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Do We Know What We Are Doing? An Exploratory Study on Swedish Health Economists and the EQ-5D

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UNIVERSITY

# Do we know what we are doing?

An exploratory study on Swedish health economists and the EQ-5D.

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#### Abstract

The UK tariff for quality of life associated with the health states in the EQ-5D is probably not consistent with the preferences of Swedish health economists. This is worrying in view of the widespread use of the tariff values and the fact that health economists likely are better able than ordinary citizens to report their preferences for health states in a valid and reliable manner. We suggest this result is taken into account when the EQ-5D instrument is used, and that researchers should be cautious in using the UK (or any other) value sets. Our results also indicate that the variation across citizens in preferences for health may be a more complex issue than previously observed and deserves further study. An intriguing question for the future is to what extent health economists use methods and instruments that they themselves do not believe in.

#### JEL classification: I10; I14; I18

Keywords: health-related quality of life; EQ-5D; valid; respondents; health economists; UK tariff

# 1. Introduction

The development of cost-utility analysis has been an important contribution of health economics to public policy.<sup>1</sup> By constructing quality weights for various health states, it becomes possible to compare health interventions that have different effects on length of life and on quality of life. Several measures of Health-Related Quality of Life (HRQoL) have been developed (Drummond et al., 2015). One of the most frequently used has been the EQ-5D, which describes a person's wellbeing in five different dimensions and with three possible levels of problems in each dimension (no problem, moderate problems or severe problems).<sup>2</sup>A standard procedure to elicit preferences for health states described through EQ-5D is the Time Trade-Off (TTO). We believe, however, that health economists have taken too lightly on the problem that people are ill equipped to assess questions of such abstract nature.

We suggest that the TTO procedure and several other approaches (e.g., the standard gamble) entail choices that are so far removed from everyday experiences of ordinary people that this method likely will provide substantially biased estimates of the HRQoL associated with various health states. The trade-off between quality of life and longevity will also be misrepresented. To illuminate this problem, we use Swedish health economists as respondents, assuming that this professional group is much better equipped to comprehend the assumptions and implications of the TTO technique.

As we shall see, we find in our examples that Swedish heath economists provide HRQoL estimates that seem decidedly different from those obtained by asking the general public. This suggests that more research efforts are needed to ensure that prioritization using the EQ-5D is a good thing.

Our aim with this paper has been to explore this issue and see if there is evidence consistent with the hypothesis that a lack of comprehension among non-economists systematically affect the HRQoL estimates. We have no intention of proving that this is the case – our more modest ambition is to see if there is cause to be concerned about the current state of our evidence on health-state utilities. We find that there is indeed cause for concern, and that further research on these issues would be welcome. Similarly, van Nooten et al. (2018) argue that we need a much better understanding of the factors that affect the individual's preferences for health. It seems imperative that our understanding of preferences for health is improved. If economic evaluations are to be of use in the health care sector, they must surely be transparent and be known to be based on adequate estimations of the citizens' preferences for health.

To establish quality weights, economists endeavor to tap into the preferences of ordinary citizens. The respondents are given information about health states and subsequently are asked to make

<sup>&</sup>lt;sup>1</sup> This being said, there are many well-known theoretical and empirical problems involved in cost-utility analysis, such as the relationship between utility maximization and the maximization of QALYs or the treatment of conditions worse than death (see, e.g., Dolan et al. 2005 and Drummond et al. 2015). For the purpose of this paper, however, we accept the overall premises of the QALY approach.

<sup>&</sup>lt;sup>2</sup> The EuroQoL Group is constantly engaged in improving their methods. Currently a version with five symptom levels instead of three is advocated. The main reason is that the version with three symptom levels seem unsensitive to small changes in health. Cf. Devlin & Krabbe (2013) and the website of the EuroQoL Group (www. EuroQoL.org).

intertemporal choices between different health-scenarios. As this requires interviewing a considerable number of people, a common and sensible solution is to use values obtained from studies in other countries. In particular, the so called UK tariff (Dolan et al. 1995, 1996) has been utilized in several countries, including Sweden. Therefore we chose this well-known and established instrument as a point of departure and instrument for comparisons.

# 2. The UK value set for EQ-5D and Swedish health economists

Dolan et al. (1995, 1996) interviewed a random sample of the British general public too find out how they valued chronic health states in relation to a life in full health. Using the TTO procedure, a health state is given a weight somewhere between zero (dead) and one (full health). Regression analysis was then used to investigate the effect on quality of life of the different EQ-5D dimensions and problem levels. The result is an algorithm that easily can be used to obtain a valuation for each of the 245 possible health states. In a TTO (as with many other procedures), respondents are asked to make choices that entails trading length of life against quality of life. To make such choices is very far from the respondents' everyday experiences. The typical respondent is unlikely to ever have envisaged such a trading possibility. Consequently, the respondents are unlikely to grasp the full implications of the TTO exercises they perform.

The potential problem is illustrated by some of the values in the UK tariff. Some relatively minor health problems are rated so low that an individual should be willing to give up more than two years out of ten in order to get rid of the problem. In the absence of firm evidence that this is indeed the case, we simply refuse to believe that this is an accurate description of the health-related preferences of Swedish citizens. Our intention is not to make a comprehensive evaluation of all the different HRQoL weights in the EQ-5D. It is simply to point out that at least in some cases, the weights seem dubious.

To begin to get a handle on this problem, we suggest using health economists as respondents instead of the general public.

# 3. The preferences of Swedish health economists

# 3.1 General considerations

We decided to try an approach that would reduce as far as possible the problem with answers being biased by the hypothetical nature of the problem. We therefore decided to elicit valuations from Swedish professional health economists. This may seem like an odd choice, because this group is unlikely to have preferences that correspond to the average in the population (e.g., they have more education, have been trained as health economists, have different experiences in life etc.). However, we believe that there are important advantages in using this group which outweighs the disadvantages.

The obvious idea behind this set-up is that a health economist by training should be able to grasp the implications of a TTO exercise, to understand at a fundamental level that the answers to such an exercise is really meant to reflect individual choices and preferences. Health economists are familiar with the issues of prioritization in health care and the fact that health must somehow be measured. They understand the health-state valuations elicited from individual respondents may actually have direct policy implications. In brief, health economists seem better able to give carefully reflected answers that represent their personal preferences in a reliable and valid manner.

Health economists may also seem more likely to have stable preferences regarding health, whereas the common citizen likely would only form such preferences when necessitated in connection with our investigations. A final advantage is that we could reduce the length of our questionnaire substantially, since the respondents were familiar with concepts such as TTO, QALYs etc.

Finally, we judged that the breach of personal integrity represented by our investigation is infinitesimal and can be ignored in view of the fact that health economists are well acquainted with issued of prioritisation and measurement of health and health-related utility.

# 3.2 The sample

We recruited a sample of Swedish health economist (see below) and essentially asked them if they were happy with the HRQoL estimates in the UK tariff and, if not, in which direction and how much they would like to see a change.

We decided that using personal interviews and getting them done quickly was the only way we could hope that the respondents would not talk about the questionnaire to potential respondents who had not yet answered. The respondents are colleagues who work closely together and so normally would discuss such an experience as our questionnaire among themselves. Furthermore, using personal interviews likely maximize participation rates.

We focussed on health economists who were public university employees or who worked in the Swedish Institute of Health Economics (IHE), a consultancy firm that collaborates a lot with various public entities. Since we had decided to administer the questionnaire in face-to-face interviews, we based the sample on workplaces in the proximity of our offices, i.e., Lund University and Linköping University.<sup>3</sup> We added three government agencies in Stockholm that necessarily deal a lot with QALY calculations.<sup>4</sup> Hence we constructed something of a convenience sample, but we do not see this as a major problem given that our purpose has been to raise questions rather than answering them.

For a university employee to qualify as a health economist, the respondent should either be working on a PhD thesis in health economics, or have written a PhD thesis in health economics, or have published two or more health economic papers in international peer reviewed scientific journals (the latter covers the senior faculty). For those working in one of the government agencies or in the IHE to qualify as a health economist the respondent should have a Master degree in economics and have worked on health economic issues for at least one year, or alternatively have taken an advanced course in health economics.

<sup>&</sup>lt;sup>3</sup> The universities in Linköping and Lund are two of the largest communities of health economists in Sweden.

<sup>&</sup>lt;sup>4</sup> The Swedish Council on Health Technology Assessment (SBU), The Dental and Pharmaceutical Benefits Agency (TLV), and The Swedish Agency for Health and Care Services Analysis (*Myndigheten för vårdanalys*).

We used Swedish in the questionnaire in order to maximize the likelihood that it was correctly understood by the respondents, hence we excluded those who were not fluent in Swedish from the study. These criteria gave us 51 potential respondents and as it turned out, no one of the potential respondents declined participation.<sup>5</sup> Of the 51 respondents, 21 were female and 17 were above 40 years of age.

With such a small sample, special attention has to be paid to the anonymity of the respondents. We could not, for example, note of which of the six organizations the respondents belonged to, nor could we make detailed analyses of the effects of the age and gender of the respondents.

## 3.3 Data collection

The respondent answered the questionnaire at a face-to-face meeting with one of the authors. They were first asked I' they were willing to spend 10 minutes to answer a questionnaire, which was part of a research project. If they agreed to participate (which they all did), they were handed the questionnaire to read and to answer. When the respondent had answered the questions, the questionnaire was put in an unmarked envelope and sealed. We collected all envelopes in a pile and only opened them after all the respondents had been contacted. Thus anonymity was ensured.

The interviews were conducted by the three authors. For convenience the same author did all the interviews in a particular organizational unit. We cannot check for interviewer bias – if we had put an office-id on a questionnaire we would have made it too easy to identify individual respondents. After the interviews, the author emphasized that the respondent should not mention the survey to anyone, until they had been told that the data-collection period was finished. The interviews took place AD 2014, in weeks 35 and 36

# 3.4 The questionnaire

The EQ-5D, as mentioned, describes a health state in terms of five dimensions where quality of life can be at three different levels in each dimension. For example, having no health problem in any dimension could be designated (1, 1, 1, 1, 1) in the EQ-5D, while having some problems with walking about because of some pain in a knee would come out as (2, 1, 1, 2, 1). In other words, moderate problems are designated by "2", no problems is "1" (and severe problems would be "3").

Turning now to our own questionnaire, the *first page* gave a short introduction that informed the respondents that all respondents would be health economists because this group has a great potential to fully comprehend the issues involved. The *second page* of the questionnaire began with an explanation of the EQ-5D classification. It was pointed out that a value of 0.727 for the quality of life in a particular health state implies that the individual would be willing to sacrifice more than a quarter of remaining life time in order to become completely healthy. In the lower part of the second page, the Swedish version of the EQ-5D classifier was shown.

<sup>&</sup>lt;sup>5</sup> Three health economists at the IHE acted as respondents in a pilot study and were consequently excluded from the main analysis.

On the *third page*, the respondents were told that they would be asked to put a value on three selected health conditions. We emphasized that they would be making a trade-off between length of life and quality of life; that these choices would refer to three different states of health; and that the values would be compared with the values these three health states received in the UK tariff. As a help to decision making, the lower part of the third page contained a table which showed what a certain HRQoL value (with ten years left to live) would imply in terms of years, months, and days that the respondent would be willing to sacrifice in order to become healthy. Furthermore, the HRQoL values of the three health states in the UK were included and presented in bold in this table.

We note that with the TTO format, the whole set-up signals trade-offs. For this reason, a respondent could be reluctant to give an answer that signals "no trade-offs" (which would presumably disappoint the interviewer). Suppose, for example, that an individual is asked to indicate how much time in perfect health that would be equally good as 10 years in health state X (implicitly trading quality of life against longevity). In that case, there may well be s a tendency to avoid answers close to "10 years in perfect health". It may also matter a lot in which sort of time-units the question is posed. If the question uses years and months, we should perhaps not expect answers in days and hours.

In order to reduce such a bias, the table on the third page explicitly contained possible answers down to just a few days (and thus implicitly allowing for HRQoL values very close to 1.0). We would not, however, be surprised if there was a remaining bias of this kind.

The *fourth page* of the questionnaire consequently contained a table with information about three health states, together with their EQ-5D classification: (2, 1, 1, 2, 1), (2,1, 1, 2, 2) and (2, 1, 1, 1, 2) and their weights in the UK tariff. Furthermore, we decided that giving concrete examples from the real world of diseases would substantially reduce the hypothetical nature of the exercise. Consequently, our three EQ-5D conditions were exemplified by the following practical examples: arthritis, angina pectoris and Chronic Obstructive Pulmonary Disease (COPD), Table 1.

#### Table 1

Our reason for choosing these three health states was that it seemed comparatively easy (but see below) to give concrete and well-known examples of medical conditions that could correspond to these EQ-5D states – arthritis in the knee, angina pectoris, and COPD.

The *fifth page* in the questionnaire was where the respondents gave their own valuation of the three health states (we emphasized that they should report how they value their own health, not that of some unknown citizen). The first column gave the EQ-5D classification and the concrete example, e.g., (2, 1, 1, 2, 1), arthritis. The second column gave the HRQoL from the UK tariff for the particular configuration, e.g., 0.727 for (2, 1, 1, 2, 1). In the third column, the respondent stated whether this value from the UK tariff val++++ue seemed "too high", "just about right", or "too low", when judged by the personal preferences of the respondent. If the answer was "just about right" the respondent was told to move to the next health state. If the answer was "too high" or "too low", the respondent was asked to state what should be the HRQoL instead and write it down. This was repeated for our three cases.

In view of the small sample, there was no point in addressing some otherwise relevant issues. We did not, for example, try to vary the order of the three health states in our questionnaire, even though one can be fairly certain that the order has a framing effect.

Another well-known problem in this context is anchoring. In a sense, this whole paper is about anchoring as it concerns the attitudes toward the existing values in the UK tariff (anchoring can also take the form that responses use the exact numerical values form the UK tariff). It seems likely that anchoring will tend to reduce the difference between Swedish health economists and the UK tariff, and so is less of a problem here. We should also mention that we ignore discounting issues throughout the paper. Given our short time span, discounting seems unlikely to have an important impact on the results.

Our format did not discourage anchoring (rather it encouraged it), and it would tend to move responses towards the values in the UK tariff. Hence when we find differences between our respondents and the UK population these stand out as even more interesting.

On the *sixth and final page* of the questionnaire the respondents were asked to state their ages (below forty or not) and gender (female or male).

#### 4. Results

With three possible answers (too high, roughly right, too low) and three cases, there are (3\*3\*3) 27 different configurations of answers (e.g., "too high, roughly right, too high", "too high, too high, too low" etc.). However only 13 of these configurations appear among the answers, and the 6 most common configurations represent 42 of the respondents. By far the most common configuration was "too low, too low." This pattern of answers was chosen by 19 out of 51 respondents. Hence it would seem that using health economists as respondents do give us higher HRQoL weights as expected.

In Table 2, we compare the average responses from Swedish health economists regarding our three chosen health problems (arthritis, angina, COPD) with the UK tariff, and we can see that our responses indicate higher HRQoL than in the UK tariff for both arthritis and angina. However, for COPD we received the unexpected result that the valuation was pretty much the same for our health economists and the UK general public.

#### Table 2

We soon identified the reason for the unexpected result. A look at the data reveals that 12 of our respondents actually gave a higher QoL rating to angina (Case 2) than to COPD (Case 3). This should essentially be impossible in our set-up – by construction our Case 3 (health state (2,1,1,1,2)) strictly dominates Case 2 (2,1,1,2,2) – they have the same configuration except on item 4, where Case 3 has higher HRQoL than Case 2. In principle this result could be taken to imply irrational behaviour. However, we believe that in retrospect it was a mistake to choose COPD as an example of the third Case. The third Case was EQ-5D classified as (2. 1. 1. 1. 2); in other words, some problem with walking and some worries but otherwise ok. Several remarks

during the interviews indicated that a number of respondents did not accept COPD as a moderate health problem. "Asthma" would probably have been a better label on our third Case.

Consequently, from now on, we focus exclusively on our first two health states. In these two cases, Swedish health economists on average clearly seem to be of the opinion that HRQoL is higher than suggested by the UK tariff. Of our 51 respondents, 29 found the UK tariff to be too low for both health states. A further 9 respondents were of the opinion that one of the HRQoL estimates was "just about right" and while the other was "too low".

The difference in average HRQoL between the Swedish health economists and the UK general population seems potentially important both for arthritis and for angina. For example, the figures for arthritis imply that a Swedish health economist is not willing to sacrifice more than 2 years in order to become completely healthy. The corresponding trade-off for the UK is that a UK citizen would find it useful to sacrifice up to 2 years and 8 eight months (i.e., eight months more) to become healthy, thus implicitly caring less about longevity compared to quality of life when compared to the Swedish respondents. A difference of this magnitude cannot be ignored in health policy.

A common problem with questionnaires aimed at the general public is the often low response rate, frequently below 50%, which makes any conclusions regarding the population precarious. We, on the other hand, have a 100% response rate. For this reason and because we have reduced the risk that our results reflect misunderstandings rather than variations in preferences, it seems worthwhile to explore the answers in some detail.

Note first that there was no significant difference between female and male respondents in our sample, and no relevant difference between those above 40 years of age and those below 40, Table 3.

### Table 3

Tables 4a and 4.b show the distribution of responses over different HRQoL values for arthritis (and angina). There is a very substantial variation across individuals (note the anchoring effect of the UK tariff in both cases), Table 4a. This variation is noteworthy in view of the fact that our sample was a much more homogenous group than the population in general (all had university education etc.). Furthermore, it seems that the responses concerning our two health states display very different distributions of responses. In fact, at some levels of aggregation, they look like the inverse of each other (Table 4b). For the benefit of future studies, we note that here is substantial minority of respondents who indicate that the HRQoL in our arthritis case is 0.9 or more (Table 4b), a relatively impressing difference when compared to the UK value of 0.727 (or compared to the average among Swedish health economists (0.84)).

These observations suggest that there is more to be done in order to ensure that the weights that enter economic evaluations do in fact lead to better outcomes in health care.

#### Table 4a

#### Table 4b

#### 5. Discussion

We have demonstrated in this paper that using health economists to answer questions about HRQoL seems to lead to a different set of values than what you get from the general public. The values obtained from Swedish health economists put more emphasis on length of life than on quality of life compared to the UK tariff. This is important as large-scale surveys have been conducted in a number of countries,<sup>6</sup> and if these lack in validity, the quality of economic evaluations may be compromised.

There are many potential factors behind these facts. It is possible – but not certain – that this difference is due to the hypothetical nature of the method used to elicit preferences, and the concomitant difficulties for common citizens to comprehend this entire approach to public decision-making.

A similar problem to the one we have been discussing is whom to ask for a health valuation – the sick or the healthy? The choice is between eliciting preferences from those who have actually experienced the health condition in question and those who have not. Burström et al. (2014) strongly advocates using experienced values and provide evidence that experienced values should be higher than the UK tariff. This is what we would expect, given the well-known tendency for people to adapt to being chronically ill.<sup>7</sup> An interesting task for the future would be to investigate experienced values among health economists. It would of course necessitate a larger sample of health economists than we had access to for this study. For the current investigation, the Burström et al. (2014) result could possibly imply that their greater medical knowledge of health economists would place them closer to experienced values than a survey of the general population would, so it could be the difference between experienced and non-experienced values that are driving our result.

There could of course be cultural differences between the UK and Sweden that explain the difference. We may also note that the data for the UK tariff was collected almost 20 years before our questionnaire was distributed to health economists, and preferences are likely to change over time. The income of our sample would presumably have been considerably above the income of the UK respondents (but it is not obvious how increasing incomes should affect the trade-off between quality of life and longevity). Furthermore, training as a health economist likely changes your preferences, and it seems likely that the characteristics of those persons who select into health economics are not random. In general, any factor believed to affect our preferences regarding health could be part of an explanation of the differences between our sample and that of Dolan and colleagues.<sup>8</sup>

While acknowledging all these competing explanation (and many others), we would still argue that it would be good if our results stimulate research into the considerable differences in preferences for health that seem to exist.<sup>9</sup>

<sup>&</sup>lt;sup>6</sup> For example, the UK, Finland, Denmark, Germany and Japan.

<sup>&</sup>lt;sup>7</sup> Our interviews took place before the publication of the Burström et al. (2014) paper, and we checked that our respondents were unaware of their results.

<sup>&</sup>lt;sup>8</sup> Factors that have been investigated for their influence on health valuations, generally with mixed results, include, e.g., age, gender, marital status, health status, education, income and religion. Cf. van Nooten et al. (2018) for an overview of this literature.

<sup>&</sup>lt;sup>9</sup> Cf. Luke (23.34): "father forgive them for hey know not what they do".

Neither should we forget that the rather unexpected distribution of responses across levels of health-related quality of life suggests that there is much that remains to be done in order to increase our understanding of these preferences.

We hope that this work will continue, as economics has much to offer the health care sector, but we also hope that future research will rise to the explicit and implicit challenges in this paper. If economists wish to preserve their integrity and credibility in multi-disciplinary situations, it is vital that the measures we propose for prioritization are valid and transparent. It appears that we still have some way to go to reach that point. Finally, it interesting to note that the UK tariff have been extensively used in Sweden, despite the fact that many (possibly a majority) of economists consider the weights to be questionable.

#### Acknowledgements

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Health condition in the EQ-5D classification	Average weight in the UK tariff	Examples of conditions that could fit the description in column 1
(2,1,1,2,1)	0.727	Arthritis (some problems in walking about, some pain).
(2,1,1,2,2)	0.656	Angina (some problems in walking about, some pain, some worry).
(2,1,1,1,2)	0.779	COPD (some problems in walking about, some worry

# Table 1. Examples of the EQ-5D translated into familiar conditions

Table 2: HRQoL weights from two populations

	Arthritis	Angina	COPD
	(Case 1)	(Case 2)	(Case 3)
Swedish health economists	0.837	0.716	0.776
UK general public (the "tariff")	0.727	0.656	0.779

## Table 3: HRQoL weights by age and gender

[95% confidence intervals in square brackets]

++	Swedish health economists				UK general
	Divided by age		Divided by gender		public
	Below 40	Above 40	Female	Male	
	(n=31)	(n=17)	(n=20)***	(n=28)	
Case 1	0.83	0.85	0.832	0.841	0.727
(arthritis)	[0.791-0.869]	[0.806-0.894]	[0.783-0.881]	[0.754-0.927]	
Case 2	0.721	0.754	0.738	0.73	0.656
(angina)	[0.685-0.757]	[0.70-0.805]	[0.652-0.823]	[0.652-0.807]	

	Number of answers in interval	
Quality weight interval	Arthritis	Angina
1.0	1	0
0.95-0.99	8	2
0.90-0.94	9	6
0.85-0.89	7	3
0.80-0-84	7	7
0.75-0.79	4	5
0.70-0.74	9*	7
0.65-0.69	1	16 *
0.60-0.64	1	2
0.55-0.59	0	1
0.50-0.54	0	1
All	47	48

# Table 4a: The number of responses across HRQoL values,Swedish health economists, interval length = 0.05

\*The value from the UK tariff lies in this interval.

Table 4b:	The number of responses across HRQoL values
	Swedish health economists, interval length $= 0.10$

	Number of answers in interval	
Quality weight	Arthritis	Angina
0.90-1.0	18	6
0.80-0.89	14	10
0.70-0.79	13 *	12
0.60-0.69	2	18 *
0.50-0.59	0	2
All	47	48

\*The value from the UK tariff lies in this interval.