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Seeing and doing: Valuing visual impairment using simulation spectacles

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Abstract

When health states are valued by non-patients, the usual practice is to present them with verbal descriptions of the health state(s) in question. It is now quite common, for example, for health states to be described using disease specific and/or generic measures. The implication of such representations of health is that those other than the person valuing the state determine the main features of the health state. However, in an attempt to avoid information overload, the information given may be too selective, and/or particular details that matter to the respondents may not be included. In this study, we explore an alternative approach, where respondents are presented with a quasi-simulation of the health state in question. In valuing progressive visual impairment, we use specially designed spectacles that distort the vision of the subject in ways that resemble different stages of the disease. The condition is *experienced* by the respondent rather than being verbally *explained* to them. A pilot study with 33 respondents indicates that this has methodological implications for the valuation exercise, in that many respondents find it difficult to conceive of full health with visual impairment. The implications of this for the QALY model are discussed.

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1. Introduction

There are many issues associated with valuing health states, such as how those states should be described and valued, and who should be asked to value them (Dolan, 2000). This study addresses the issue of how health states are presented to respondents. When valuations are elicited from non-patient respondents, the usual practice is to give them some form of verbal description of the state to be valued. This can be done by using one of the generic health state classification systems such as the EQ-5D (Brooks, 1996), or by naming a condition, perhaps accompanied by a description of that condition. Either way, the information given to respondents about the health state is highly selective. This means that a health state description may not provide information that the respondent would have found relevant and important if they had been given it. Moreover, health states are usually described in negative terms, concentrating on the dysfunctional attributes of health and/or the limitations of the condition.

The objective of this study is to explore ways in which health states associated with progressive eye disease can be presented to non-patient respondents in the form of simulated states, so that the states are "experienced" by them, as opposed to being "explained" to them. In order to simulate visual impairment, spectacles representing different degrees of impaired vision are used. These are large plastic goggles, and can be worn on top of ordinary spectacles. This paper reports on the design and results of a pilot study, and discusses the implications for a larger-scale study.

2. Methods

2.1 The basic structure of the interviews

The structure of the interviews is summarised in Figure 1. The differences between versions will be discussed in more detail in 2.3 below, once the basic structure of the interview has been outlined. All respondents were first asked to describe their own health in terms of the EQ5D, two questions on vision taken from HUI-3 (Feeny et al, 1995), and three questions from the VFQ25 (Mangione et al, 1998). These questions are referred to as "EQ5D+5" and are shown in Figure 2. In the second version, this was followed by a time trade-off (TTO) valuation of the respondent's present health.

Respondents were then asked to try on three pairs of spectacles, representing varying degrees of visual impairment, and to rank them in order of preference. The three health *states* were then valued in a pre-determined order. The spectacles representing the first state were handed to the respondent, and they were invited to walk around the room, look at books and out of the window. They were then asked to complete the EQ5D+5 questionnaire for that state and then to value it using the TTO method. The procedure was repeated for the second and third states.

Two deteriorating health *profiles* consisting of these states were then presented to respondents and they were asked to rank them alongside the three states. They then valued the two profiles using the TTO. The profiles were presented in the form of a diagram showing the different durations of the three states. There were four variants of the questionnaire, shown in Figure 3 and discussed more fully in 2.2 below.

There then followed a willingness-to-pay (WTP) exercise regarding a move from the worse profile to the better profile. The respondent was handed 10 cards in a random order with different money amounts on and an example of what this could buy:

£0	–
£50	Pair of shoes
£100	TV licence
£250	Car tax + annual service
£500	Wide screen TV
£1,000	Furniture
£2,000	2 week family holiday
£5,000	New kitchen
£10,000	New family car
£50,000	Sell your house or take a loan

The respondents were asked to put the cards into two separate piles – one for amounts that they would be willing to pay and another for amounts that they would not be willing to pay. After doing this, they were asked to state the maximum amount they would be willing to pay. This *random card sort procedure* is one that has been developed by Michael Jones-Lee and Graham Loomes in the context of valuing the health benefits from reductions in air pollution. Finally, the respondent was asked a series of background questions which were taken from the standard EQ-5D questionnaire and modified to ask about the respondent's experience in visual impairment as opposed to severe illness in general.

2.2 The states and profiles – the four variants

The three health states valued in this study were chosen to represent mild and severe visual impairments (at which stage patients undergo a surgical operation), and a post-operative state. These were labelled E, G, and J, respectively. Each respondent valued the states in this order, irrespective of their own ranking of the states.
The first profile, X, represented the natural disease progression from mild to severe visual impairment, followed by the post-operative state. The second profile, Y, represented the results of an intervention that slowed down the progression of the disease, so that it took longer to move from state E to state G, and thus to state J i.e. the timing of the operation was delayed.

A common duration is often used when using the TTO method. For example, a ten-year fixed duration was used to generate a tariff of values for the EQ-5D (Dolan, 1997). However, a ten-year duration is unrealistic for respondents in the younger age groups and, importantly, does not fit the natural history of eye disease (about ten years with moderate visual impairment, five years with severe visual impairment, and the rest of life in the post-operative state). Therefore, different time horizons were used for each of three respondent age groups: ten years for age 60+; 20 years for age 40-59; and 40 years for 18-39. These roughly reflect the differences in life expectancy across these groups.

Taking the 40-59 age group as the reference case, the baseline for profile X was 10-4-6 i.e. ten years in the mild state, four years in the severe state, and six years in the post-operative state. Profile X for the 60+ age group was proportional to this i.e. 5-2-3. The 18-39 age group was broken up into two subgroups. The first subgroup was given a profile that was proportional to the reference case i.e. 20-8-12. The second subgroup was given a profile comprising of 10-4-26, which means the first 20 years of their time horizon is split in the same way (10-4-6) as in the reference case.

The baseline for Profile Y was generated by extending the duration of the mild state by four years and leaving the duration of the severe state unchanged, thus delaying the post surgery state by four years. Therefore, Profile Y for the 40-59 age group was 14-4-2. Retaining proportionality, Profile Y for the 60+ group becomes 7-3 i.e. there is no post-operative state. Profile Y for the two 18-39 subgroups was constructed following the rules above, resulting in profiles of 28-8-4 and 14-4-22.

2.3 Deriving values - the two versions

The same TTO board and interviewer scripts were used as in the MVH study (Gudex, 1994), with appropriate adjustments for different durations. In the first version of the questionnaire, TTO values for the three states and two profiles were elicited in the standard way; that is, they were valued against a shorter period of time in full health. The value of each state profile is given by T/T_0, where T is the number of healthy years equivalent to T_0 years in the state or profile. However, some respondents to this version seemed to be unable to ignore their present health conditions when asked to imagine themselves with the visual impairment alone. So in the second version, the health state in question was now defined as the visual impairment *in addition to present health* (i.e. with existing health conditions), as opposed to the visual impairment alone (i.e. with no other conditions). To accommodate this change, the anchor for the TTO was also changed from full health to present health.

In order to “chain” the value of each state through the value of present health, a TTO valuation of present health against full health was introduced near the beginning of the interview in version 2 (see Figure 1). Assuming the disutility of multiple disabilities is additive, the values associated with visual impairment are then calculated as:

$$U(Q_{FHVI}) = U(Q_{PHVI}) + (1 - U(Q_{PH})) = \frac{T^*.T^{**}}{T_0^2} + \left(1 - \frac{T^*}{T_0}\right),$$

where Q represents quality of life, subscripts $_{FHVI}$ and $_{PHVI}$ represent visual impairment anchored to full health and present health respectively, T^* is the number of healthy years equivalent to T_0 years in present health, and T^{**} is the number of years of present health equivalent to T_0 years in present health with visual impairment. See the Appendix for a numerical example.

2.4 The analyses

Since profiles X and Y are combinations of states E, G, and J, and since all the states and profiles last for the same total duration, there is a logical ordering to the states and profiles, and thus it is possible to test for internal inconsistencies. A respondent was defined as inconsistent if his TTO valuations did not reflect either of the following orderings: E>Y>X>G>J, or E>Y>X>J>G.. The difference between the severe and post-operative states is very small and so J>G was not treated as an inconsistency.

The small number of respondents in each of the experimental groups means that it is not possible to compare valuations in the ways we intend to in the larger scale study. For example, given that respondents were asked to classify each of the states using the EQ-5D, the direct TTO values can be compared to the population values reported in Dolan (1997). We might expect differences between the two sets of values because of the use of simulation spectacles and/or the use of different durations.

A comparison can be made within the existing data between the indirect and direct values of the profiles, since values for X and Y can also be constructed from the valuations for each of the states E, G, and J. If the assumption of additive separability holds (i.e. if the value of a given health state is independent of what state precedes or succeeds it) and if future health is undiscounted, then the indirect valuations of the health profiles will be the same as those elicited directly. The WTP-per-QALY can be calculated by dividing the monetary valuation for the move between X and Y by the implied difference in the number of QALYs between those profiles. This implied difference in QALYs can be calculated using the indirect or direct valuations of the profiles.

The effect of respondent's own health on the valuations can be explored by comparing the results across the two versions. This is done by regressing the TTO responses on the respondents self-reported health (expressed in terms of the EQ5D single index), with additional categorical variables for the state or profile valued. Individual level responses are used and the random effects model is employed to account for trends in individual responses. The regression is run for the two versions separately and the coefficients are compared (STATA ver.6 is used).

2.5 The sample

Letters of invitation were sent out to 700 people randomly selected from the electoral register in two wards in Sheffield. The reply slip asked respondents to indicate their sex and age group, and to indicate which interview times they could make. They were offered £15 to attend an interview at the University of Sheffield, conducted by one of the authors (SA). In total, 160 (23%) agreed to take part. Amongst these, women and those aged 18-39 were over represented relative to the general population. Based on their age and sex, 50 were invited for interview. Of these, 38 (76%) turned up. The first 5 interviews were treated as pre-pilots to establish the feasibility of the exercise and to finalise the interview protocol (for details, see Figure 1). This paper reports on the main pilot with the remaining 33 respondents.

3. Results

Table 1 shows the inconsistency rates in individual TTO values by version. A small number of respondents violated the relationship that profile X is better than the worst state (the smaller of G and J) but, overall, the consistency rates are very good. This is probably due to the insertion of the ranking exercises in the light of the experiences in the pre-pilot. Table 2 shows the mean direct TTO values. Values for version 2 are standardised in the way described above. The aggregate responses are consistent in both versions. Note that mean values for version 1 are always lower than the mean values for version 2.

Table 3 presents the average values derived by using the respondents' assessments of the three states in terms of EQ-5D and converting these into single indices using the EQ-5D tariff values (Dolan, 1997). Comparing this table with Table 2, it can be seen that for states G and J, indirect values are lower than direct values, and the direct values from version 1 are lower than those from version 2. Table 4 presents the implied value of the two profiles, calculated indirectly from the valuations of states E, G, and J and their associated durations within each profile. It can be seen that the difference across versions is greater than the difference between profiles within a version. As would be expected, the indirect values for profile Y are higher than for profile X. Comparison with Table 2 indicates that the indirect values of the declining profile are higher than the corresponding direct values.

Table 5 shows the average WTP for a QALY. Only data from respondents whose direct TTO value for profile X is strictly lower than that for profile Y are used. Ten and eight respondents from version 1 and 2, respectively, were excluded from this part of the analysis because their TTO values for the two profiles were equal. Table 5 shows that the distributions of WTP-per-QALY are very wide and highly skewed. Furthermore the median values are very small compared to, for instance, the cost/QALY threshold (of £30,000) that is allegedly being used by NICE. The WTP-per-QALY based on the indirect approach is larger than that based on the direct approach but still comes in at less than £30,000.

Alternatively, the ratio of mean QALY gain and mean WTP for the move from profile Y to X can be calculated without excluding any of the respondents. This results in values around £11,000 and £18,00 per QALY for the direct and composite approach for version 1, and £6,000 under either approach (but the composite approach slightly larger) for version 2.

Table 6 reports the results of the regression analysis using the valuation of the respondent's present health. The last column indicates that there is no statistically significant difference in the intervals between the states and profiles across the two versions and that a significant difference is attributable to the presence or absence of the effect of the respondent's present health.

4. Discussion

The objective of the present pilot study was to examine the feasibility of presenting respondents with health states associated with visual impairment using simulation spectacles rather than written descriptions. Although the sample size was small given the pilot nature of the study, the results are encouraging. Very few respondents had ordinal inconsistencies in the TTO responses and the differences in TTO values between the different states and profiles are robust across direct TTO valuations and chained TTO valuations.

There was, however, one important and unexpected finding. Some respondents found it difficult to imagine visual impairment alone when there was an existing disability. (Note that between 40-50% of respondents reported some problem on at least one EQ-5D dimension.) Since this finding is not commonly reported in studies that use written descriptions, it may be that respondents who are not in full health may find it possible to picture themselves firstly in the described state (without their present condition) and secondly in full health (again, without their present condition). Alternatively, and perhaps more likely, they may not be able to do this, but simply do not recognise that they are unable to. When the health state in question is simulated, respondents find it difficult to imagine themselves in the way required. This is likely to be because the simulated experience makes the health state more vivid and realistic, and so it becomes more difficult to imagine the state in question without the pre-existing condition. A further consideration is the case where the respondent's condition happens to be some mild visual impairment: it will be very difficult for the respondent to imagine herself with the simulated visual impairment alone, free of the pre-existing visual impairment.

This finding was picked up after a dozen or so interviews, and led to the re-organisation of the valuation procedure for the second half of the sample. The health state to be valued was changed from the visual impairment alone to the visual impairment alongside the existing conditions of the respondent and the better alternative state was changed from full health to the respondent's present health. In order to standardise the obtained values, these values then have to be chained to full health via a TTO valuation of the respondent's present health. This chaining procedure is predicated on the assumption that multiple impairments are additive.

So, we would seem to be faced with a choice between the analytical simplicity of anchoring on full health and the cognitive ease of anchoring on present health. There is no obvious correct choice, but we think that the second choice (using version 2) is better – it is certainly "kinder" to respondents. Moreover, the potential bias in version 1 goes only in one direction. This is because responses can be confounded by existing conditions, in which case the valuations will be biased downwards. In this respect, it is interesting to note that TTO values from version 2 are higher than those from version 1.

In addition, the responses from version 2 are not as affected by respondents' own health level as those from version 1. The regression coefficient for version 1 indicates that a 0.1 increment in respondent health level will lead to a 0.06 increment in the TTO values. This contradicts earlier findings where the opposite relationship was observed (Dolan et al, 1996) but is consistent with the possibility that respondents are not evaluating visual impairment alone, but are instead evaluating visual impairment alongside their existing health conditions. Thus, our recommendation for the large-scale study is to use version 2.

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Figure 1: The versions

	pre-pilot (n = 5)	1 (n = 19)	2 (n = 14)
(1) describing present health in EQ5D+5	✓	✓	✓
(2) TTO of present health	×	×	✓
(3) ranking of visual states E, G, J	×	✓	✓
(4) visual state E			
(a) describing state E in EQ5D+5	✓	✓	✓
(b) TTO of state E	✓ ‡	✓ ‡	✓ §
(5) visual state G			
(a) describing state G in EQ5D+5	✓	✓	✓
(b) TTO of state G	✓ ‡	✓ ‡	✓ §
(6) visual state J			
(a) describing state J in EQ5D+5	✓	✓	✓
(b) TTO of state J	✓ ‡	✓ ‡	✓ §
(7) ranking of states E, G, J, and profiles X, Y	×	✓	✓
(8) TTO of profile X	✓ ‡	✓ ‡	✓ §
(9) TTO of profile Y	✓ ‡	✓ ‡	✓ §
(10) WTP for difference Y-X	✓	✓	✓

† EQ5D+5 consists of EQ5D, 2 questions on vision from HUI, and 3 selected questions from VFQ25.
‡ TTO of the state/profile alone, with immediate death and full health as anchors.
§ TTO of state/profile plus present existing disabilities, with immediate death and present health as anchors.

Figure 2: The "EQ5D+5"

EQ5D

(1) Mobility
→ no problems walking about / some problems / bedridden

(2) Self Care
→ no problems dressing or washing / some problems / unable

(3) Usual Activities
→ no problems / some problems / unable

(4) Pain/Discomfort
→ none / some / extreme

(5) Anxiety/Depression
→ not anxious or depressed / moderately / extremely

HUI-3

(6) Which one of the following would best describe your ability, during the past week, to see well enough to read ordinary newsprint?
→ able without glasses / able with glasses / unable to see well enough with glasses / unable at all

(7) Which of the following would best describe your ability, during the past week, to see well enough to recognize a friend on the other side of the street?
→ able without glasses / able with glasses / unable to see well enough with glasses / unable at all

VFQ-25

(8) At the present time, would you say your eyesight in both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very poor, or are you completely blind?

(9) Do you accomplish less than you would like to because of your eyesight?
→ 5 levels from "All of the Time" to "None of the Time".

(10) I need a lot of help from others because of my eyesight.
→ 5 levels from "Definitely True" to "Definitely False"

Note that these are summaries to illustrate the items included in EQ5D+5 and does not reproduce the exact wording.

Figure 3: The two profiles and the four variants

Fig 1.a Profiles for the 18-39 age group, variant 'F'

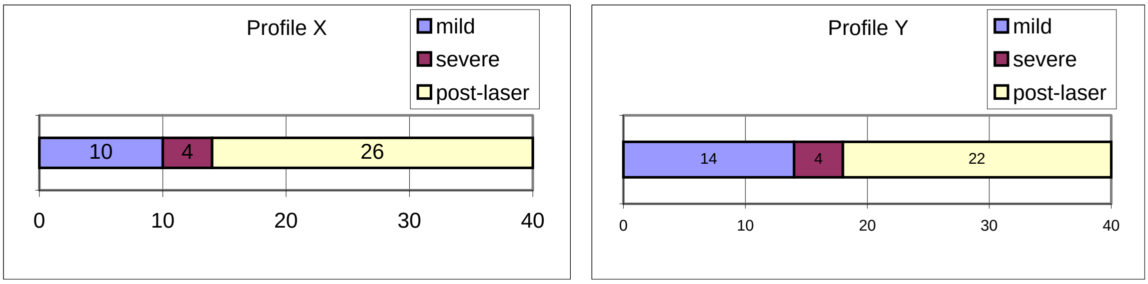


Fig 1.b Profiles for the 18-39 age group, variant 'P'

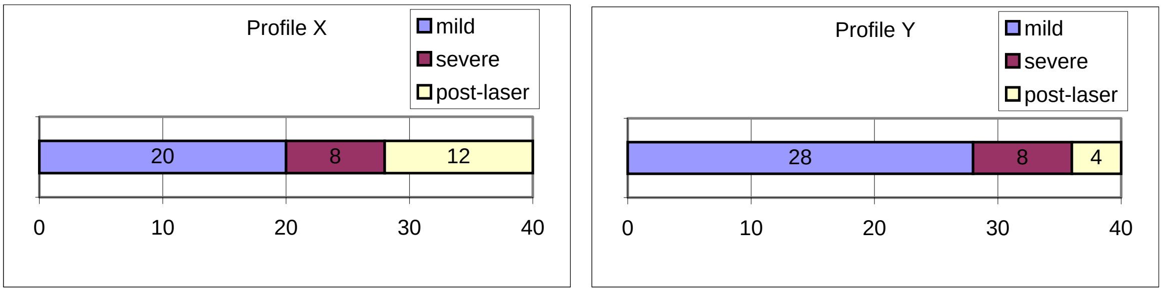


Fig 1.c Profiles for the 40-59 age group

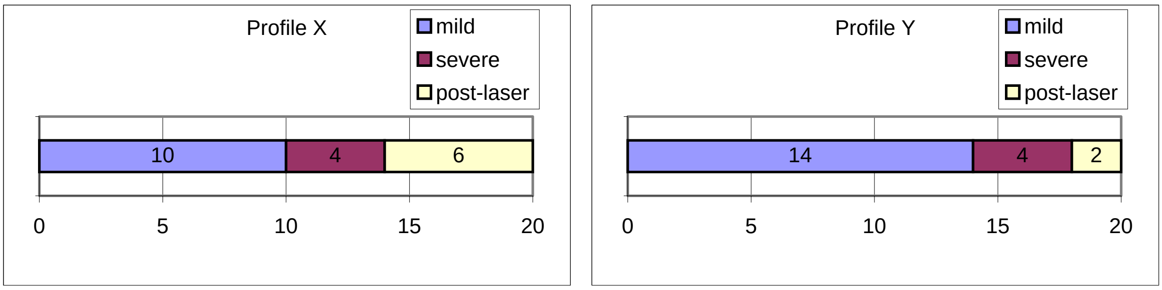
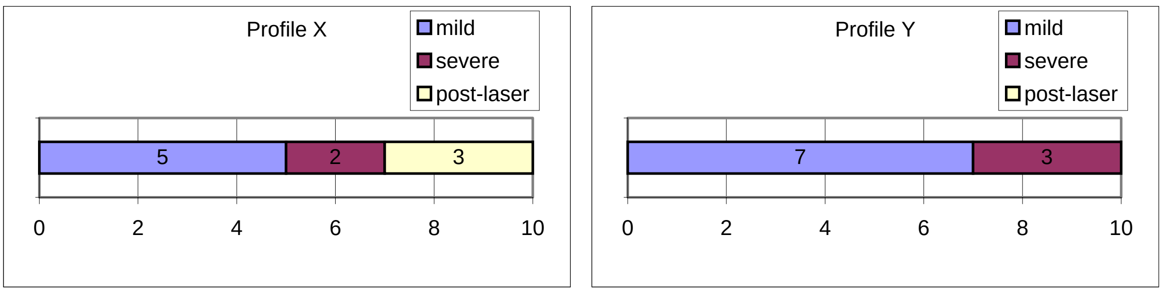


Fig 1.d Profiles for the 60 and above age group



Summary:

variant name	18F	18P	40	60
respondent age group	18-39	18-39	40-59	60+
reference duration of TTO	40 years	40 years	20 years	10 years
profile X (E-G-J)	10-4-26	20-8-12	10-4-6	5-2-3
profile Y (E-G-J)	14-4-22	28-8-4	14-4-2	7-3

Table 1: Inconsistencies

Inconsistency	version 1		version 2	
	n	%	n	%
E<Y	0	0	0	0
Y<X	0	0	0	0
X<min{G,J}	3	16	1	7
Any	3	16	1	7

Table 2: Direct TTO valuations of states and profiles

	version 1		version 2	
	mean	std	Mean	std
State E (mild)	0.56	0.34	0.76	0.27
Profile Y (with intervention)	0.41	0.26	0.61	0.30
Profile X (without intervention)	0.34	0.27	0.57	0.29
State G (severe)	0.30	0.30	0.50	0.31
State J (post-operative)	0.29	0.29	0.55	0.30
N	19		14	

Table 3: Indirect values of states using the EQ-5D tariff values

	version 1		version 2	
	mean	std	Mean	std
State E (mild)	0.71	0.23	0.59	0.23
State G (severe)	0.18	0.34	0.11	0.30
State J (post-operative)	0.19	0.37	0.14	0.33
N	19		14	

Table 4: Indirect TTO values of profiles using QALY model

	version 1		version 2	
	mean	**std**	**mean**	**Std**
Profile Y (with intervention)	0.45	0.29	0.68	0.27
Profile X (without intervention)	0.41	0.28	0.64	0.27
n	19		14	

Table 5: Direct and indirect WTP for a QALY (in £1000s)

(a) Version 1

WTP per QALY	n	mean	std	min	median	max
Direct approach	9	14.3	32.2	0.4	3.8	100.0
Indirect approach		27.0	52.7	1.0	10.0	166.7

(b) Version 2

WTP per QALY	n	mean	std	min	median	max
Direct approach	6	3.4	2.3	0.8	3. 7	6.3
Indirect approach		4.2	2.0	1.9	3. 9	7.8

Table 6: The effect of the respondent's present health on TTO valuations

	version 1		version 2		*p*-value B1=B2 ‡
	B1	**p**	**B2**	**p**	
Present health	0.569	0.024	-0.256	0.449	0.001
State G †	-0.254	0.000	-0.265	0.000	0.788
state J	-0.265	0.000	-0.216	0.000	0.247
profile X	-0.214	0.000	-0.192	0.000	0.609
profile Y	-0.149	0.000	-0.151	0.000	0.953
constant	0.067	0.770	0.983	0.001	0.000

† State E is the default dummy.
‡ The *p*-values of the Wald test: B1 = B2.

Appendix: An example of anchoring visual impairment on present health

Suppose a respondent is asked to value visual impairment (VI) with his present health condition (PHVI), using TTO with a time horizon of 10 years. The anchoring state is present health (PH). Suppose further that this respondent is indifferent between 5 years in his present health with no visual impairment and 10 years in his present health with visual impairment.

From this observation, we want to deduct the utility associated with full health with visual impairment (FHVI) on a scale anchored on death (utility: 0) and full health (FH; utility: 1). In order to do so, the respondent is asked to value his present health against full health. Let us assume that he is indifferent between 8 years in full health and 10 years in present health.

Since:

5 years in present health = 10 years in present health with visual impairment,

therefore, using constant proportional time trade-off assumption:

10 years in present health = 20 years in present health with visual impairment.

Furthermore,

8 years in full health = 10 years in present health.

Then, by transitivity:

8 years in full health = 20 years in present health with visual impairment.

The last statement implies that the utility associated with present health with visual impairment is 0.4. To calculate the utility associated with full health alone (without visual impairment), the value of the difference between present health and full health needs to be added. Given that the utility of full health is 1 and the utility of present health is 0.8, the difference is 0.2. Thus, the utility of full health with visual impairment is 0.6.