The impact of disease information on general public preferences for health states: Comparing labeling, disease-specific, and adaptation information

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Abstract: The Washington Panel on cost effectiveness argued that '…the best articulation of society's preferences for a particular state would be gathered from a representative sample of fully informed members of the community'. In the UK, NICE currently recommends generic preference-based health-related quality of life questionnaires, namely, the EQ-5D, for use in cost effectiveness analysis. The EQ-5D UK value set was obtained from a population of *uninformed* general public.

Our aim was to investigate what effect information had on valuations of health states. We compared patient valuations, obtained using a variety of methods, and we compared public valuations, which were a) uninformed b) informed with labeling c) informed about the condition d) informed about adaptation to the condition.

Generic preference-based questionnaires (EQ-5D and SF-6D), the visual analogue scale (VAS) and the time trade-off (TTO) valuation techniques were administered to a sample of patients with age-related macular degeneration (AMD; N=54). Health utilities were calculated using standard general population tariffs for the EQ-5D and SF-6D and directly from patient TTO and VAS scores. A general public sample were presented with patient health states with varying additional information and asked to value these states using the TTO.

This is the first study to compare the impact of condition-specific information, labeling and adaptation information on health state valuations within the same population. Early results suggest that that the framing of information leads the public to different valuations, although a larger study is required to confirm this.

Introduction

It is widely accepted in the health economics literature that the general public should value health states. As payers in a tax-funded health system, it is considered right that the public's preferences are taken into account when allocating health care resources. Furthermore, the public offers an unbiased view of health states, unaffected by the condition they are valuing.

Having said this, there are serious information problems within health, which may mean the public lack information about health conditions. Indeed, the Washington Panel on Cost Effectiveness argued that '…the best articulation of society's preferences for a particular state would be gathered from a representative sample of fully informed members of the community'.[1]

In the UK, NICE currently recommends generic preference-based health-related quality of life questionnaires, namely, the EQ-5D, for use in cost effectiveness analysis. The EQ-5D UK value set was obtained from a population of uninformed general public by conducting TTOs on EQ-5D health states.[2]

Concerns have been raised about the performance of the EQ-5D in some health conditions.[3] Information provided by the questionnaire may give the uninformed valuer limited information on what it is like to live with a disease and how one may adapt to achieve high quality of life despite what may initially appear to be disabling limitations of a chronic condition.[4] This information problem may be accentuated by the relatively short nature of generic preference-based health-related quality of life (HRQoL) questionnaires used to value health states: the EQ-5D-5L questionnaire consists of 5 questions each with 5 levels.

Vision loss is one such example where lack of information about the condition and the process of adapting to it may not be fully captured in the EQ-5D health state.[3, 5] There has been work in age-related macular degeneration (AMD) suggesting that patients value their health more severely than the general public using the TTO.[6]

Recognising these limitations, contact lenses simulating AMD have been tried as a method of informing the public about AMD prior to valuing the health state.[7] Indeed, health utilities derived from this approach were used in NICE's technology appraisal of AMD treatments.[8] However, contact lenses do not simulate the loss of central vision that typically occurs with AMD. Furthermore, wearing lenses for a short time cannot inform about the process of adapting to living with the disease, which is believed to be significant in some AMD patients.[9]

Perhaps most importantly, if we are to maintain cross-program comparability for cost utility analysis, the method of informing for health state valuation should be as standardised as possible across conditions. Simulating an eye condition may be technically feasible, but simulating a disease in the general public would be challenging and ethically undesirable in many other conditions. For this reason, we believe that the provision of information prior to the valuation task is the most promising way to close the information gap if bias can be avoided.

Research on the effect of additional information on health state valuations is limited. A study investigated the effect of labeling on health state valuations in two different conditions - cancer and irritable bowel syndrome (IBS). It found no significant differences between health state values when the description contained no label or an IBS label. A cancer label affected health state values and the impact depended on the severity of the state; values were significantly lower for worse states, but there was no significant difference for mild states.[19]

This study takes a single condition where there are thought to be information problems and seeks to determine if the framing of information influences valuations of EQ-5D health states by the general public. We chose four levels of information: none, labeling, a patient description and information about adapting to the condition.

The primary aim of this study was to investigate the effect of different types of information on valuations of AMD heath states by the UK general public. A secondary aim was to assess the performance of methods for eliciting preferences within AMD patients. This forms the pilot for a larger study.

Methods

Patient health state valuation

54 patients with AMD (wet or dry) with a range of visual acuities were recruited from clinics at Moorfields Eye Hospital, London. An optometrist administered a series of health status questionnaires in a random order (Table 1). Questionnaires were interviewer-administered due to the condition limiting participants' ability to read.

Table 1: Health status questionnaires

Questionnaire	Preferences	Valuation technique
EQ-5D	UK public (EQ-5D-5L interim value set)	TTO (preference-based)
SF-6D	UK public (UK valuation of SF-36 US v1)	SG (preference-based)
VAS	Own	VAS (non-preference-based)
TTO	Own	TTO (preference-based)

Four health utilities were derived for each respondent's own health state:

- The EQ-5D and SF-6D were selected as they are the most widely used generic preference-based measures with UK public tariffs. Patients were asked which health state within the descriptive system they were in, and these were converted to utilities using UK public preferences.
- The TTO was selected as a preference-based measure of own health utility, which is considered less cognitively demanding than the standard gamble in this patient population. Patients were asked to value their own health state using a 10-year TTO using a ping-pong technique against perfect health and this was converted to a utility.
- The VAS, while being a non-preference-based measure, was selected as it generates a health utility without considering time. Time-preferences may be significant in an elderly population. Patients were asked to value their own state using the EQ-5D VAS and the VAS score was converted to a utility.

Public information pilot

A sample of 40 members of the general public were randomised into 4 groups to receive different levels of information about AMD (see Appendix 1) before completing TTO valuations on AMD patient health states elicited in the patient study (Table 2).

- Group 1 were asked to perform a series of 4 TTOs on 4 unlabeled AMD patient EQ-5D profiles. (uninformed).
- Group 2 read a short objective description of AMD from the NHS Choices website before being asked to perform a series of 4 TTOs on the same 4 AMD patient EQ-5D profiles. (labeling) [10].
- Group 3 read a short objective description of AMD and a patient description of their quality of life with the condition before being asked to perform a series of 4 TTOs on the 4 AMD patient EQ-5D profiles. (disease information) [11]
- Group 4 received a short objective description of AMD, a patient description of their quality of life with the condition, and a description of how to adapt to life with the condition before being asked to perform a series of 4 TTOs on the 4 AMD patient EQ-5D profiles. (adaptation) [12]

Table 2: Groups for public valuation pilot study

Group	Valuation information
1	EQ-5D-5L profile
2	+ labeling
3	++ disease information
4	+++ adaptation

Note: Descriptions seen by participants are presented in Appendix 1.

An electronic TTO programme was developed to collect public utility values on patient health states. The TTO was consistent with the York MVH study (including 10-year timescale, ping-pong technique, certainty of health over time period, slider props).[13]

The programme consisted of the following:

- An introduction screen

- Sociodemographic questions
- An introduction to the TTO technique
- Information about AMD (groups 2, 3, 4 only)
- 4 TTOs on 4 patient EQ-5D health states (the state was labeled as 'macular degeneration' in groups 2, 3 and 4, and unlabeled in group 1).

Each participant completed TTOs on the same four EQ-5D profiles. The order in which health states were presented was not varied.

The EQ-5D profiles were selected from AMD patients who had reported no significant comorbidities so as to present to the public health states that could plausibly be due to AMD in an otherwise healthy individual. The health states are described in Table 3.

Table 3: Patient EQ-5D profiles selected for valuation by the public

Health state 1 (31312), 0.76*	**Health state 2 (31211), 0.82***	**Health state 3 (11112), 0.88***	**Health state 4 (21513), 0.43***
I have moderate problems in walking about	I have moderate problems in walking about	I have no problems in walking about	I have slight problems in walking about
I have no problems washing or dressing myself	I have no problems washing or dressing myself	I have no problems washing or dressing myself	I have no problems washing or dressing myself
I have moderate problems doing my usual activities	I have slight problems doing my usual activities	I have no problems doing my usual activities	I am unable to do my usual activities
I have no pain or discomfort	I have no pain or discomfort	I have no pain or discomfort	I have no pain or discomfort
I am slightly anxious or depressed	I am not anxious or depressed	I am slightly anxious or depressed	I am moderately anxious or depressed

**Utility scores derived using the EQ-5D-5L UK interim value set*

In the patient sample, t tests and regression analysis were used to assess the association between health utilities derived from different instruments. Multiple regression was used to estimate the impact of disease and sociodemographic variables on health utilities derived from each instrument.

In the public sample, regression analysis was used to estimate the impact of levels of information and health states on health utility values while controlling for sociodemographic characteristics.

Analyses were conducted using Stata 11.2 (StataCorp).

Results

Patient health state valuation

53 patients completed the four health utility instruments. The sample represented a typical AMD patient population (Table 4). There were more females than males in the sample due to the age of the sample. There were more wet than dry AMD patients due to the larger number of wet AMD patients visiting hospital clinics since wet AMD has treatment options available whereas there are no treatments currently licensed for dry AMD.

Table 4: Patient demographic information (n=53)

Variable	Value	
Mean age, years (SD)	84.1 (6.5)	
Gender	35 female (65%)	19 male (35%)
Diagnosis	42 wet AMD (78%)	12 dry AMD (22%)
Mean time since diagnosis, years (SD)	7.2 (6.4)	
Mean visual acuity in better seeing eye with current eyeglasses, logMAR (SD)	0.68 (0.32), 6/30	

Mean and median patient-reported health utility values are given in Table 5. EQ-5D utility scores were skewed towards 1.0, perfect health (left skew). SF-6D scores were centred around 0.6. The EQ-5D gave 2 utilities of states worse than death. The TTO had a lower mean than both the EQ-5D and SF-6D and a large standard deviation. The VAS displayed a right skew. This was confirmed in a histogram, which also highlights that a number of patients were non-traders on the TTO task (Figure 1).

Table 5: Patient reported health utility values

	Mean (SD)	Median	Interquartile range	t test (vs EQ-5D)	Wilcoxon signed-rank, z (vs EQ-5D)
EQ-5D	0.607 (0.285)	0.658	0.264		
SF-6D	0.621 (0.115)	0.620	0.140	-0.438	1.084
TTO	0.497 (0.365)	0.425	0.750	**2.154****	1.602
VAS	0.560 (0.224)	0.500	0.250	**1.676****	**1.926***

, **, * indicates significance at 90%, 95% and 99% respectively*

Figure 1: Histogram of EQ-5D, SF-6D, TTO and VAS scores

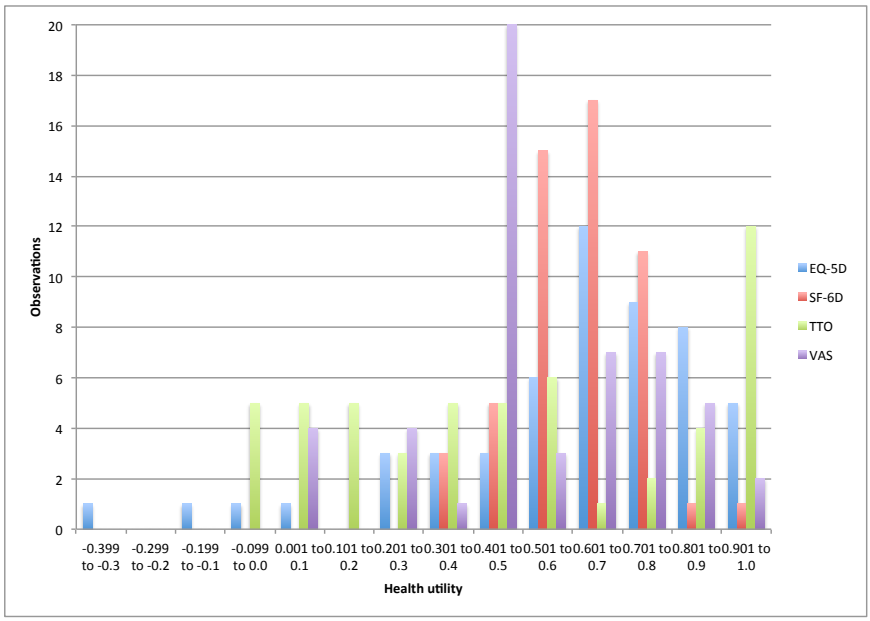
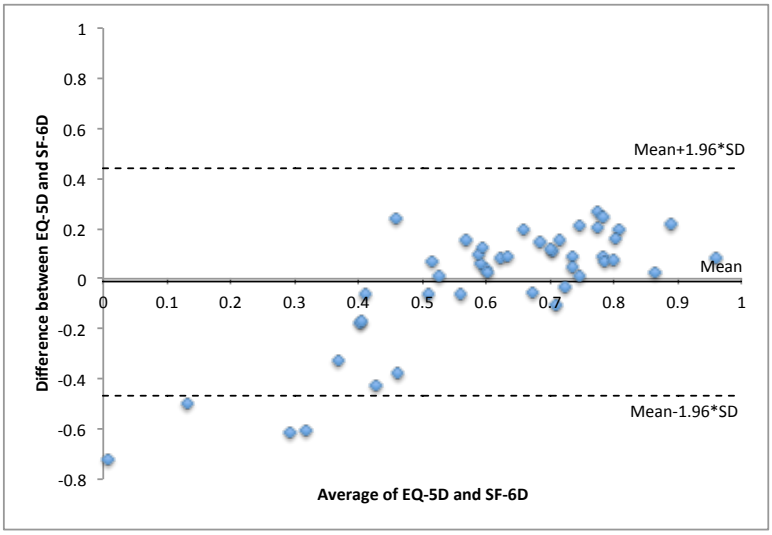
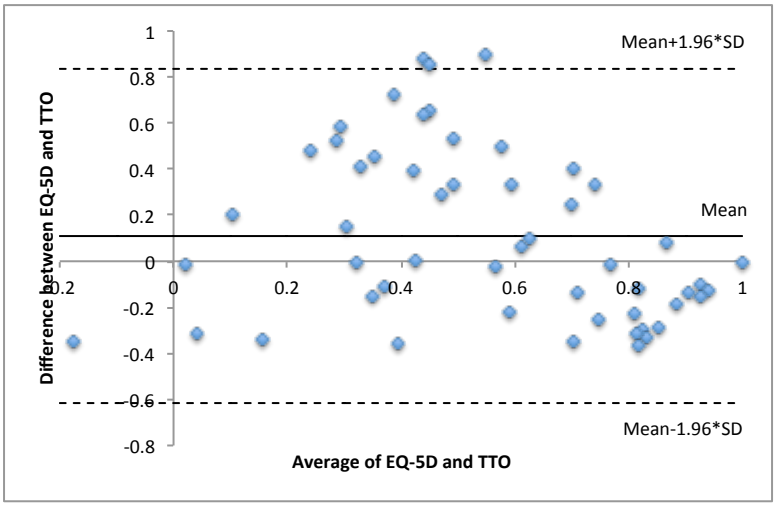


Figure 2: Bland-Altman plots: i. EQ-5D and SF-6D, ii. EQ-5D and TTO





Bland-Altman plots were constructed to assess agreement between EQ-5D and SF-6D and EQ-5D and TTO since the EQ-5D health states were to be used in the public valuation tasks for the information study. The plots showed wide limits of agreement (Figure 2).

Paired-sample t-tests were conducted to compare health utility scores between instruments (Table 5). There was a significant difference in scores between EQ-5D and TTO and EQ-5D and VAS ($p<0.05$). There was no significant difference between EQ-5D and SF-6D scores ($p>0.3$). Due to the skew of the EQ-5D EQ-5D scores, non-parametric Wilcoxon Signed Rank tests were also conducted (Table 5). There was a significant difference in scores between EQ-5D and VAS only ($p<0.1$).

Multiple regression was conducted to assess the impact of variables on health utility values (Table 6). The association between health utility and habitual visual acuity (VA) in the better seeing eye was assessed since VA is a widely used proxy for health utility.[14] VA was not a significant predictor of variations in any health utility measure.

Patient characteristics were added to the model: Age, gender, time since diagnosis and diagnosis (wet or dry). Only wet or dry diagnosis was a significant predictor of EQ-5D score ($p<0.05$), with wet AMD predicting higher utility. Diagnosis was also a significant predictor of SF-6D score, but not TTO or VAS.

Table 6: Regression results for health utility scores

	EQ-5D		SF-6D		TTO		VAS	
	Short	Full	Short	Full	Short	Full	Short	Full
Constant	0.648 (0.083)	0.864 (0.504)	0.609 (0.036)	0.601 (0.218)	0.528 (0.118)	1.872 (0.727)	0.612 (0.070)	0.027 (0.432)
Better eye VA	-0.034 (0.111)	0.012 (0.132)	0.024 (0.048)	-0.001 (0.057)	-0.032 (0.158)	0.068 (1.902)	-0.062 (0.093)	-0.088 (0.113)
Age		-0.002 (0.006)		0.001 (0.003)		**-0.016*** (0.008)		0.007 (0.005)
Gender (female)		-0.026 (0.077)		-0.026 (0.033)		-0.001 (0.111)		0.064 (0.066)
Time since diagnosis		-0.003 (0.006)		0.001 (0.003)		-0.004 (0.009)		0.001 (0.005)
Diagnosis (dry)		**-0.189**** (0.087)		**-0.081**** (0.038)		0.048 (0.125)		-0.070 (0.075)
R-squared	0.002	0.101	0.005	0.109	0.001	0.088	0.009	0.078
Obs	53							

*Standard errors reported in parentheses. *, **, *** indicates significance at 90%, 95% and 99% respectively*

Table 7: Regression results for EQ-5D scores with respect to patient utility measures

	TTO	VAS
Constant	0.462 (0.062)	0.098 (0.075)
Utility measure	**0.291***** (0.102)	**0.908***** (0.125)
R-squared	0.139	0.508
Observations	53	

*Standard errors reported in parentheses. *, **, *** indicates significance at 90%, 95% and 99% respectively*

The agreement between patient own health utilities and the EQ-5D UK public value set for the patient-reported health states was assessed by regression analysis (Table 7). Patient health utility measures (TTO and VAS) were significant predictors of the EQ-5D UK public value set ($p<0.05$). However, the variance accounted for was low, particularly for the TTO (R-squared=0.139).

Public information pilot

40 members of the general public completed 150 TTO tasks. Participants were randomly drawn into one of four information groups prior to beginning the task resulting in 13, 7, 7 and 13 participants entering groups 1, 2, 3 and 4 respectively. There were more females than males in the sample and the mean age was slightly lower than the UK average (Table 8).

Table 8: Public demographic information (n=40)

Group	1 (n=13) uninformed		2 (n=7) labeling		3 (n=7) information		4 (n=13) adaptation	
Mean age (SD)	36.8 (11.1)		38.1 (12.4)		29.1 (6.7)		35.7 (9.8)	
Gender	F: 9	M: 5	F: 6	M: 1	F: 5	M: 2	F: 6	M: 7

The public TTO valuations for each health state by each group are summarised in Table 9. Utilities were generally skewed towards 1.0 (left skew).

Table 9: Public utilities by group

	Health state 1 (0.76*)		Health state 2 (0.82*)		Health state 3 (0.88*)		Health state 4 (0.43*)	
Group	Mean (SD)	Median	Mean (SD)	Median	Mean (SD)	Median	Mean (SD)	Median
1 (uninformed)	0.73 (0.24)	0.81	0.85 (0.16)	0.90	0.87 (0.20)	0.94	0.49 (0.39)	0.51
2 (labeling)	0.64 (0.22)	0.73	0.70 (0.23)	0.78	0.90 (0.09)	0.93	0.45 (0.46)	0.63
3 (information)	0.49 (0.56)	0.68	0.72 (0.30)	0.88	0.88 (0.14)	0.95	0.58 (0.53)	0.71
4 (adaptation)	0.81 (0.16)	0.83	0.87 (0.12)	0.90	0.88 (0.16)	0.96	0.69 (0.21)	0.73
All	0.70 (0.30)	0.78	0.80 (0.20)	0.88	0.87 (0.17)	0.93	0.56 (0.37)	0.63

**EQ-5D-5L UK interim value set*

Multivariate regression was conducted to assess the impact of information and health state on health utility values (Table 10). Dummy variables were coded for levels of information and for health state.

Table 10: Regression results for public health utilities

	Short	Full	Info vs. no info
Constant	0.700 (0.054)	0.739 (0.129)	0.702 (0.093)
Group			
2 (labeling)	-0.062 (0.065)	-0.068 (0.072)	
3 (information)	-0.094 (0.065)	-0.092 (0.083)	
4 (adaptation)	0.079 (0.055)	0.061 (0.064)	
2-4 combined			-0.003 (0.048)
Health state			
2 (31211)	0.102 (0.063)	**0.123*** (0.726)	**0.106*** (0.064)
3 (11112)	**0.174***** (0.061)	**0.197***** (0.071)	**0.174***** (0.063)
4 (21513)	**-0.136**** (0.061)	**-0.125**** (0.070)	**-0.134**** (0.062)
Age		0.001 (0.003)	
Gender (female)		**-0.107*** (0.057)	
Health (Poor)		0.001 (0.034)	
Joint sig. health state (F)	**9.68*****	**8.04*****	**9.20*****
Joint sig. group (F)	**3.02****	1.48	
R-squared	0.210	0.233	0.160
Observations	150	126	150

*Standard errors reported in parentheses. *, **, *** indicates significance at 90%, 95% and 99% respectively. G1: No information, HS1: 31312*

Differences between health state and differences between information group were significant in the short model (HS: $p<0.001$; Group: $p<0.05$).

Health states 3 and 4 were associated with significantly different utility compared with health state 1 conditional on the covariates included.

In the full model - adjusted for age, gender and own health perception (excellent, very good, good fair, poor) – the impact of heath state on health utility score was significant whereas information group was not significant (HS: $p<0.001$; Group: $p>0.2$). Health states 2, 3 and 4 were associated with significantly different utility compared with health state 1. Gender was also a significant predictor of health utility.

Groups 2, 3 and 4 were combined to compare the effect of information against no information. The effect of information on health utility score was not significant in this model, however health states remained significant predictors.

Discussion

Patient health state valuation

The EQ-5D and SF-6D produced similar mean health utility values using the general public tariffs, whereas agreement between the EQ-5D and TTO was weak. We found no significant difference between patient EQ-5D and SF-6D scores. EQ-5D scores were significantly different from TTO scores and VAS scores using parametric tests.

One reason for the weak correlation with the TTO may be that patients are elderly, so the 10 years of perfect health may have a different value later in life. The difference between patient TTOs and EQ-5D scores may also be due to the TTO not measuring HRQoL in this population. Non-health time-related concerns such for living alongside a partner have anecdotally been mentioned as important when AMD patients undertake a TTO exercise.[15] Furthermore, the age of the patient sample and prevalence of comorbidities may make it hard to imagine living 10 years in perfect health. Having said this, whether or not the task is measuring HRQoL, the suggestion that patient preferences may not match those of the public raise questions on the allocation of health resources.

We found that better seeing eye VA was not significantly associated with health utility in the short or full models. This finding is concerning given that most cost utility analyses of AMD interventions have used Markov models based on the association between VA and health utility.[14, 16] However, it is also unsurprising given that most AMD patients have several chronic conditions unrelated to vision on account of their age, which may have a greater impact on the utility. Indeed, the low explanatory power of VA has been identified in other studies and another measure of vision such as contrast sensitivity may be better associated with health utility.[17] Given that our own study did not measure VA, but recorded it from hospital notes, another explanation for the weak agreement could be that the hospital notes may not represent up-to-date measures of the patient's vision.

Age was significant at $p<0.1$ in the TTO full model, with older patients reported lower utility, suggesting time effects could affect the patient TTO task. This could also be confounded by older patients possibly having more comorbidities.

Diagnosis (wet or dry) was significant in some models, with dry AMD predicting lower health utility in the EQ-5D and SF-6D models. This could be due to there being no treatment for dry AMD (as opposed to wet AMD where anti-VEGF therapy has been shown to be an effective treatment),[18] leading patients with dry AMD to feel less positive about their condition.

Public information pilot

The small sample size makes it difficult to draw firm conclusions in the public study. We found that Group 1 (no information) provided health utility values similar to the EQ-5D UK value set. This could be expected as the task was similar to the MVH study.

There was a trend (not significant) towards lower utility in groups 2 (labeling) and 3 (disease information) and higher utility in group 4 (adaptation) with respect to group 1 (no information). This may suggest that informing the public about the condition through labeling and patient description leads them to value the health state more seriously, but informing them that one can adapt to the condition leads to less serious valuations. Although it should be noted that the provision of information suggesting one can adapt over time may be confounded by the certainty of health condition over time required for the TTO task.

In any case, the significant difference between information groups overall in some models suggests that the way information about AMD is framed has an effect on public valuations of AMD health states.

Conclusions

From our patient study, we conclude that within the valuation task, there is an inherent difference when asked to value ones' own health compared with a hypothetical health state: patient TTOs and VAS health utilities differed significantly from EQ-5D or SF-6D scores from public tariffs.

No health utility measure is predicted by the most widely used measure of vision (better seeing eye VA). However, comorbidities mean that visual measures may be inherently poor predictors of health utility in elderly patients.

From our public information pilot study, we conclude that the framing of information leads the public to different valuations, although a larger study is needed to confirm whether the ordering trend of 'No information>Labeling>Disease Information<<Adaptation information' is significant.

Limitations

There are several limitations with this study beyond the small sample sizes. Firstly, in the mostly elderly sample of AMD patients, health utility may be driven by several chronic conditions. We did not attempt to isolate the visual component of health utility and so chose to present a real description of an AMD patient's health. As conditions cannot be assumed to be additive, including overall health in the valuation task is the only way to generate a health utility.

Secondly, a between subjects design was chosen since the nature of the task meant that the order of giving information could not be randomized within subjects (as information could not be taken back once given) and we wanted to exclude the possibility of an ordering effect whereby the valuations with more information were the latter valuations. We cannot exclude the possibility of differences between groups (despite randomisation), although this will be less of a problem in a larger scale full study and controlling for more sociodemographic factors in the regression models.

Finally, the challenge with providing accurate and objective information on the disease makes it difficult to compare utilities derived for different diseases

where information has been provided. The standardization of information is a topic which we do not address in this study as we have focused on one disease. However, we would suggest future research in this area is required if attempts are made to inform public valuation exercises.

Future work

We intend to run a large-scale public study (n=240) using an internet panel to test the significance of the effect of different types of information on health state valuations. We also intend to extend the study to include medical doctor (ophthalmologist and general practitioner) valuations, hypothesising that medical doctors, as information agents, may behave like 'fully informed' members of the general public.

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Appendix 1

Information provided to public

1. Labeling

The health states that you are about to be presented with describe a person with macular degeneration (although please note that this condition may not be the only cause of their health state). Please read this description of macular degeneration carefully:

Macular degeneration is a painless eye condition that leads to the gradual loss of central vision (the ability to see what is directly in front of you). Central vision is used while:

* reading
* writing
* driving

Macular degeneration does not affect the peripheral vision, which means that the condition will not cause complete blindness. The peripheral vision is sometimes known as "side vision".

2. Disease information: adapted patient description (in addition to label)

Here is a description by a patient, Shirley, of what it may be like to live with macular degeneration:

Shirley's granddaughter Caroline is four years old, and for most of her life, her grandmother has had macular degeneration, a condition that causes a loss of central vision.

"She always wanted to know what was wrong with Nana," says Shirley.

For the longest time, Caroline couldn't understand why her grandmother had trouble getting around. "I was always bumping into things," says Shirley. "And I didn't dare hold her when she was a baby – I was afraid of dropping her."

AMD also made it difficult for Shirley to see Caroline's face. "I would look at someone and see eyes on each side, but I couldn't see anything in the middle. There was no nose or mouth or anything."

Shirley first began to notice her vision was changing 10 years ago. "A road would look like it was hilly when in fact it was straight, and things like the edge of the stove or a painting would look like they were wavy. It was the strangest thing."

Her vision loss progressed rapidly, and soon she had to give up driving and reading, two activities that had been very important to her. Losing the ability to drive forced Shirley into retirement, because she no longer had a way to get to her job. And her long-time, three book-a-week habit fell by the wayside.

"I got very depressed." she recalls

3. Information on adaptation (in addition to label and disease information)

These are adjustments that can be made to adapt to life with macular degeneration:

* Getting around

You will be able to rely on peripheral or remaining vision, hearing, or the white cane to provide guidance. Devices such as telescopes can be used to identify street signs and addresses.

* Recognising faces

Arrange for a friend or peer to accompany you. It may be easier for them to explain to people that their smiles and waves can't be seen and to encourage them to identify themselves when they want to talk to you.

* Usual activities (reading and driving)

Driving is one activity that people with severe vision loss find extremely hard to give up. However, activities such as reading can continue with a little patience and adjustment. For instance, large-print books or a magnifier may help with reading. Talking books are an excellent substitute when reading becomes too difficult.