60 above	22 (35%)	29%

1: (45), 2: Includes everyone 16 and above, 3: (46)

Table 1 Background characteristics of participants and UK population

Health state	Before value (SD)	After value (SD)	Change (SD)	Cohen's d	UK Values	Changes (%)	Changes bigger or equal than absolute value of 0.1 (%)	Increased valuations	Decreased valuations	Participants not changing from better than dead or worse than dead (%)
44535	0.07 (0.47)	0.01 (0.56)	-0.058 (0.08)	0.11	0.07	47 (82%)	34 (72%)	22	25	49 (86%)
11331	0.74 (0.22)	0.75 (0.2)	0.018 (-0.01)	0.09	0.87	35 (61%)	24 (69%)	21	14	57 (100%)
32322	0.64 (0.32)	0.62 (0.35)	-0.024 (0.03)	0.07	0.69	42 (74%)	29 (69%)	19	23	55 (96%)
31131	0.75 (0.24)	0.76 (0.2)	0.011 (-0.04)	0.05	0.87	39 (68%)	29 (74%)	24	15	57 (100%)
11334	0.30 (0.52)	0.27 (0.54)	-0.028 (0.02)	0.05	0.58	47 (82%)	32 (68%)	21	26	52 (91%)
44553	-0.02 (0.56)	0.02 (0.58)	0.04 (0.01)	0.07	0.01	45 (79%)	35 (78%)	23	22	48 (84%)

Table 2 Mean health state values before and after group meeting, difference between the two, and UK values. Both MVH transformation and untransformed values are reported. Each digit represents the level of each dimension, (i.e. 1 is no problems and 5 is unable/extreme problems). The order of the digits is the order of the dimension in the questionnaire.

Themes	**Summary**	**Hypothesis**	**Quantitative findings**	**Comparison**
Agreement or disagreement	Health state valuation is largely personal. Disagreements are generally not solved but are explained away	No systematic aggregate changes; but possible individual level changes	No statistically significant changes at the aggregate level. Relatively large number of changes (61% to 82% of valuations for each health state) at the individual level.	Concordance at both levels
The valuation process	Health state valuation is largely personal; adaptation, environment and context of valuation are all seen as personal			
Own opinion	Few indications of change of mind (less 1 per group) and surprises, but uncertainty about opinion			
Grouping of health states	Health states are polarized between 31131 and 11331 compared with 44535 and 44553	At individual level health states 31131 closer to 11331 and 44535 to 44553	About 50% of individuals who made changes had more similar values for 31131 and 11331 after than before; same for 44535 and 44553	Discordance
Health states	Health states ranked by favourability during discussion: 11331, 31131, 32322, 11334, 44553, 44535	Second TTO should conform to ranking. In particular the ranking of 31131 and 11331 should reverse. Same for 44535 and 44553.	Rankings conform except for that 11331 is not ranked above 31131	Mixed. Concordance for 44553 compared to 44535, but not for 11331 compared to 31131

Table.3 Summary of themes, hypothesis generated from summary, related quantitative findings, and comparison between qualitative and quantitative findings

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