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Questioning the differences between general public vs. patient based preferences towards EQ-5D-5L defined hypothetical health states

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ABSTRACT

The purpose of this article is to explore whether any differences exist between the general population and patient based preferences towards EQ-5D-5L defined hypothetical health states. The article discusses the role of adaptation and self-interest in valuing health states and it also contributes rigorous empirical evidence to the scientific debate on the differences between the patient and general population preferences towards hypothetical health states. Patient preferences were elicited in 2015 with the EQ-5D-5L questionnaire using time trade-off and discrete choice experiment design and compared to the Spanish general population preferences, which were elicited using identical methods. Patients were chosen on a voluntary basis according to their willingness to participate in the survey. They were recruited from patient organisations and a hospital in Madrid, Spain. 282 metastatic breast cancer patients and 333 rheumatoid arthritis patients were included in the sample. The analysis revealed differences in preferences between the general population and patient groups. Based on the results of our analysis, it is suggested that the differences in preferences stem from patients being more able to accurately imagine "non-tangible" dimensions of health states (anxiety or depression, and pain or discomfort) than the general population with less experience in various health states. However, this does not mean that general public values should not be reflected in utilities derived for coverage decision making.

1. Introduction

The primary purpose of the cost-effectiveness analysis is to assist a decision making process. In cost-utility analysis, which is a sub-group of cost-effectiveness analysis, the benefits are measured as quality-adjusted life-years or QALYs. The cost-effectiveness ratio of health care interventions is evaluated by dividing the total costs of a therapeutic intervention by the number of QALYs gained. The QALY model is a numerical economic valuation model used to set priorities in health insurance schemes, where weights are based on preferences toward health related quality of life (HRQoL). Preferences are quantitative expressions of certain health states.

The position of the US Panel on Cost Effectiveness in Health and Medicine is that "...these weights should be based on community preferences, rather than those of patients, providers, or investigators" [1,p. 1256]. In the EU, the NICE Methods Guide states that "the valuation of health- related quality of life measured in patients (or

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by their carers) should be based on a valuation of public preferences from a representative sample of the UK population. . ."[2,p.43]. These views are supported by many others, as most European countries recommend an instrument that is based on the general public preferences [3]. The most popular arguments in favour of the general public preferences are that community members better represent taxpayers and potential patients [4,5], and that they are hidden behind a "veil of ignorance", making them blind to their own self-interest and therefore establishing principles of justice which would ensure fair distribution of resources [5]. Additionally, an argument against the use of patient preferences is the concept of adaptation [e.g. 6–10], which presents a normative problem in the case of HRQoL. Patients generally value health states higher than the general public [11], which in turn leads to a lower priority for treatment. Another limitation of the use of patient preferences is the inability to assess rare adverse treatment events due to a lack of patients with relevant experience [5] and patients being able to answer [12,13].

The scientific discussion on whether QALYs should comprise patient preferences as opposed to community preferences is still ongoing [2,4,5,11–26]. Several studies provide empirical evidence on the differences between patient and general public preferences. While some of these studies demonstrated no compelling differences [e.g. 12,14,15], the evidence of the differences between the groups has been growing [e.g. 2,4,11,16–20,26]. To our knowledge our study was the first to compare general and patient preferences towards hypothetical health states – we assumed that patients who adapt to the worse health state would attach higher utilities to the surrounding hypothetical health states compared to the general public.

The objective of this article is to inspect the following arguments:

1 Patient preferences are different from general population pReferences
2 Patients are not blind to their own self-interest; patients value health states lower than the general public.
3 Adaptation: Patients value health states higher than the general public.

We treat self-interest and adaptation as two sides of the same coin and its effect on hypothetical health state valuation is reversed. If patients adapt then the more severe the patients (experienced) health is, the less priority she will give to the same or similar hypothetical health state, whereas if patients have self-interest, the more severe the patients (experienced) health is the more priority she will give to the same or similar hypothetical state.

2. Materials and methods

This paper compares the patient and the general population preferences towards EQ-5D-5L defined hypothetical health states. The EQ-5D-5L descriptive system of health states consists of five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Each of the dimensions can take one of five levels of severity (no problems, slight problems, moderate problems, severe problems, and unable to/extreme problems). The existing general population values for selected health states were obtained for Spain and used as a benchmark to compare to the new patient based preferences. Patient groups were selected in which the clinical changes are well reflected in the EQ-5D-5L instrument and used in clinical areas [27]. Among the diseases listed metastatic breast cancer and rheumatoid arthritis were chosen.

In order to assure comparability, the EuroQol defined protocol for preference elicitation would be strictly followed. Differences in collecting the data can have potential influences on respondents' responses [28,29], which have important implications for the validity of the results, and for the soundness of the public policy developed from evidence using questionnaire-based research [30]. As personal interviews with computer assisted EQ-5D-5L questionnaire using time trade-off (TTO) and the discrete choice experiment (DCE) design were used on the Spanish general population, the identical method was used to elicit preferences from patients. In this article, the arguments are supported using the results gained using TTO methodology. The main disadvantage in applying DCE models is that these models generate values on an arbitrary scale, and not on the metric of the quality (of life) component of the quality-adjusted life-year scale. However, EuroQol decided to include a DCE task in the pilot studies for the valuation of the EQ-5D-5L questionnaire to further investigate the merits of DCE for health state valuation [31].

The TTO method is designed to elicit preferences for health states by letting a respondent imagine living a defined number of years in an imperfect health state. The respondent has to indicate the number of life years in full health at which he/she is indifferent between both options: the longer period of living in imperfect health state and the shorter period of life in full health.

Sample size was defined by analysing the EQ-5D-5L data gathered by EQ-VT (EuroQol valuation technology) from three countries (the Netherlands, United Kingdom and Spain) to assess the minimum number of observations required. Using a standard error of 0.05 as a threshold implied a minimum of 125 observations per health state per disease area, where each respondent values 10 hypothetical health states. Hence, 19 states ("55555" in both blocks) were divided over 2 blocks. Two blocks of 10 health states were balanced with respect to utility (i.e. both blocks should contain a mix of mild, moderate and severe states). The sample size was determined at 300 patients per disease area. The main difference is that general population assessed 86 health states, while patients assessed only 19 health states, a subset of 86 health states due to smaller sample size in the study resulting from financial restrictions.

Ethical approval was obtained on March 13, 2015 at Puerta de Hierro Majadahonda Hospital. Patients were selected using non-probabilistic methods on a voluntary basis according to their willingness to participate in the survey. 28 patients who were contacted rejected to start the interview or decided not to continue interview in the middle of the interview. The reasons for that are threefold: as only two patient groups were selected, patients know each other. As many of them talked about their experience

Table 1
Distribution of problems by dimension of breast cancer patients.

	Mobility	Self-care	Usual activities	Pain/Discomfort	Anxiety/Depression
No prob.	76.2%	81.5%	66.3%	50.7%	55.9%
Slight	12.0%	11.0%	21.3%	37.6%	28.1%
Moderate	9.9%	6.8%	11.7%	10.6%	14.6%
Severe	0.7%	0.7%	0.4%	1.1%	1.1%
Extreme	1.1%	0.0%	0.4%	0.0%	0.4%

with friends and relatives, they influenced the behavior of others to enroll in the study and some of them decided not to attend. Further, some of the patients got too tired during the interview due to its longevity (the average duration of the interviews was 43 min). The last reason for not continuing is the patients realizing the nature of the task – it seemed too realistic and reminded them of their own or their friends' situation and was hence too emotional to make it to the end. They were selected from patient organisations and hospitals in Madrid, Spain. 615 face to face interviews with the patients were performed by 4 different interviewers from June until November 2015.

The data analysis was generated using R [32]. A formal test of differences was performed using Welch's two sample *t*-test and Wilcoxon rank sum test with continuity correction. In order to test whether one group attached higher or lower values, the one-sided test was used.

Regression models were used in order to examine the causes of differences, where the dependent variable was a TTO score and independent variables were severity levels on 5 health dimensions, which were treated as discrete variables with no problems (value 1), some problems (2), moderate problems (3), severe problems (4), and extreme/unable (5). Besides these variables, dummy variables were used to distinguish between patients and members of the general population.

Lastly, we added five variables, one for each health dimension, termed "adaptation", with a purpose to test if a person's valuations of hypothetical health states are dependent on their own health states. We tested if patients' experiences with impaired health are reflected in their valuations. If a coefficient of "adaptation" variable is positive, it implies that patients value hypothetical health states, which are similar to their experiences with disease, less severely. A positive coefficient measures the extent to which adaptation is reflected in their valuations of hypothetical health states. On the other hand, a negative coefficient implies that patients value hypothetical health states, which are similar to their experience with disease, more severely, following the insurance principle or so called self-interest. In order to put the value of the adaptation coefficient in a comparable range of values with other variables in the model, adaptation variable was defined as the natural logarithm of the squared ratio of the severity level of the hypothetical state dimension, and the severity level of the experienced (self-reported) health dimension. Hence, adaptation variables measure the relative distance on the health dimension between the hypothetical and self-reported health states. If a patient values hypothetical health states that are more severe than a self-reported health state, the value of adaptation variable is positive, whereas if a person values hypothetical health states that are less severe, the value of adaptation variable is negative.

"TOTAL" model did not distinguish between general population and patients and did not consider adaptation; "GENERAL POPULATION & PATIENTS" model was used to distinguish between general population and patients while "PATIENTS & ADAPTATION" model was used to distinguish between general population and patients while accounting for adaptation or self-interest.

3. Results

Sample size of the patient population was 615, providing a total number of 6150 estimated health states. Sample size of breast cancer patients was 282 persons (243 women and 39 men), and the sample size of rheumatoid arthritis patients was 333 persons (198 women and 135 men). As presented in Table 1 below, within the breast cancer group, the largest share of patients reported problems with pain. Anxiety or depression was the second most problematic health dimension reported by breast cancer patients, where 44.1% reported at least some problems. Problems with usual activities were reported by 33.7%, while 23.8% of the breast cancer patients reported problems with mobility.

Within the rheumatoid arthritis group (Table 2), the largest share of patients reported problems with pain. Contrary to the breast cancer group, men reported more pain than women. Again, the second most problematic health dimension reported by rheumatoid arthritis patients was anxiety or depression (41.9% reported at least some problems). Problems with usual activities were reported in 33.3% of the respondents with rheumatoid arthritis. 28.2%

Table 2
Distribution of problems by dimension of Rheumatoid arthritis patients.

	Mobility	Self-care	Usual activities	Pain/Discomfort	Anxiety/Depression
No prob.	71.8%	79.8%	66.7%	51.0%	58.1%
Slight	17.5%	13.3%	23.1%	37.2%	27.9%
Moderate	9.8%	6.6%	9.9%	11.5%	12.9%
Severe	0.6%	0.3%	0.3%	0.3%	0.9%
Extreme	0.3%	0.0%	0.0%	0.0%	0.3%

Table 3
Differences between general population and patient population.

	Mobility	Self-care	Usual activities	Pain/Discomfort	Anxiety/Depression
No prob.	−14.2%	−14.7%	−25.1%	−16.9%	−23.3%
Slight	6.9%	8.8%	16.6%	14.5%	14.1%
Moderate	6.8%	5.6%	8.7%	3.5%	9.6%
Severe	−0.1%	0.5%	−0.1%	−1.1%	0.0%
Extreme	0.5%	−0.2%	0.0%	0.0%	−0.3%

of the rheumatoid arthritis patients reported problems with mobility and 20.2% of the rheumatoid arthritis group reported problems with self-care.

In Table 3, the differences in self-assessed health between general population and patient population samples are presented. Compared to general population, patients in the sample had on average 18.84% more problems regarding health dimensions. Slight and moderate problems were reported 19.02% more often in the patient population compared to the general population sample. The share of severe and extreme problems was similar between groups.

The patient sample differed (in terms of the problems defined by EQ-5D) the most in usual activities, as 25.1% had more problems compared to general population. Patients were 16.6% more likely to experience slight problems and 8.7% more likely to experience moderate problems with usual activities.

Anxiety/depression was the health dimension that had the second largest difference, as patients had a 23.3% higher prevalence of problems in that health dimension compared to the general population. Patients are 14.1% more likely to suffer from slight anxiety or depression and 9.6% more likely to suffer from moderate anxiety or depression. 15% more patients reported problems with pain and discomfort, self-care and mobility.

At a 5% significance level, the two tests produced slightly different results in comparing the general population and patients values. The Wilcoxon rank sum test rejected the null hypothesis in 16 out of 19 health states, or in 84.2% of health states, while the *t*-test rejected the null hypothesis in 17 out of 19 or in 89.5% of health. Sorted by the sum of the values of the 5 dimensions, patients value health states in the upper end of the spectrum higher compared to the general population, and lower in the lower end of the spectrum (Fig. 1).

The results of the regression analysis are presented in Table 4. Estimated coefficients of the "GENERAL POPULATION & PATIENTS" model reveal suggest statistically significant differences between the patients' valuations and the general public valuations on four health dimensions. Patients consider problems related to mobility and usual activities to be less problematic, as patients' value average decrease on these health dimensions less severely than the general population (0.058 and 0.030 respectively). On the other hand, patients consider problems related to pain or discomfort, and anxiety or depression more severely, as the averaged decrease in utility is higher (−0.075 and −0.128 respectively). "GENERAL POPULATION & PATIENTS" model explains 48% of the variation of the TTO score ($R^2_{adj} = 0.480$), which is 3.4 percentage points more than the "TOTAL" model ($R^2_{adj} = 0.446$).

"PATIENTS & ADAPTATION" model was used to explain the differences found in the "GENERAL POPULATION & PATIENTS". When tested for adaptation, a positive relationship between individual health states and valuated hypothetical health states was found only on health dimension describing usual activities (0.068). In the other cases, when the coefficient displayed statistical significance, the effect was reversed. The indications of self-interest were found at health dimensions self-care (−0.06), pain or discomfort (−0.033), and anxiety or depression (−0.021). A negative coefficient indicates that a person's valuation of a health dimension in the hypothetical health state valuation depends on his own health state, and that the severity of his condition lowers his valuation of the health dimension, thus leading to the same effect as self-interest.

The inclusion of adaptation variables affected the estimated "Patient" coefficients. In the case of usual activities the difference between general population and patients amounts to −0.069, which was not statistically different from zero in the "GENERAL POPULATION & PATIENTS" model because patients adapt to the same extent (0.068). The sum of coefficients ("Patient" and "Adaptation") in the "PATIENT & ADAPTATION model roughly equals the value of the 'Patient' coefficient in the "GENERAL POPULATION & PATIENTS" model. On the other hand, taking into account self-interest in the case of pain or discomfort and anxiety or depression, the differences stemming from being patient are diminished to the extent of the self-interest. Accounting for adaptation or self-interest only slightly affects the R^2, which is 0.4 percentage points more than the "GENERAL POPULATION & PATIENTS" model ($R^2_{adj} = 0.484$).

4. Discussion

A survey was conducted to answer the question as to whether preferences towards health states differ between the general population and patients, which differs from previous surveys and studies as both groups value the same hypothetical health states. By comparing preferences from the general population, which are thought of as evaluating some of the possible imaginable (future) health states (i.e. hypothetical) to hypothetical values of the patients the study departs from debating experience-based vs. hypothetical health state valuation.

In order to enable the comparison between the general population and patient preferences, our choices in the selection of the instrument for preference elicitation were restricted. Additionally, as the preference was to select an

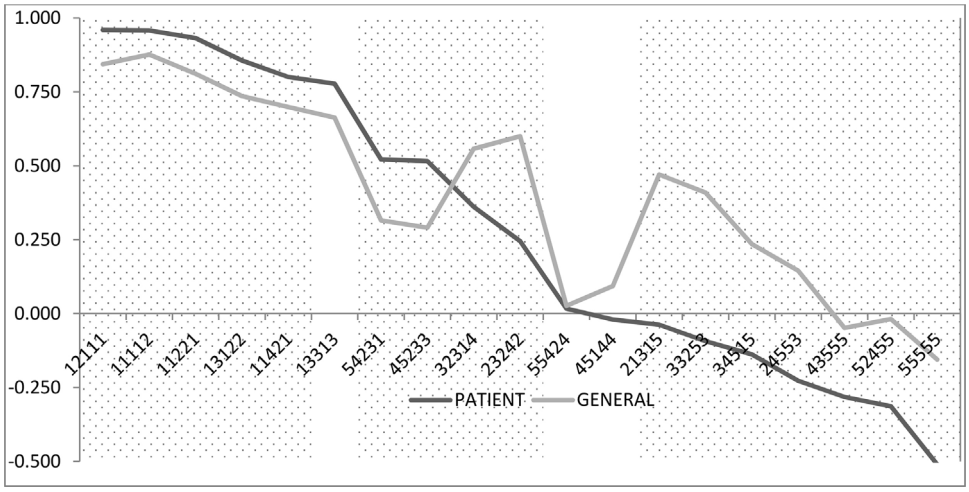

Fig. 1. Average health states' values (general population and patient representatives).
Remark: Statistically significant differences at 5% significance level using Wilcoxon rank sum test are depicted in shaded areas.

instrument for preference elicitation which is widely used and popular within Europe, the EQ-5D-5L version was chosen. The instrument choice further determined the choice of countries, as the selected country needed to have an existing population based EQ-5D-5L value set.

Using the EQ-5D-5L data from previous studies, the sample size was determined to 250 respondents per disease area, resulting in 19 health states. This subset was selected out of 86 health states and included in the EQ-VT design used in the Spanish general population valuation study In order to estimate the preference for all EQ-5D-5L states, more health states and consequently a larger sample is needed. Patients were selected using non-probabilistic methods, on a voluntary basis according to their willingness to participate in the survey. A sampling procedure is therefore equal to EQ-5D valuation studies carried out in general population and does not limit comparability of the results. The quality check of the process was very strict in all phases, and the collected data were routinely checked for quality. In case of quality deviations, the analysis of deviations and corrective actions were immediate. On the other hand, at the time of general population valuation study in Spain, the quality criteria were not as strict and the process was not a subject of such strict control. This fact could have an impact on the final values and differences in values between both sets.

The diseases included in the study are metastatic breast cancer and rheumatoid arthritis. The diseases were selected in which the clinical changes are well reflected in the EQ-5D instrument and according to the linkages and existing network between the consortium and patient organisations. The study was carried out only in Spain. Therefore no conclusions could be reached on the differences in valuations among the countries, and on similarities in the differences between general population and patient valuation sets across countries. In order to check for such differences, more countries should be included in the valuation task. Further studies are recommended to address whether mapping from the general to patient population is possible, especially due to the fact that eliciting preferences from patients are a demanding task in many regards, e.g. patient recruitment, training of the interviewers and conducting patients' interviews.

As the interviewers in our study specialised in one of the diseases, the interviewer effect could not be accounted for. The processes of education and conducting the interviews with the patients were more demanding for patients than for the general population. The importance of the task and the impact the results of the study would have for the health care system was difficult to explain to the patients.

Due to changes in patients' health states it was difficult for them to keep to the appointments. As the interviews were long (43 min on average), patients found it difficult to focus, and often became tired in the interview process. What made the process even more exhausting was the fact that they compared all the health states to their own health states, or to the health states of their friends and relatives, which made interviews very frustrating for them as well as for the interviewer. Often, the patients needed a break to relax and to discuss the issues with the interviewers, at which point they were offered psychosocial support by the interviewer before the continuation of the interview. The critical moment was valuing "worse than dead" health states as the respondents refused to think about death. The issue noticed in the interviews that could possibly affect the answers of the patients was their hope for a cure within the time period traded in TTO exercise, due to which patients refused to value the unchanged health states through time, finding this highly unrealistic. Also, the impact of religious beliefs could be noticed, as the believers responded that an option with a greater number of years needed to be selected due to their religious beliefs and expectations of friends and family members, no matter the severity of the health state. These respondents did not allow themselves to express their own preferences, but rather expressed the preferences inflicted on them by society and religion. The research of the impacts was out of the scope of this study,

and further studies are needed to offer deeper insights into the issue.

Regarding recruitment, the patients in the same disease areas were familiar with each other, and their decision to cooperate in the interviews was influenced by the experiences of the patients who had been interviewed – negative as well as positive comments were spread among the patients, making the recruitment process more demanding and time consuming.

Analysis confirmed statistically significant differences between patients' valuations and general public valuations on four health dimensions: mobility, self-care, pain or discomfort and anxiety or depression. Patients consider problems related to mobility and self-care as less problematic, while problems related to pain/discomfort and anxiety/depression are seen as more problematic. The largest disagreement is on the anxiety/depression dimension. These results suggest that not all health dimensions defined by EQ-5D are equally well understood by the general public. A possible explanation for the differences in the valuation is that problems with mobility, self-care, and usual activities are easier to imagine and understand. The easiness to understand and visualize problems on these three dimensions might explain why differences are not as large as those with pain/discomfort and anxiety/depression, as problems on the last two dimensions are due to being more of a physical nature, and are clearly more difficult to visualize by the general public behind a "veil of ignorance" as they are blind to self-interest. However, this might not be true: a part of general population still has experience with various health states and it is only a specific part of general population, healthy individuals, who are behind a "veil of ignorance". Moreover, as suggested by Brazier et al. [33], for patients the reference point they are reasoning from may have shifted and full health may be difficult to imagine. Considering that the argument that community members are the preferred source of preferences because they are behind a "veil of ignorance" and blind to their own self-interest holds, we would expect to observe the largest differences in a health dimension with the largest prevalence discrepancy (usual activities). However, no statistically significant differences were observed in that dimension between the general population and patients with rheumatoid arthritis or breast cancer. Moreover, we have found adaptation to the problems related to usual activities and self-interest in the problems related to self-care, pain or discomfort, and anxiety or depression. Adaptation to problems related to usual activities cancel out the patients differences, while self-interest slightly diminished the differences on pain and anxiety dimensions. Overall, adaptation or self-interest did not have a substantial impact on differences between general population and patients' valuation of hypothetical health states.

On the studied populations we have shown that adaptation is a highly complex problem and although we found its presence on one dimension only, we found the opposite process described in this article as self-interest, on three dimensions. This is in line of our assumption that these concepts constitute two sides of the same coin. In regard to the source of the differences between both groups we could not prove them to be the consequence of adaptation of patients. However, it is possible that the argument of impact of adaptation on higher values of health states is just a small part of the whole story.

Some authors support the argument of self-interest arguing that "permitting patients unlimited access to care based on post-illness preferences would too often result in the provision of marginally beneficial care" [34]. Alternative view, as expressed by Versteegh et al. [35] is that this might be correct, but is not relevant to the debate on whose preferences to use: ". . .the insensitivity to costs of treatments induced by insurance and in some cases the decreased marginal utility of money is irrelevant for the question whose values count in valuing health states. Patients are only called upon to value health states. . .., but the desirability of a treatment itself is not, in any direct sense, asked".

5. Conclusions

Analysis confirmed significant differences between patients' valuations and general public valuations on four out of five health dimensions: mobility, self-care, pain or discomfort and anxiety or depression. The differences, however, differed in their direction among the dimensions: while patients consider problems related to mobility and self-care as less problematic than general population, problems related to pain/discomfort and anxiety/depression are seen as more problematic. Possible explanation for such phenomena is tangibility of dimensions.

In the article the framework was set up in order to explore the role of adaptation in explaining the differences among both groups' valuations. The variable "adaptation" was defined as the natural logarithm of the squared ratio of the severity level of the hypothetical state dimension, and the severity level of the experienced (self-reported) health dimension. Overall, adaptation or self-interest did not have a substantial impact on differences between general population and patients' valuation of hypothetical health states. In regard to the source of the differences between both groups we could not confirm them to be the consequence of adaptation of patients to the lower health states. Arguments for not using patient preferences due to adaptation might therefore not play a prominent role in decisions on preferences source.

The inclusion of patients in the health state valuation process would impact the allocation of health care funds; however, it is not clear to which direction such changes would lead. Further research into differences in valuations of mild vs. severe health states valuations, scale recalibration in patients and patterns across countries and diseases is suggested.

Conflict of interest statement

Valentina Prevolnik Rupel is a member of the EuroQol Group, a not-for-profit organization that develops and distributes instruments that assess and value health.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.healthpol.2017.03.011.

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