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The impact of disease adaptation information on general population values for rheumatoid arthritis states

Helen M. McTaggart-Cowan[*,a], Aki Tsuchiya[a,b], Alicia O'Cathain[a], John E. Brazier[a]

[a]School of Health and Related Research, University of Sheffield, Sheffield, UK

[b]Department of Economics, University of Sheffield, Sheffield, UK

[*] Corresponding author

School of Health and Related Research

University of Sheffield

Regent Court

30 Regent Street Sheffield, UK S1 4DA

h.m.cowan@sheffield.ac.uk, hmctc@hotmail.com

Abstract

Economic evaluation of healthcare technologies uses values for hypothetical health states elicited from the general population rather than patients. However, they may not consider adaptation. This study explored the extent to which the general population changes their initial values, and the factors that influenced this change, after being informed about adaptation. Three rheumatoid arthritis (RA) states were used for illustration. Two respondent groups were interviewed. The Initially Uninformed Group initially valued the RA states. An adaptation exercise followed, where they listened to recordings of patients discussing how they adapted; they then valued the same states again. The Informed Group underwent the adaptation exercise before valuing the states. The difference between the valuations was examined using t-tests. A multivariate regression was developed to assess the factors that impacted individuals to change their initial values. After undergoing the adaptation exercise, the Initially Uninformed Group statistically increased their values for the RA states. When the second values of the Initially Uninformed Group were compared to the first values of the Informed Group, there were no statistical differences, implying that there was no interviewer effect. Younger and healthier individuals were more likely to increase their initial values after being informed about adaptation.

Keywords: health state values, utility, general population, disease adaptation, time trade-off

1. Introduction

Globally, there is an insatiable demand for resources that greatly exceeds available supply. Within a publicly-funded healthcare system, resources available to meet its demands are scarce. Decision-makers are therefore faced with the challenge of how to allocate these resources to ensure that fair and efficient decisions are being made.

The National Institute for Health and Clinical Excellence (NICE) recommends that economic evaluation be used to ensure that transparent and consistent decisions are made (National Institute for Health and Clinical Excellence, 2009). Specifically, cost-effectiveness analysis (CEA) permits the comparison of the healthcare technology under investigation and a suitably chosen alternative, where their benefits are quantified using quality-adjusted life years (QALYs) (National Institute for Health and Clinical Excellence, 2008). The QALY is a measure that combines information regarding both duration and quality of life (QOL) into a single index (Drummond et al., 2005). Values describing QOL represent the desirability individuals place on living in a particular health state. These values are anchored by a value of one for full health and zero for dead; a higher value indicates a greater preference for a given health state.

It has been advised that information about QOL, in the form of health state values, should be obtained from informed members of the general population rather than from patients (Gold et al.,1996). Respondents are asked to envision what life in the impaired state would be like. This method follows the concept that, in a publicly-funded healthcare system, members of the general population are the tax-payers and their responses should meet societal preferences for maximizing health. However, the drawback is that they may not be informed. They may not fully comprehend life with a health condition. In particular, they may not consider adaptation – a process to adjust to a new or changed situation – to the impaired health state. This inattention can significantly alter the direction of resource allocation when their values are incorporated into CEA (Gold et al., 1996; Brazier et al., 2005).

The current challenge for researchers is to find ways to refine the elicitation of health state values such that the general population are informed about disease adaptation. While a few studies have used ‘adaptation exercises’ (Ubel et al., 2005; Damschroder et al., 2005, 2008), the act of

providing respondents with information about adapting to life in a hypothetical health state has not been empirically examined in sufficient detail. Ubel et al. (2005) prompted individuals to think about a previous emotionally challenging life event and to assess how their emotions towards that event changed over time. By encouraging them to consider the possibility of adaptation, their QOL ratings for paraplegia increased. In another study, Damschroder et al. (2005) used the person trade-off approach to assess the ability of a similar adaptation exercise to encourage the general population to consider adaptation to paraplegia. The study findings demonstrated that, after undergoing the adaptation exercise, respondents increased the value placed on pre-existing paraplegia and on new onset paraplegia, relative to saving healthy lives. However, in their subsequent follow-up study, the adaptation exercise did not have a significant impact on general population's standard gamble and time trade-off values (Damschroder et al., 2008).

In addition to the introspective approaches described above, other techniques may include providing information on the size and the nature of adaptation experienced by patients over time and presenting respondents with their personal values, as well as patient values, for the investigated health states (Brazier et al., 2005); these methods are the foci of this present study. Thus, this study aims to firstly evaluate whether disease adaptation information 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 are used as an illustration.

2. Methods

2.1 Study Participants

A representative sample of the general population was recruited using the AFD Names and Numbers version 3.1.25 (AFD Software Limited, Ramsey, UK). It provides access to 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 Initially Uninformed Group or the Informed Group – and individually interviewed in their own homes. They had the option of either receiving £10 for their participation or donating this amount to the

Arthritis Research Campaign. The University of Sheffield ethics committee approved the study protocol.

2.2 Study Design

The design of the study is illustrated in Figure 1. The Initially 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 (i.e., mild, moderate, and severe) – were rated on a visual analogue scale (VAS), graded from zero (worst imaginable state) to 100 (best imaginable state). The three RA states were developed in an earlier study (McTaggart-Cowan et al., 2010) and presented in Figure 2. The respondents were not explicitly told that they were valuing states pertaining to RA to avoid any pre-conceived ideas they may have had regarding the condition. The respondents then valued the same RA states using a self-completed bottom-up titration time trade-off (TTO) exercise (Gudex, 1994). For the TTO, there was a choice between two alternatives, both with certain prospects: 25 years in the hypothesized RA state or x years – varied from zero to 25 years – in full health; both prospects were followed by death. States worse than dead were permitted. A 25-year time horizon was chosen as the trade-off, instead of the conventionally used 10-year time frame (Dolan et al., 1996), to provide sensitivity to assess any changes that may arise in subsequent valuations and to avoid easy calculations of the implied values by the respondents. The health states were written on individual cards, which were shuffled by the interviewer. The state on top of the pile was shown to the respondent to rate first until all health states were seen by the respondent. This process ensured that the order in which the respondents valued these states was randomized for each individual.

An adaptation exercise followed (McTaggart-Cowan et al., 2009). The interviewer asked the participants if they knew the common symptoms of RA and whether they knew someone living with the condition. They then listened to the first of three audio-recordings of patients discussing adapting to life with RA (Appendix 1) and were encouraged to discuss, and reflect upon, the content with the interviewer. 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 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, they were subjected to a patient values presentation, where patient TTO values for the states (Tijhuis et al., 2000) they previously valued were provided. They were also shown their personal TTO values for the RA states they had valued. After the presentation, they repeated the same valuations using both VAS and TTO.

The rationale for having two participant groups in the study design was to identify potential interviewer effects. Evaluating the effect of the adaptation exercise with a single group may run the risk of individuals changing their valuations to please the interviewer; this is known as prevarication bias (Hiebert and Nordin, 2006). Similarly, there is a chance that an interviewer may inadvertently persuade the respondents to change their values in an attempt to obtain positive research results. Therefore, by comparing the second values by the Initially Uninformed Group with the first values by the Informed Group, the potential for interviewer effects can be determined.

After the second valuation, all respondents provided demographic information and completed the EuroQol-5D (EQ-5D). The Initially Uninformed Group completed the Reasons to Change Questionnaire (RCQ). The RCQ, developed based on the results of an earlier qualitative study (McTaggart-Cowan et al., 2009), aimed to determine the rationales respondents may have for altering their initial health state values. The items of the RCQ (Table 1) were evaluated using a five-point response scale ranging from strongly disagree to strongly agree.

2.3 Data Analysis

2.3.1 Study Sample

Participants were characterized in terms of sex, age range, education level, employment status, illness experience, and, as a proxy for current health status, their EQ-5D preference-weighted index (Brooks, 1996). 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 and χ^2 tests evaluated whether differences existed between the demographic variables and group allocation of the individuals.

2.3.2 Health State Values

All health state values were standardized onto a [0,1] scale (The EuroQol Group©, 1990). For the VAS approach, this was achieved by:

$$\text{Value}_{\text{Standardized}} = \frac{(\text{Unstandardized Health State Value} - \text{Dead Value})}{\text{Full Health Value} - \text{Dead Value}}. \quad (1)$$

For the TTO approach, two methods were used. This depended on whether the health state was considered to be better or worse than dead. The value for a better than dead health state was calculated as:

$$\text{Health State Value}_{\text{States better than dead}} = t/25, \quad (2)$$

where t is the number of life years for which a respondent was indifferent to living in the hypothesized health state and living in full health. For states worse than dead, the common practice is to transform values so that the negative values fall in the range of [-1,0] (Patrick et al., 1994):

$$\text{Transformed Health State Values}_{\text{States worse than dead}} = -(25 - t/25). \quad (3)$$

Values were then assessed as to whether they were internally consistent. Respondents were hypothesized to prefer milder symptoms rather than more severe symptoms. Therefore, responses that were not considered internally consistent were: states not rated in the order of mild RA $\succ$ moderate RA $\succ$ severe RA, where '$\succ$' represents a greater preference for the first state over the second. Inconsistent responses were removed from subsequent analysis. The resulting values are characterized as means and standard deviations.

2.3.3 Statistical Tests of Association

Statistical tests were conducted to assess the effect of the adaptation exercise, the effect of the patient value presentation, and the effect of the interviewer. Statistical significance for all tests was defined as $p \leq 0.05$.

The Effect of the Adaptation Exercise

Paired t-tests were conducted to compare the first and second values of the Initially Uninformed Group. If statistically significant changes are observed, this indicated that the adaptation exercise may have had an influence on the valuations.

The Effect of the Patient TTO Values Presentation

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

The Effect of the Interviewer

The presence of an interviewer effect can be evaluated through independent t-tests. Statistically significant changes between the Initially Uninformed Group's second valuation and the Informed Group's first valuation would suggest that individuals in the former group may have increased their second values due to an interviewer effect.

2.3.4 Factors that Influence Individuals to Change their Values

A multivariate linear regression model was developed to identify what aspects of the disease adaptation information may have encouraged the respondents to change their health state values (i.e., difference between second and first values). This was achieved by developing a relationship between the continuous change in values for both VAS and TTO methods and respondents' demographic information and responses to the RCQ.

Principal Components Analysis

The items of the RCQ were first subjected to principal components analysis (PCA), a statistical technique that simplifies complex sets of data by transforming possibly correlated variables into a smaller number of uncorrelated variables (Kline, 1994). 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.

First, the inter-correlation between RCQ items was examined. If any items did not correlate well with other items ($r<0.20$) (Field, 2005), then they were removed, as some correlation between items was needed to identify principal components. Similarly, items were excluded if they were too highly correlated ($r>0.80$) with other items (Field, 2005); this alleviated the potential for multicollinearity. Within each set of items that demonstrated either low or high correlation, an

item was removed one at a time and the R-matrix was assessed. The chosen item to be excluded should result in R-matrix with the highest determinant (i.e., $>1 \times 10^{-5}$). The inter-correlation between items was re-assessed to ensure all remaining items were moderately inter-correlated ($0.20<r< 0.80$).

Second, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity assessed whether the dataset was suitable for PCA. The KMO test statistic assesses the patterns of correlations in a given dataset. A KMO value of zero indicates that the correlation patterns are widely spread such that the sum of partial correlations is large relative to the sum of correlations. A KMO value of one indicates that the patterns of correlations are compact and distinct, resulting in reliable components. An adequate value for the KMO test statistic is 0.5-0.7 but ideally this value should be higher (Field, 2005). The Bartlett's test of sphericity examines whether the original correlation matrix is an identity matrix (e.g., all correlation coefficients are zero); some relationships between variables need to be present for PCA to be successfully applied to a given dataset. A significant Bartlett's test statistic implies that the R-matrix is not an identity matrix and hence PCA can be applied to the data.

Finally, the ideal number of principal components for the given dataset was determined using the Kaiser criterion. The Kaiser criterion is based on the eigenvalues, which are determined during the extraction of the components. The eigenvalues associated with each factor represent the variance explained by that particular linear component. The identified principal components were to be considered as potential explanatory variables in the regression modelling.

Multivariate Linear Regression

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. 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.

First, 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.

Then using backwards regression, a model containing only main effects was constructed. All variables were entered into the model simultaneously; all insignificant variables ($p>0.05$) were removed simultaneously from the final model. Interaction terms were then manually entered into the model one at a time. This was repeated until no additional interaction term improved the overall fit of the model. The F-test statistic examined the overall significance of the model and the R^2 assessed the overall model fit.

3. Results

3.1 Characteristics of the Participants

Two hundred individuals participated in the study. To recruit this number of respondents, invitation letters were posted to 649 addresses; a response rate of 32% was achieved. The participants were equally allocated into either the Initially Uninformed or the Informed Groups (Table 2). Within each group, there were 48 males and 52 females of varying ages. The age-sex distribution aligned with the data obtained from the current census results (UK Statistics Authority, 2009). The two groups were similar in terms of martial status, education level, employment status, illness experience, and EQ-5D indices. The mean (SD) time for the participants to complete the interview process was 46.9 (11.6) minutes.

3.2 Health State Values

After removing inconsistent responses, 175 VAS values (84 responses by the Initially Uninformed Group and 91 responses by the Informed Group) and 179 TTO values (90 responses by the Initially 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 Mild RA $\succ$ Moderate RA $\succ$ Severe RA (Table 3).

3.2.1 The Effect of the Adaptation Exercise

Results from the paired t-tests showed that the Initially Uninformed Group changed their values for most health states ($p<0.01$). This suggested that the adaptation exercise may have had a role in altering respondents' initial health state values.

3.2.2 The Effect of the Patient TTO Value Presentation

The paired t-tests revealed that the Informed Group only showed statistically significant changes for only severe RA 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.

3.2.3 The Effect of the Interviewer

When independent t-tests were conducted to compare the second valuation of the Initially 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' in Table 3). This suggests that individuals in the Initially Uninformed Group slightly inflated their values when appraising the health states during their second valuation but this increase was not found to be statistically significant.

3.3 Linear Regression

3.3.1 Number of Principal Components in the Reasons to Change Questionnaire

When the inter-correlation between the RCQ items was examined, two pairs of items were highly correlated with each other: UNDARTHDIS and UNDARTHLIFE; and RECORDING and TALKING. The exclusion of the latter item of each of these pairs resulted in a larger R-matrix determinant and the desired moderate inter-correlation values between all items ($0.20<r<0.80$). The PCA yielded KMO test statistics of 0.73, which exceeds the range of adequacy (0.5-0.7). The result from Barlett's tests of sphericity was statistically significant ($p<0.01$), indicating that the R-matrix was not an identity matrix.

Seven principal components were identified (Table 1). The principal components were best described as personality, information, coping strategies, opinions of arthritis, empathy, ease with the valuation exercises, and illness experience.

3.3.2 Univariate Analyses

Univariate analyses indicated that change was influenced by age ($p<0.01$), current health status ($p<0.01$), illness experience ($p<0.02$), personality ($p<0.04$), information ($p<0.01$), and ease with the valuation exercises ($p<0.01$) (Table 4). Individuals who were more likely to change their values were those that were younger, healthier, had no illness experience, had positive personalities, were receptive to the new information presented, and had no difficulty with the valuation exercises.

3.3.3 Multivariate Analyses

Table 5 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. Inclusion of two interaction terms improved the overall fit of the model that explains changes in health state values. Initial values increased when individuals valued the severe RA state using the TTO and when healthy individuals (i.e., with an EQ-5D index ≥ 0.95) gained an improved opinion of arthritis, after undergoing the adaptation exercise.

4. Discussion

The main finding from this study is that individuals increased in their valuations of RA health states following the adaptation exercise. The results also revealed that an individual's age and current health status influenced their willingness to alter their valuations after being informed about adaptation.

The influence of the adaptation exercise on the individual's initial values was detected by statistically significant changes between the two valuations provided by the Initially Uninformed Group. The patient values presentation, however, had a minimal effect on the Informed Group's valuations; the only difference detected was when individuals in the Informed Group valued the severe RA state by TTO. This may be due to respondents being already informed with the audio-recordings prior to the first valuation and the patient values presentation may not have provided any further, or different, insight.

The results indicate that when using the VAS, 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 (Brazier et al., 2007). The lower VAS values may be a result of the respondents not considering the duration of the health states when making their assessments (Robinson et al., 1997). Alternatively, the TTO may have 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 (Robinson et al., 1997).

The results assessing the 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' (Dolan et al., 1996); this transformation has been used elsewhere in the literature (Patrick et al., 1994). 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. Thus, the results may be an underestimation of the amount of change observed because two different scales were utilized to measure states better and worse than dead.

Using the Initially Uninformed Group responses, the factors that influenced respondents' decisions to change their health state values were explored. 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 slightly improved the overall fit of the model. The low R^2 was not considered to be 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.

To our knowledge, this is the first study that assessed what factors may influence the general population to change their health state valuations when presented with an adaptation exercise. Adaptation exercises have previously been used (Ubel et al., 2005; Damschroder et al., 2005, 2008) but this study was the first to utilize audio-recordings to demonstrate how real patients live with, and adapt to, the condition. Interestingly, Damschroder et al. (2008), which also used the TTO approach, found that administration of the adaptation exercise had no effect on the health state values; this is contrary to the present results. This discrepancy between the results may be related to the fact that Damschroder et al. (2008) used a generic adaptation exercise (i.e., think back to a previous different life event and assess how your emotions toward this event changed over time) to encourage respondents to consider disease adaptation when valuing health states pertaining to paraplegia, below-the-knee amputation, colostomy, and severe pain. An adaptation exercise of this type may not have encouraged the respondents to focus specifically on concepts of adaptation related to the health states they were valuing. In the current work, the adaptation exercise was condition-specific, such that respondents were aware that people with RA can adapt to their health condition over time. They could then choose whether to apply this information directly to their health state values.

The study results may be influenced by a labelling effect. When the Initially Uninformed Group valued the health states during the first attempt, they were not told that the health states pertained to RA. However, when they underwent the adaptation exercise, they were informed that the audio-recordings were patients living with RA. As a result, when they completed the valuation exercises for the second time, they had the label of 'RA' in their minds. Since individuals in the Informed Group completed the adaptation exercise first, they were informed the states pertained to RA for both valuation attempts. The use of labels may have affected the individuals' aggregate values, and their corresponding changes. This may have led to lower values due to the introduction of emotion and stereotype into their valuations. On the other hand, an opposite effect may result with health state labels. By not providing a label, respondents may have initially associated the health states to be more severe than when the same scenario was presented to them with labels. In either of the aforementioned scenarios, labels may have confounded the impact of the adaptation exercise on general population values.

The concern that individuals would inflate their second values after hearing the recordings of the patients' interviews because of an interviewer effect was alleviated. Results from the independent t-tests between the values subjected to the adaptation exercise (i.e., the second values by the Initially Uninformed Group and the first values by the Informed Group) showed no statistically significant differences. However, this lack of cross-group differences may not be conclusive that an interviewer effect was not presence; this may also be, perhaps, due to the different processes involved with the two groups (i.e., greater reflection and labelling effect).

For this study, audio-recordings from the Health Talk Online website (DIPEx Health Experiences Research Group, 2008) were used to inform the general population respondents about adaptation to RA. While it was considered advantageous to use actual patients discussing how they have dealt with their health condition, the information available on the aforementioned website may have been biased towards the positive end as its primary intention is to provide educational and supportive material for patients. The recordings therefore may not have fully addressed the entire range of adaptation issues for the respondents to consider. The inclusion of first audio-recording aimed to highlight the struggles a patient may face, and hence provide a more complete picture of life in the described health states. However, an astute respondent may recognize that this patient was in her first year of having RA and that after some time, she may begin start making changes to her life to accommodate her illness. As a result, the adaptation exercise used may have portrayed a distorted picture of adaptation in RA; especially since the severity of the patients' condition to not align with the health state descriptions.

The preceding discussion introduces the issue of what type of information, if any, should be presented to the general population to inform them about adaptation. Specifically, should a normative approach be taken (i.e., information about fully adapted patients) or should a more comprehensive range of patient views be included (i.e., incorporating patients with differing degrees of adaptation using a combination of laudable and non-laudable techniques)? By including all forms of adaptation, respondents can make the assessment as to how they want to incorporate this information into their valuations. This would allow the influence of specific aspects of the adaptation process on an individual's health state values to be examined.

Developing a greater understanding of how information may influence health state values is important before adaptation exercises are used to guide healthcare resource allocation decisions.

There is a need to incorporate these informed general population values into a CEA and to compare them with those obtained using 'uninformed' general population – and even patient – values. However, this may not be a simple exercise of populating existing CEAs with the informed values and examining its impact on the incremental cost-effectiveness ratios. Decisions will need to be made as to how best to assess the impact these values have on a CEA. Should the respondent be asked to value health states after being informed about a fully adapted patient? Or, should the respondent be informed about a series of events – onset of disease, during the adaptation process, and after a period of adaptation – and be asked to provide a value for each of these events? In the latter scenario, the theoretical model of the QALY will need to be reconsidered. By calculating individual QALYs for each of the event, quantity and quality of life can no longer be regarded as utility independent. This could significantly impact the standard practice of using tariffs or valuation sets in economic evaluation of healthcare technologies.

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 individual's age and current health status have a significant effect on the magnitude of change in their health state values. The results from this study contribute to the emerging field of developing better informed general population values.

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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.

Figures

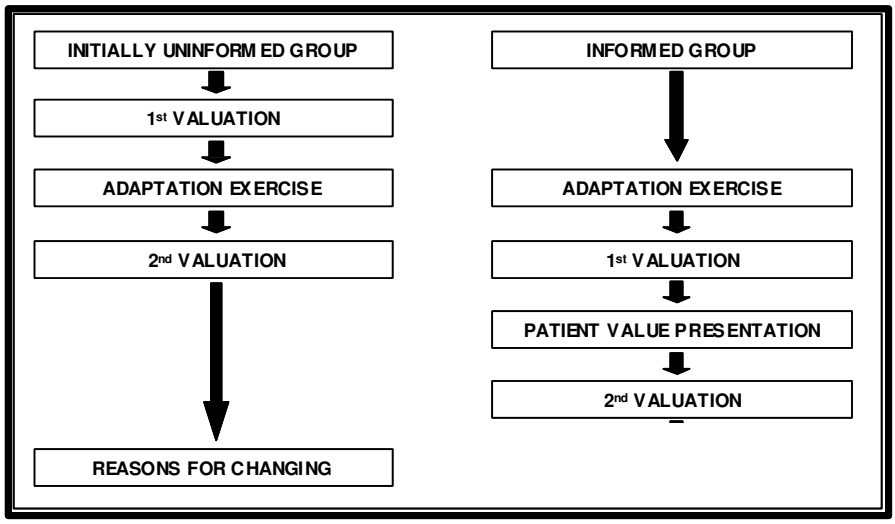

Figure 1: Data collection process

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	Principal Component (Factor Loading)
UNDARTHDIS	Taking part in today's session has helped me to understand more about the disease of arthritis	Information (0.72)
UNDARTHLIFE	Taking part in today's session has helped me to understand more about what it is like to live with arthritis	Personality (---)
UNDARTHPAT	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	Opinions of arthritis (0.61) Personality
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	(0.58)
WORSEDIS	Taking part in today's session has helped me to realize that there are worse diseases to have than arthritis	Opinions of arthritis (0.54)
NOTOLD	Taking part in today's session has helped me to realize that arthritis is not "just a part of getting old"	Opinions of arthritis (0.69) Personality
PAINOK	Taking part in today's session has helped me to realize that living with pain is not always a horrible thing	(0.49)
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	Personality (0.65)
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	Personality (0.65)
COVERUP	Taking part in today's session has helped me to realize that I can cover up the signs of arthritis to appear normal	Recognition of coping strategies (0.82)
SELFCOPE	Taking part in today's session has helped me to realize that people can cope with having arthritis by themselves	Recognition of coping strategies (0.79)
FAMCOPE	Taking part in today's session has helped me to realize that family and friends can help people cope with arthritis	Personality (0.44)
PATCOPE	Taking part in today's session has helped me to realize that I can cope with arthritis because patients cope with it	Recognition of coping strategies (0.54)
RECORDING	My opinions about arthritis changed after hearing the recordings	Information (0.76)
TALKING	My opinions about arthritis changed after	Information (---)

	talking to the interviewer	
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	Empathy (0.69)
OTHERSHOE	In general, I feel that I can "put myself in other people's shoes" and see things from their point of view	Empathy (0.65)
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	Empathy (-0.66)
POSOUTLOOK	In general, I feel that I have a positive outlook on life	Personality (0.75)
ADAPT	In general, I feel that I am the type of person that can adapt to change	Personality (0.73)
HLTHPRBSELF	In general, I feel that I personally know what it is like to have a health problem	Illness experience (0.83)
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	Illness experience (0.73)
FIRSTEXER	In general, I feel that I understood the first valuation exercise	Ease with valuation exercises (0.89)
SECDEXER	In general, I feel that I understood the second valuation exercise	Ease with valuation exercises (0.85)
TRADEOFFDIFF	In general, I feel that I had a difficult time deciding how long I wanted to live with arthritis on the valuation exercises	Information (0.74)

Table 2: Characteristics of the study participants[a]

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

[a]Reported 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		
Visual Analogue Scale							
Full Health	1st	0.95 (0.07)[e]	0.02	0.95 (0.10)	0.01	0.16	---
	2nd	0.97 (0.05)[e]		0.96 (0.09)			
Your own health	1st	0.76 (0.25)[d]	0.02	0.78 (0.20)	0	0.95	---
	2nd	0.78 (0.23)[d]		0.78 (0.20)			
Dead	1st	0.01 (0.05)	0	0.01 (0.07)	0	0.87	---
	2nd	0.01 (0.06)		0.01 (0.06)			
Mild RA	1st	0.55 (0.18)[e]	0.07	0.58 (0.18)	0.02	0.12	---
	2nd	0.62 (0.17)[e]		0.60 (0.18)			
Moderate RA	1st	0.37 (0.19)[e]	0.06	0.41 (0.18)	0	0.40	---
	2nd	0.43 (0.17)[e]		0.41 (0.16)			
Severe RA	1st	0.16 (0.20)[d]	0.04	0.19 (0.17)	-0.01	0.25	---
	2nd	0.20 (0.15)[d]		0.18 (0.15)			
Time Trade-off							
Mild RA	1st	0.81 (0.25)[d]	0.06	0.87 (0.24)	-0.03	0.93	0.81
	2nd	0.87 (0.22)[d]		0.84 (0.28)			
Moderate RA	1st	0.64 (0.32)[d]	0.06	0.66 (0.42)	0.03	0.54	0.73
	2nd	0.70 (0.34)[d]		0.70 (0.39)			
Severe RA	1st	0.25 (0.48)[e]	0.17	0.36 (0.54)[d]	0.06	0.47	0.66
	2nd	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: Univariate analyses for model assessing changes in health state values

Explanatory Variables	Model Fit		Individual Estimates		
	F-test	p-Value	Coefficient	Standard Error	p-Value
Health States (referent group = Severe RA)	1.98	0.14			
Mild RA			-0.048	0.027	0.07
Moderate RA			-0.045	0.027	0.10
Valuation Method (referent group = VAS)	2.20	0.14			
TTO			0.033	0.022	0.14
Sex (referent group = male)	0.07	0.79			
Female			-0.006	0.022	0.79
Age (referent group = less than 30 years)	5.76	< 0.01			
30-59 years			-0.068	0.030	0.02
Over 60 years			-0.115	0.034	< 0.01
Current Health Status (referent group – EQ-5D<0.65)	5.31	< 0.01			
EQ-5D> 0.95			0.087	0.028	< 0.01
EQ-5D= 0.65-0.95			0.037	0.033	0.26
Illness Experience (referent group = no illness experience)	3.41	0.02			
Has arthritis			-0.083	0.034	0.02
Knows someone with arthritis but has no direct illness experience			-0.007	0.024	0.78
Has chronic illness but not arthritis			-0.068	0.032	0.03
Components of the Reasons to Change Questionnaire					
Personality			0.029	0.014	0.04
Information			0.033	0.013	0.01
Recognition of coping strategies			0.018	0.011	0.10
Opinions of arthritis			0.013	0.010	0.20
Empathy			-0.001	0.012	0.90
Ease with valuation exercises			0.027	0.010	< 0.01
Illness experience			-0.017	0.012	0.13

Table 5: 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

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