

To change or not to change: Understanding why members of the general population alter their values for rheumatoid arthritis states

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Introduction

Optimal allocation of resources is a crucial issue in publicly funded healthcare systems. One proposed method to ensure that resources are being spent most advantageously is to use cost-effectiveness analysis [1]. This analysis assesses health benefits on the basis of quality-adjusted life years (QALYs) rather than in units specific to the condition under investigation. The Washington Panel on Cost-effectiveness in Health and Medicine recommends that QALYs for a specific health state should be obtained from members of the general population rather than from patients who are actually in that state [2]. Using general population values ensures that policy decisions best represent societal priorities. However, the drawback of using responses from the general population is that they may not understand the implications of living in the investigated health state and, more importantly, may not consider the possibility of adapting [3].

There is an absence of empirical studies exploring the formation of general population values collected from respondents who have been informed about disease adaptation. This study aims to address this gap by meeting two objectives. Firstly, this study evaluates whether either the use of an adaptation exercise or a patient value presentation alters general population values for hypothetical health states. Secondly, the study identifies the factors which influence an individual to change their initial health state values after being informed about disease adaptation. Three rheumatoid arthritis (RA) states have been used as an illustration.

Methods

Study Participants

A representative sample of the general population in England was recruited using the AFD Names and Numbers version 3.1.25 (AFD Software Limited, Ramsey, Isle of Man, UK). This software provides access to a comprehensive list of names and addresses to over 39 million people living in the UK. A randomized sample of households from various neighbourhoods in two South Yorkshire towns was invited to take part in this study. Interested participants were

randomly allocated into one of two groups – the Uninformed Group or the Informed Group – and interviewed on a one-to-one basis in their own homes.

Study Design

The design of the study is illustrated in Figure 1. Participants in the Uninformed Group first completed a series of valuation exercises. Six health states – full health, own current health, dead, and three RA states of different severities (developed in an earlier study [4] and presented in Figure 2) – were rated on a visual analogue scale (VAS), graded from zero to 100. These extremes represented the worst and best imaginable states, respectively. The respondents then valued the three RA states using a self-completed bottom-up titration time trade-off (TTO) exercise [5]. For the TTO, there was a choice between two alternatives, both with certain prospects: 25 years¹ in the hypothesized health state or x years – which is varied from zero to 25 years – in full health; both prospects were followed by death.

An adaptation exercise followed. Participants were asked if they knew the common symptoms of arthritis² and whether they knew someone living with arthritis. They then listened to the first of the three recordings of patients discussing adapting to life with RA (Appendix 1) and were encouraged to discuss, and reflect upon, the information in the recording. This process was repeated with the remaining two recordings. After the adaptation exercise, the participants repeated the VAS and TTO valuation tasks described in the preceding paragraph.

Participants in the Informed Group, on the other hand, underwent the adaptation exercise *before* valuing the health states by VAS and TTO (as shown in Figure 1). After the adaptation exercise and first valuation, these respondents were subjected to a patient values presentation, where patient TTO values for the states [6] they previously valued were provided. The participants were also shown their personal TTO values for the RA states they had valued. After the presentation, they were asked to repeat the same valuations using both VAS and TTO.

¹ This time horizon is chosen as the trade-off to provide sensitivity to assess any changes that may arise in subsequent valuations and to avoid easy calculation of the implied values by the respondents.

² The disease under investigation was generally referred to as ‘arthritis’, rather than as rheumatoid arthritis, to the participants. The intention of this generalized labelling is an attempt to not cognitively overburden the participants with definitions of various forms of arthritis. The interviewer had clinical definitions of both rheumatoid arthritis and osteoarthritis readily accessible if the participants questioned the distinction between the two terms.

At the final stage, the Reasons to Change Questionnaire (RCQ) was administered to both groups. This questionnaire, developed based on the results of an earlier qualitative study [7], aimed to determine the rationales respondents may have for altering their initial health state values. The items of the RCQ, presented in Table 1, were evaluated using a five-point Likert scale ranging from strongly disagree to strongly agree.

The fundamental rationale for having two groups of participants in the study design was to identify potential prevarication bias. Evaluating the effect of an intervention with a single group runs the risk of individuals changing their valuations to please the interviewer [8]. Thus, comparing the second values provided by the Uninformed Group with the first values of the Informed Group tested respondents' desire to inflate their values.

Data Analysis

To meet the study objectives, the participants' responses were subdivided in terms of the group allocation. The dataset was not pooled together because the first and second valuations of the two groups have different implications. For example, the first values by the Uninformed Group were not subjected to the adaptation exercise while the first values by the Informed Group were; thus, aggregating these values would not be meaningful. The values obtained from the VAS and TTO approaches were transformed to a [0,1] scale as done previously [9].

All analyses described in this section were conducted using SPSS version 14 for Windows (SPSS, Chicago, IL, USA). Statistical significance for all tests was defined as $p \leq 0.05$.

Study Sample

Participants were characterized in terms of their sex, age range, education level, employment status, illness experience, and, as a proxy for current health status, their EuroQol-5D (EQ-5D) preference-weighted index [9]. Categorical variables are presented as the proportion of the sample within each group while continuous variables are presented as means and standard deviations (SDs). Independent t-tests evaluated whether differences existed between the demographic variables and group allocation of the individuals.

Exclusion of the Health State Values

To ensure that the results from the statistical analysis would be meaningful, the internal consistency of the responses was evaluated. Respondents were hypothesized to prefer fewer and

milder symptoms rather than greater and more severe symptoms. Therefore, responses that were not considered internally consistent were: (i) any health states rated higher than Full Health; and (ii) states pertaining to RA not rated in the order of State X \succ State Y \succ State Z, where ' \succ ' represents a greater preference for the first state over the second. Inconsistent responses – not respondents – were removed from subsequent analysis. For example, suppose that an individual valued State Y \succ State X on the VAS; subsequently, all VAS responses for this individual were excluded but their TTO values were retained for analyses. The resulting health state values were characterized as means and SDs.

Statistical Tests of Association

As explained below, a series of statistical tests were conducted to assess the effect of the adaptation exercise, the effect of the patient value presentation, and the individuals' potential desire to please the interviewer.

The Effect of the Adaptation Exercise

Paired t-tests were conducted to compare the first and second health state values of the Uninformed Group. If statistically significant changes were observed between the values, this indicated that the adaptation exercise had influenced the individuals' valuations.

The Effect of the Patient TTO Values Presentation

Paired t-tests were also conducted between the first and second health state values provided by individuals in the Informed Group. Statistically significant changes between these values would indicate that the presentation of the patient values influenced the valuations.

The Potential Desire to Please the Interviewer

By conducting independent t-tests, the presence of prevarication bias can be evaluated. Statistically significant changes between the Uninformed Group's second valuation and the Informed Group's first valuation would suggest that individuals in the Uninformed Group increased their second values in order to satisfy the interviewer. If no differences were detected, any significant results from the paired t-tests evaluating the effectiveness of the adaptation exercise would suggest that the Uninformed Group did not inflate their initial values.

Factors that Influence Individuals to Change their Values

One of the principal outcomes from this work was to use the RCQ to identify what aspects of the adaptation exercise may have encouraged individuals to change their values for the hypothetical health states (e.g. the difference between valuation 2 and valuation 1). To examine the factors influencing this change, individual-level data were explored; results obtained in this fashion are more statistically powerful than at the aggregate level. Individual-level analysis was only conducted using responses in the Uninformed Group. The rationale behind this decision was that the first valuation of the Informed Group was subjected to the adaptation exercise and the RCQ does not distinguish between the effect of the adaptation exercise and the effect of the patient values presentation.

Principal Components Analysis

Before regression models were constructed, the items of the RCQ were subjected to principal components analysis (PCA). PCA is a statistical technique which aims to simplify complex sets of data by transforming possibly correlated variables into a smaller number of uncorrelated variables, referred to as 'principal components' [10]. The first principal component accounts for the largest fraction of the variability in the dataset while each succeeding component accounts for as much of the remaining unexplained variability as possible. This technique was used to reduce the number of RCQ items to a more tractable number. As a result principal components, rather than individual items, were included as explanatory variables in the regression model.

Multivariate Linear Regression

Linear regression describes a relationship between one or more explanatory variables and the dependent variable (i.e. the continuous change in health state values for both VAS and TTO methods). The multivariate linear regression function is represented by a linear combination of more than one regression coefficient. The coefficients indicate the magnitude of the change in the predicted health state value for every one-unit increase for a given explanatory variable, while holding all other variables in the model constant.

The following main effects were expected to influence changes in health state values: sex, age, illness experience, current health status, RCQ principal component scores, RA state valued, and valuation method used; all categorical variables were dummy-coded. The creation of interaction terms was based on researcher judgement, guided by the results from the qualitative study [7]. It was expected that the RCQ component scores might interact individually with sex, presence of

chronic condition, experience with arthritis, current health status, RA state, and valuation method. Illness experience was expected to interact with an individual's current health status. In addition to these two-way interactions, three-way interaction terms were constructed between RA states, valuation method, and the RCQ component scores.

Before multivariate linear regression was conducted, univariate analyses identified those variables which individually best explained the changes observed in the health state values. The explanatory variables were considered on their own in the model and their significance was evaluated using the t-test statistics. If the variable was comprised of more than one level – for example, age group – the model fit was assessed using the F-test statistic.

Using backwards regression, a model containing only main effects was constructed. All variables were entered into the model simultaneously. Only those that had a significance level of $p < 0.05$ remained in the final model. When the main effects model was finalized, interaction terms were manually entered into the model one at a time. The best fitting of these interaction terms was then added to the model, and the process was repeated for the remaining interaction terms. These steps were repeated until no additional interaction term improved the overall fit of the model. The F-test statistic was used to examine the overall significance of the model. A significant F-test statistic implies that there is at least one regression coefficient statistically different from zero. The overall fit of the model was assessed using the R^2 value.

Results

Characteristics of the Participants

A total of 200 individuals participated in the study. The participants were equally allocated into either the Uninformed or the Informed Groups (Table 2). Within each group, there were 48 males and 52 females of varying ages. The distribution of the ages and sexes of the participants in each group were selected to align with the data obtained from the current census results [10]. The two groups were similar in terms of marital status, education level, employment status, illness experience, and EQ-5D indices. The mean (SD) time for the participants to complete the entire interview process was 46.9 (11.6) minutes.

Health State Values

After removing inconsistent responses, 175 VAS values (84 responses by the Uninformed Group and 91 responses by the Informed Group) and 179 TTO values (90 responses by the Uninformed Group and 89 responses by the Informed Group) remained. The aggregate health state values for the VAS and TTO approaches demonstrated that the expected trends were observed, such that Full Health > Your Own Health > State X > State Y > State Z > Dead (Table 3).

The Effect of the Adaptation Exercise

Results from the paired t-tests showed that the Uninformed Group changed their values for most health states; only the Dead state by the VAS did not result in a statistically significant change. This provided evidence that the adaptation exercise was effective at altering respondents' initial health state values.

The Effect of the Patient TTO Value Presentation

The paired t-test revealed that the Informed Group only showed statistically significant changes for two states: Full Health by VAS ($p < 0.05$) and State Z by TTO ($p < 0.01$). This demonstrates that the patient value presentation, when preceded by the adaptation exercise, had a limited role in altering health state values, such that it only influenced change for the most extreme health state.

The Potential Desire to Please the Interviewer

When independent t-tests were conducted to compare the second valuation of the Uninformed Group and the first valuation of the Informed Group, there were no significant differences between these two values across all states (denoted as 'p-values' on the right column in Table 3). These results suggest that individuals in the Uninformed Group did not inflate their values when appraising the health states during their second valuation simply to please the interviewer.

Linear Regression

Number of Principal Components in the Reasons to Change Questionnaire

Seven principal components were identified based on the RCQ responses by the Uninformed Group (results not presented). The principal components were best described as personality, information, coping strategies, opinions of arthritis, empathy, ease with the valuation exercises, and illness experience.

Univariate Analyses

Univariate analyses were conducted to assess what variables were statistically significant when included individually in a model addressing changes in health state values. The results indicate that change was influenced by age ($p < 0.01$), current health status ($p < 0.01$), experience with illness ($p < 0.02$), personality ($p < 0.04$), information ($p < 0.01$), and ease with the valuation exercises ($p < 0.01$). For example, individuals who were more likely to change their values were those that were younger in age, healthier, had no illness experience, had positive personalities, were receptive to the new information presented, and had no difficulty with the valuation exercises.

Multivariate Analyses

Table 4 presents the main effects and the interaction terms that influenced individuals to change their initial health state values. The main effects included age, current health status, coping strategies, and exercise ease.

The model had a constant value of 0.09 units, which represented the baseline level of change amongst all participants. When completing the second valuation for the RA states, older individuals were less likely to increase their initial values. Relative to younger individuals (i.e. less than 30 years of age), those between 30-59 years only increased their values by 0.03 units (i.e. 0.091 – 0.059) and those over 60 actually decreased their values by 0.02. Change was also influenced by the individual's current health status. Relative to individuals in poorer health (i.e. EQ-5D index of less than 0.65), those with better health (i.e. EQ-5D index > 0.95) increased their values by 0.15 whereas those with moderate health (i.e. EQ-5D index 0.65-0.95) raised their values by 0.10. Although the moderate EQ-5D group was not statistically significant, it was included in the model to ensure that all EQ-5D levels were captured in the full model. Individuals who had better coping strategies increased their initial values by 0.11, whereas those who found the valuation exercises easy increased their values by 0.12.

The results indicated that the inclusion of the two interaction terms improved the overall fit of the model that explains changes in health state values. When individuals valued the severe RA state using the TTO, initial values increased by 0.21. Individuals who were healthier (i.e. with a EQ-5D index greater than 0.95) and had an improved opinion of arthritis, after undergoing the adaptation exercise, increased their values by 0.12.

Discussion

The main finding from this study was that individuals can be informed about disease adaptation. This is demonstrated by the increase in their valuations of RA health states following the use of the adaptation exercise. Furthermore, the study revealed that an individual's age, current health status (as represented by the EQ-5D index), coping strategies, and ease with the valuation exercises influenced their willingness to alter their valuations.

Values for Health States

Administration of the adaptation exercise had an influence on the individual's initial health state values. This was detected by statistically significant changes between the two valuations provided by the Uninformed Group across most health states. On the other hand, the patient value presentation had a minimal effect on the health state valuations; the only difference detected was when individuals in the Informed Group valued the severe RA state by TTO. The latter result applies for respondents who had been informed about adaptation prior to the first valuation; the potential impact of the patient value presentation in place of the adaptation exercise was not investigated in this present study.

The only health state that yielded a change in the negative direction was State X using the TTO approach for the Informed Group; however, this was not statistically significant. Nor was a reduction observed when State X was valued by VAS. Qualitatively, however, when these participants observed the patient values before the second valuation, many of them commented that they were surprised that patients would be willing to give up 4.8 years of their lives (from a total of 25 years) to not have to live with a mild form of RA. Thus, it is assumed that the observed reduction in values was a result of incorporating the information gained from the patient value presentation.

The concern that individuals would inflate their second values after hearing the recording of the patients' interviews because of a desire to please the interviewer was alleviated. This is supported by the fact that the results from the independent t-tests between the values subjected to the adaptation exercise (i.e. the second values by the Uninformed Group and the first values by the Informed Group) showed no difference. As such, this provided evidence that the impact of

the adaptation exercise on the health state values can be effectively compared using the Initially Uninformed Group's values.

The results indicate that, when using the VAS as the technique for valuation, individuals were more likely to provide lower values for life in various RA states on a [0,1] scale when compared to using TTO. This result contributes to the current body of evidence stating that different valuation techniques yield different results [12]. The lower VAS values may be a result of the respondents not considering the duration of the health states when making their assessments [13]. Alternatively, the TTO encouraged the respondent to think about time spent in the impaired health state in one-year increments. A "threshold of tolerability" may have contributed to the higher TTO values. States would have to fall below a certain point before respondents would be willing to give up any time at all on the TTO [13].

Changes in Health State Values

The difference between the values provided by the two groups demonstrates a larger change between the values of the Uninformed Group's respondents. This indicates that the patient value presentation, for respondents who had already undergone the adaptation exercise, had less of an impact on altering the individuals' initial health state values than did the adaptation exercise.

The valuation methods influenced the individuals' health state values differently. The VAS had a greater affect on the individuals' valuation for the mild RA state, such that a larger change between the valuations was detected when compared to TTO. On the other hand, a greater change was detected when individuals valued the severe RA using the TTO method. This may be a result of the differing range of sensitivity for each of the valuation methods. The VAS seemed to be more capable of differentiating between responses at the upper end (close to full health) of the scale, while the TTO appeared to be more sensitive at the lower end.

The results obtained from assessing change in health state values need to be interpreted with care especially in cases where individuals, at first, valued a state as being worse than dead and then, after being informed about adaptation, their impression of the state improved to being better than dead. The reason for this concern is that states worse than dead were 'transformed' [14]; this transformation has been used elsewhere in the literature [15]. This conversion allows negative values to range from -1 to 0. If this transformation had not been done, the minimum value for

states worse than dead would reach -24, if trade-offs were limited to whole years. As a result, the results may be an underestimation of the amount of change observed because two different scales to measure states better than dead and states worse than dead were utilized. However, this is expected to have only had a small effect as only 12/179 (7%) individuals appraised State Z to be worse than dead at first and improved their valuation as a state better than dead afterwards.

Regression Model

Using the responses from the Uninformed Group, the factors that influenced respondents' decisions to change their health state values were explored. Consistent with the results obtained from the statistical tests of association, whether individuals were younger in age or whether they had better health (i.e. high or moderate EQ-5D indices) influenced their likelihood to change their initial values. The answers to the RCQ revealed that an individual's coping strategies and their ease with the valuation exercises also contributed to the individual's willingness to alter their initial values. The inclusion of interaction terms improved the overall fit of the model. Individuals valuing the most severe RA state by TTO tended to increase the second valuation more when compared to the milder two states. This was not unexpected since many individuals, after being informed about their values for the extreme state and its implications, reported that they were surprised that they were going to give up that many years of life to avoid living with RA; this was consistent with the findings from the qualitative study [7]. In addition, healthier individuals with an improved opinion of arthritis were more likely to change their values for the most severe RA state.

The model predicting changes in individuals' health state values had a low R^2 . This low value is not a cause for concern since the objective of this analysis was to assess the relative effect of the different respondent characteristics on the valuations rather than to find a model that explained all the variance in the changes in health state values.

Study Strengths and Limitations

To our knowledge, this is the first study that assesses what factors may influence members of the general population to change their health state valuations when presented with an adaptation exercise. While the implementation of an adaptation exercise has been used previously [16-18], this current study was the first to utilize interviews from patients to promote concepts of disease adaptation.

While the use of patient interviews was a novel technique in discussing concepts of disease adaptation, the optimal way of describing adaptation to members of the general population remains to be determined. Patient interviews tap into the respondents' emotions such as empathy regarding health and illness; this may not be appropriate from a decision-maker's perspective due to the desire that valuations should be made behind a veil of ignorance [2]. Furthermore, the order which the interviews was played may have affected the participant's decision to alter their initial QOL value. By starting with a negative patient interview and then improving the messages in the subsequent interviews, this potentially could have led the participants to increase their values.

Although the objective of the RCQ was to gain information about the complex rationales for why respondents changed their health state values, it may not have utilized all the constructs. While valid and reliable instruments that measure personality and empathy levels could have been used, the RCQ was believed to be superior, as it was based directly on information gained from an earlier qualitative study [7] and, thus, was directly related to the adaptation exercise used in the study.

The use of an external organization to collect the data provided an objective way to obtain health state values. If the lead author had conducted the interviews, her desire for people to change their values might have been evident to the participants; as such, the participants' desire to please may have been much greater. Instead, she accompanied the interviewer for 7% (14/200) of the interviews over the course of the data collection process to ensure quality and consistency in the interviews being conducted. The participants were not made aware that the lead researcher was present, in case this biased their answers in any way. They were informed that the additional person present was to observe the interviews for training purposes.

This study included participants recruited from two South Yorkshire towns. Although the sample was representative of the national age and sex distribution, it is unlikely that the results obtained are generalizable to all of the UK. As this study was a methodological in nature, the results were used to inform rather than to apply in practice.

Individuals who participated in the study were provided with £10 for their time. While it is acknowledged that the provision of a financial incentive may result in differential participation

amongst individuals with different socio-economic backgrounds, the researchers felt that an incentive was needed to encourage reasonable participation rates. This was a result of the fact that the target sample was members of the general population, who had no vested interest in the topic, and that the interviews took a substantial amount of time (48 minutes on average). Otherwise, the study results could have been biased towards people who had a particular interest in RA (either patients or family members and/or friends of patients).

Conclusions

In conclusion, the use of an adaptation exercise encouraged individuals to change their initial values for RA states; the patient value presentation, on the other hand, had a negligible effect on further change for participants who had already been informed through the adaptation exercise. Statistical tests and regression models revealed that an individuals' age and current health status have a significant effect on the magnitude of change in their health state values. The results from this study add to the debate of whose values should be considered when making decisions regarding healthcare.

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Figures

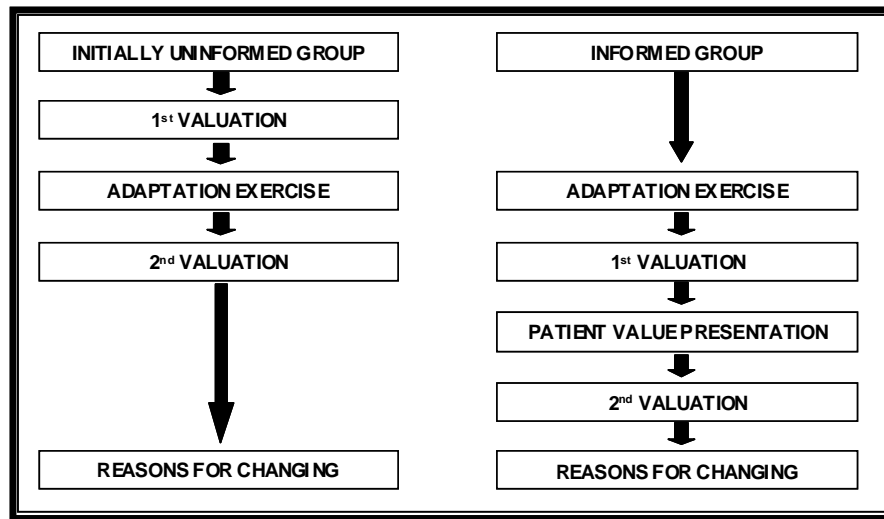


Figure 1: Data collection process

Mild RA	Moderate RA	Severe RA
You have some difficulty bending down to pick up clothes from the floor.	You have some difficulty bending down to pick up clothes from the floor.	You have much difficulty bending down to pick up clothes from the floor.
You have some difficulty climbing up 5 steps.	You have much difficulty climbing up 5 steps.	You are unable to climb up 5 steps.
You have no difficulty lifting a full cup or glass to your mouth.	You have some difficulty lifting a full cup or glass to your mouth.	You have much difficulty lifting a full cup or glass to your mouth.
You have some difficulty standing up from a straight and armless chair.	You have much difficulty standing up from a straight and armless chair.	You have much difficulty standing up from a straight and armless chair.
You have mild pain and discomfort.	You have moderate pain and discomfort.	You have extreme pain and discomfort.

Figure 2: Descriptions of RA Health States

Table 1: The Reasons to Change Questionnaire

Variable	Definition
UNDARTHDIS	Taking part in today's session has helped me to understand more about the disease of arthritis
UNDARTHLIFE	Taking part in today's session has helped me to understand more about what it is like to live with arthritis
UNDARTHYPAT	Taking part in today's session has helped me to realize that that I now know as much as patients do about what it is like to live with arthritis
GOODQOL	Taking part in today's session has helped me to realize that you still could have a good quality of life when living with arthritis
WORSEDIS	Taking part in today's session has helped me to realize that there are worse diseases to have than arthritis
NOTOLD	Taking part in today's session has helped me to realize that arthritis is not "just a part of getting old"
PAINOK	Taking part in today's session has helped me to realize that living with pain is not always a horrible thing
FAMTIME	Taking part in today's session has helped me to realize that I would rather live longer with arthritis so that I can spend more time with my family and friends
NOTWEAK	Taking part in today's session has helped me to realize that having arthritis does not have to make me look vulnerable or weak
COVERUP	Taking part in today's session has helped me to realize that I can cover up the signs of arthritis to appear normal
SELFCOPE	Taking part in today's session has helped me to realize that people can cope with having arthritis by themselves
FAMCOPE	Taking part in today's session has helped me to realize that family and friends can help people cope with arthritis
PATCOPE	Taking part in today's session has helped me to realize that I can cope with arthritis because patients cope with it
RECORDING	My opinions about arthritis changed after hearing the recordings
TALKING	My opinions about arthritis changed after talking to the interviewer
PATSCORE	My opinions about arthritis changed after seeing the patient scores
IMAGINARTH	In general, I feel that if I had to, I think that I can imagine living with arthritis for the rest of my life
OTHERSHOE	In general, I feel that I can "put myself in other people's shoes" and see things from their point of view
UNFAIR	In general, I feel that it's unfair for me to value a patient's life because I don't really know what it's like to live with arthritis
POSOUTLOOK	In general, I feel that I have a positive outlook on life
ADAPT	In general, I feel that I am the type of person that can adapt to change
HLTHPRBSELF	In general, I feel that I personally know what it is like to have a health problem
HLTPRBOTH	In general, I feel that I know what it is like to have a health problem through a family member or a close friend
FIRSTEXER	In general, I feel that I understood the first valuation exercise
SECDEXER	In general, I feel that I understood the second valuation exercise
TRADEOFFDIFF	In general, I feel that I had a difficult time deciding how long I wanted to live with arthritis on the valuation exercises

Table 2: Characteristics of the study participants^a

	Uninformed Group (n = 100)	Informed Group (n = 100)	National Census^b
Males			
<i>Younger than 30 years</i>	9	13	10
<i>30-39 years</i>	10	8	9
<i>40-49 years</i>	9	9	9
<i>50-59 years</i>	8	6	8
<i>60-69 years</i>	6	6	6
<i>Older than 70 years</i>	6	6	6
<i>Total</i>	48	48	
Females			
<i>Younger than 30 years</i>	9	10	10
<i>30-39 years</i>	9	9	9
<i>40-49 years</i>	10	9	9
<i>50-59 years</i>	9	8	8
<i>60-69 years</i>	9	9	7
<i>Older than 70 years</i>	6	7	9
<i>Total</i>	52	52	
Education level			
<i>Primary school</i>	0	1	
<i>Secondary school</i>	54	63	
<i>A-levels</i>	14	12	
<i>University</i>	17	13	
<i>Other (e.g. college)</i>	14	9	
Employment status			
<i>Self employment</i>	7	6	
<i>Paid employment</i>	49	44	
<i>Unemployed</i>	8	9	
<i>Retired</i>	20	27	
<i>Looking after home</i>	5	5	
<i>Student</i>	1	1	
<i>Disabled/long-term sick</i>	10	8	
Illness experience			
<i>Has arthritis</i>	26	35	
<i>Knows someone with arthritis</i>	48	38	
<i>Has chronic illness</i>	12	9	
<i>None</i>	14	18	
EQ-5D score (mean \pm SD)	0.768 (\pm 0.349)	0.765 (\pm 0.328)	

^aReported in as a count unless otherwise indicated.

^b UK Statistics Authority (2009). *Age structure of England and Wales* [online].

http://www.statistics.gov.uk/populationestimates/svg_pyramid/default.htm [Accessed 27 January 2009].

Table 3: Aggregate health state values^a

Health State	Valuation Attempt	Groups				p-Value ^b	Patient Value Presentation ^c
		Uninformed Group		Informed Group			
		Health State Value	Change	Health State Value	Change		
<i>Visual Analogue Scale</i>							
Full Health	1 st	0.95 (0.07) ^e	0.02	0.95 (0.10)	0.01	0.16	---
	2 nd	0.97 (0.05) ^e		0.96 (0.09)			
Your own health	1 st	0.76 (0.25) ^d	0.02	0.78 (0.20)	0	0.95	---
	2 nd	0.78 (0.23) ^d		0.78 (0.20)			
Dead	1 st	0.01 (0.05)	0	0.01 (0.07)	0	0.87	---
	2 nd	0.01 (0.06)		0.01 (0.06)			
Mild RA	1 st	0.55 (0.18) ^e	0.07	0.58 (0.18)	0.02	0.12	---
	2 nd	0.62 (0.17) ^e		0.60 (0.18)			
Moderate RA	1 st	0.37 (0.19) ^e	0.06	0.41 (0.18)	0	0.40	---
	2 nd	0.43 (0.17) ^e		0.41 (0.16)			
Severe RA	1 st	0.16 (0.20) ^d	0.04	0.19 (0.17)	-0.01	0.25	---
	2 nd	0.20 (0.15) ^d		0.18 (0.15)			
<i>Time Trade-off</i>							
Mild RA	1 st	0.81 (0.25) ^d	0.06	0.87 (0.24)	-0.03	0.93	0.81
	2 nd	0.87 (0.22) ^d		0.84 (0.28)			
Moderate RA	1 st	0.64 (0.32) ^d	0.06	0.66 (0.42)	0.03	0.54	0.73
	2 nd	0.70 (0.34) ^d		0.70 (0.39)			
Severe RA	1 st	0.25 (0.48) ^e	0.17	0.36 (0.54) ^d	0.06	0.47	0.66
	2 nd	0.42 (0.50) ^e		0.42 (0.52) ^d			

^a Values standardized so that zero represents Dead and one represents Full Health.

^b P-values from the independent t-tests (testing between the second attempt of the Initially Uninformed Group and the first attempt of the Informed Group).

^c Patient values only available for TTO.

Comparison of mean values (using paired t-tests): ^d $p \leq 0.05$, ^e $p \leq 0.01$.

Table 4: Multivariate linear regression model for changes in health state values

Variables	Estimates		
	Coefficient	Standard Error	p-Value
Constant	0.091	0.037	0.01
Age			
30-59 years	-0.059	0.030	0.05
Over 60 years	-0.112	0.034	< 0.01
Current health status			
EQ-5D > 0.95	0.062	0.028	0.03
EQ-5D 0.65 – 0.95	0.012	0.033	0.71
Coping strategies	0.020	0.011	0.05
Ease with valuation exercises	0.026	0.010	0.01
Severe RA * TTO	0.114	0.028	< 0.01
EQ-5D > 0.95 * Opinions of arthritis	0.027	0.012	0.02

$R^2 = 0.09$, $F = 6.76$, $p < 0.01$

APPENDIX

Appendix 1: Transcripts of patient interviews used in the adaptation exercise

Recording One

I didn't let anyone know how bad it was. You put a front on. It wasn't until I got indoors that I'd do the little weeping and the wailing kind of thing [laughs]. So yeah, I don't, I don't think they really knew, like, as I say, my Mom didn't know until we'd gone to [the] Zoo, how bad I was. And she was really, really shocked. 'Cuz I just didn't tell, you know, I'd just got on with it. Struggled, I didn't, you know, I didn't cope with it, I struggled. But as far as everyone else was aware it wasn't as bad as, you know, obviously for [daughter's name] and my husband, they didn't really know how bad it was. So I did cope with, I could go to Hollywood, couldn't I? I could be in Hollywood. But no, I did, I did really, yeah, yeah, I did cover it.

I think one instance we'd gone to, we'd gone out with my brother-in-law and all our families and I was, just sat down normally. I was sat in a club kind of thing, you know, sat down having a drink and it was just like, 'I've got to go to the toilet' and it took me about five minutes, to get up, to get up and get out of the chair. And you know people were going, "We didn't realize you were that bad". 'Cuz I just couldn't get my body to do anything.

Recording Two

But, and then I think it was about two years ago now I started swimming and that has just been fantastic. Because that is something I can do and I do it five days a week, every morning. I started off it, doing, it was this time of year, October, I got into the pool and I could do 35 lengths and I thought by Christmas I want to swim a mile and at Christmas I did. I was doing my 64 lengths in the hour.

And now there's a new pool opened, and the same group of people go, and we all sort of, I mean they're not all sufferers, some just go because they enjoy going but we all sort of support each other, if you like, and I haven't been for two days this week so I'm already in trouble.

But I can swim now for about an, well I could swim for two hours if I wanted to but I don't because I have other things to do, but I, I have found that that has helped and my consultant, you know, just sees me, says, 'ah my swimmer'. You know, he's, he's really impressed that of the you know, the way I've sort of dealt with it. I didn't think, "Ah, my life has ended, I'm never going to be able to do anything". I just thought "Well okay, this is what it is and I'm not going to let it beat me, you know". So I don't, I try to do everything as I did before, but in moderation and that seems to have worked quite well so far. I do still have bad days and sometimes the medicine upsets me.

But I would say in general I feel better now than I did, you know, sort of four or five years ago.

Recording Three

As I said earlier on, there are three ways you can deal with arthritis and I've found this out personally when I first started this. You can be very angry and fight it. That only lasts for a certain time because the only one that's getting hurt is you. 'Cuz the more of a temper and, and that you get in the more you create, "Ooh that hurts", sort of thing.

The other thing is you can give in right from the beginning and you can say, "I can't do that". And let everybody else do it for you and give no thought to the fact that they've got their lives to live and they shouldn't be feeling that way that they've got to do it for you. And the third thing is to come terms with it and don't live against it, live with it. And when you get a bad pain just sit, whatever suits you. If you get a bad pain and painting the wall gives you relief, go and paint the wall. If you find, like me myself, the only way to get over it is to just sit quietly and rest and it will go.