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Whose health should Be Given Priority?

Ethical valuation of Swedish Pharmaceuticals

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Abstract

The official guidelines in health care state that a more severely ill patient should be prioritized over a less severely ill patient, but it is still debatable *how much more* care and resources should be allocated to this patient. The aim of this study is to address this issue. This is done through a web survey, where the social values people hold for helping patients with different levels of severity of illness are obtained. Severity of illness is measured both in terms of pain and immobility, and respondents' values are investigated through two different types of perspectives; a patient's perspective and a decision-maker's perspective. The results show that individuals are equally risk averse as inequality averse against high levels of pain and immobility, and that helping patients with a severe condition is valued twice as much as helping patients with a less severe condition.

Key Words: Risk aversion, inequality aversion, health care prioritization, severity of illness

Disclaimer: The views expressed in this thesis are those of the authors and do not necessarily express the views of the Dental and Pharmaceutical Benefits Agency, TLV.

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1. Introduction

Severity of disease is frequently regarded as a relevant factor to consider when choosing priorities in health care. However, it is problematic to express exactly what role severity should play in decision-making processes. County councils, policymakers, doctors and nurses have to apply their judgments and make difficult decisions every day. Despite knowing that a more severely ill patient should be prioritized over a less severely ill patient (The Riksdag, 1996), it is debatable *how much more* care and resources should be allocated to this patient. An effort to address this issue is made in this thesis through a web survey aimed at obtaining the social values people hold for helping patients with different levels of severity of illness. Severity of illness is measured both in terms of pain and immobility, and respondents' values are investigated through two different types of perspectives. The results indicate that individuals are equally risk averse as inequality averse against high levels of pain and immobility. Also, helping patients with a severe condition is valued twice as much as helping patients with a less severe condition.

In Sweden, severity of illness is indirectly included in the official guidelines for priority setting through the *Need and Solidarity principle*, which is one of the three principles that guides all decisions in health care (The Riksdag, 1996). The Dental and Pharmaceutical Benefits Agency, TLV, is a central Swedish government agency whose responsibility is to define whether the state should subsidize a pharmaceutical product or not, given its cost-efficiency and how high the need is. However, the government bill that defines the three principles TLV should rely on in their decision-making does not explicitly outline how to apply these principles. Therefore, TLV is currently reviewing how to define and include severity of illness in their health economic evaluations of pharmaceuticals (TLV, 2014).

When conducting health economic evaluations of pharmaceuticals, costs of different interventions and the degree of appreciation, i.e. how society values the intervention, have to be compared. The degree of appreciation is a function of treatment effect, cost per Quality-Adjusted Life Years (QALY), and the severity of the initial state. Society might prefer a small improvement for a person in a bad state rather than a larger improvement for a person in a better state (see e.g. Nord, 1993 or Jacobsson, Carstensen, & Borgquist, 2005). If society seeks to consider only health benefits, the number of QALYs gained should be the factor to

maximize in health policy. However, it has been shown that the general public, as well as policymakers, are more concerned about reducing inequalities, i.e. the distribution of QALYs, implying that they are inequality averse. Policymakers face a trade-off between efficiency (QALY maximization) and equity (QALY distribution) (Dolan & Olsen, 2001).

1.1 Purpose of the study

This study aims to obtain preferences regarding the severity of illness in terms of pain and immobility from Swedish students. The study is explorative and investigates how a pharmaceutical for a severely ill patient is valued in comparison to a less severely ill patient. From these valuations, it is possible to determine how much more resources should be directed to a severely ill patient, compared to a less severely ill patient. Whether the framing of the questions matters for the results is investigated by using two different perspectives. The perspectives the respondents will face are either an *ex-ante insurance perspective* (private) for an individual or an *ex-post distributional perspective* (public) for a policymaker. Our main research questions are:

1. How *much more* do Swedish students value helping patients of a particular severity level over another group of patients with a less severe illness?
2. Do the valuations differ when severity is measured in terms of pain compared to when it is measured in terms of immobility?
3. Do the valuations differ depending on the perspective respondents are faced with?

The main research questions are investigated through web based surveys, but the same web surveys are also conducted in a more formal laboratory setting in order to see if the results are sensitive to different methods. The questionnaires, both the original version in Swedish and a translated version in English, can be found in Appendix II.

1.2 Hypotheses

The hypotheses tested in this paper are:

- I. Helping patients with severe pain has a higher social value than helping patients with severe immobility.
- II. Respondents answering the questionnaire with the *ex-ante* perspective require a lower number of patients from the “better-off” group than respondents answering the *ex-post* questionnaire. That is, the former respondents are more risk averse than the latter respondents are inequality averse.

- III. Respondents that study health and social care value the “worse-off” patient group higher than respondents that study other subjects.
- IV. Respondents that have previous experience of illness or that have a low self-reported health status, together with females and low-income respondents value those that are “worse-off” higher than their opposites.

1.3 Background - TLV

Many industrialized countries have agencies that approve whether a pharmaceutical can enter the market and for which diseases doctors can prescribe it. Due to strict regulations in most countries, pharmaceutical manufacturers are required to establish the safety of the pharmaceutical, its efficacy and its cost-effectiveness. No comparable regulation exists for non-pharmaceutical treatments (McPake, Kumaranayake, & Normand, 2002). The Dental and Pharmaceuticals Benefits Agency, TLV, is the government body that is in charge of the determination of which pharmaceutical products or dental care procedures should be subsidized by the state in Sweden. (TLV, 2014).

All TLV’s decisions regarding pharmaceuticals are based on three general principles as they are formulated in the Government Bill 1996/97:60. Together these principles form an ethical platform (The Riksdag, 1996):

1. *The Principle of Human Dignity*: all people are of equal value and have equal rights to health care regardless of age, gender, social and economic status, etc.
2. *The Principle of Need and Solidarity*: the resources should at first hand be used in areas where the needs are the greatest, i.e. those with the severest conditions should be prioritized.
3. *The Principle of Cost-Efficiency*: the relationship between cost and effectiveness on quality of life should be reasonable.

The principles are ordered by importance, i.e. the Principle of Human Dignity is most important and must never be compromised. The second principle is related to both health and quality of life, and when making priorities, the different aspects related to health and quality of life have to be weighted together. This can concern e.g. experienced suffering, the medical prognosis or the degree of disability. Thus, the second principle states that those with the severest diseases and lowest quality of life should be prioritized. This is of course given that cost-effective treatments exist, which is the main point of the third principle (TLV, 2012).

The Government Bill 1996/97:60 states that TLV should make decisions in accordance with the above mentioned three principles; however, it does not state clearly how these principles should be weighted in situations where they seemingly point in different directions. Nevertheless, the first step in health economic evaluations is to establish a measure of cost-efficiency, which then has to be weighted by a need. A span can then be determined for how high cost per QALY is accepted for a treatment, and this span is allowed to vary depending on the severity of disease. For conditions where the severity is high, or when there are few alternative treatments, a higher cost per QALY can be accepted than for conditions of milder severity, or for treatments that have many substitutes (TLV, 2012, 2014). An attempt to quantify the values that people hold for helping patients with different severity of illness is made in this thesis. These values can then act as recommendations for how large the weights for different needs should be.

2. Literature review

The health care systems in the Nordic countries are by tradition based on egalitarian ideologies, where most importantly everyone should be granted equal access to health service (Magnusson, Vrangbaek, & Saltman, 2009). Through the development of information technologies patients have become better informed. This is one of the factors that has changed the demand for health care services over the last decades. On the supply side, not only have technological developments made health care systems more efficient, but also more expensive. When new treatments or pharmaceuticals are developed and the “market for treatments” is expanded, treatments or pharmaceuticals can be offered to patients who were previously excluded, which increases the costs in the health care sector (Magnusson et al., 2009). As the finances directed to health care are limited, the increased costs have to be weighted by e.g. reducing benefits, increasing taxes or by increasing efficiency. In the Nordic countries this has mainly been dealt with by a slow implementation of new technology, and by certain kinds of prioritizations, such as exclusion of some services from the benefit packages (Magnusson et al., 2009).

2.1 Priority setting in health care

Prioritizations in health care are usually not popular among the general public. For instance, more than a third of the Finnish public do not accept any limitations in health care (Ryynänen, Myllykangas, Kinnunen, & Takala, 1999), and more than 75% of primary care

patients in Sweden think that regardless the costs, health care should always provide the best possible care (Arvidsson, André, Borgquist, Lindström, & Carlsson, 2009). This shows that a discrepancy exists between the public's expectations of the health care sector and what the state actually can afford to provide within it.

In addition, in regards to prioritization, medical professionals prefer to prioritize by the severity of the disease and the prognosis of treatment to a wider extent than the general public and politicians. The public wants instead to prioritize by e.g. the self-induced nature of the disease to a wider extent. Further, males, younger respondents and respondents with higher education are more associated with acceptance of prioritization in general (see e.g. Ryyänen et al., 1999 or Arvidsson et al., 2009). Actual patients are more satisfied with health care services than the general public (SALAR, 2012) and public involvement in health care policymaking can lead to a higher quality, or at least a greater acceptance of the decisions that are made in regards to prioritization (Bruni, Laupacis, & Martin, 2008).

2.2 Severity of illness

Empirical studies where the respondents have to make choices of which patients to prioritize given different levels of severity of illness, reveal that the public support giving priority to the most severely ill over the less severely ill (see e.g. Jacobsson et al., 2005 or Diederich, Swait and Wirsik, 2012), especially for those who face an immediate risk of death (Cookson & Dolan, 1999). Nord (1993) finds that differences in severity seem to be more important in health program evaluations than differences in treatment effect. His respondents faced seven severity levels in terms of mobility, developed from Sintonen's scale from 1981, where each step is equally large.¹ Then, Nord measures the trade-off between severity and treatment effect. This is done through pair-wise comparisons of outcomes, where respondents are asked to state equivalence numbers for two conditions where the level of severity and/or treatment effect differed. The findings by Nord (1993) are supported by Ubel and Loewenstein (1996) and Ubel (1999). The latter replicates this study by Nord with the same scenario, in addition to some revised scenarios. Further, Green (2009) conducts a survey that in turn is based on the study by Ubel (1999). His findings add to previous studies, suggesting that the general public does not support to strictly maximize health, but rather supports some kind of

¹ According to Nord (1993), this is proved both by plotting the mean values stated from the respondents in Sintonen's study (1981), and by asking his respondents in his study about their perceptions of the scale.

‘fairness’ where severely ill patients should have at least equal priority as the less severe patients, even if the benefits from treatment are lower.

The perspectives with which a respondent is faced can affect their priority decision. Nord, Street, Richardson, Kuhse, and Singer (1996) conduct personal interviews and give one of two perspectives to their respondents. Either the respondents face an “arms-length-perspective”, meaning that they would not be affected themselves by their decisions and that they should think as policymakers, or they face a “private perspective” where they are put behind a so-called Rawlsian “veil of ignorance”². The results imply that people were more eager to maximize resources when having the perspective of a policymaker than when having the private perspective where they could be affected by their own decision one day. Similar results are also found in a previous study by Nord (1995), where respondents favored a hospital that prioritized patients with higher potential over a hospital that prioritized equally between patients, when having the “arms-length-perspective”. However, when being asked which hospital they would rather belong to, a majority wanted to belong to the latter hospital (Nord, 1995). Nord et al. (1996) argue that the view of self-interest is the most relevant for policymakers as it helps to determine how to distribute resources in line with Rawlsian justice.³

2.3 Risk aversion and inequality aversion

Inequality aversion can be measured in terms of how much society is willing to give up in order to achieve a more egalitarian distribution of income or health status. Risk aversion in health care is a concept which describes individuals’ attitudes towards uncertainty about their own future health states. Few studies make a clear distinction between inequality aversion and risk aversion, but Kroll and Davidovitz (2003) and Carlsson, Daruvala and Johansson-Stenman (2005) are two studies that make this distinction. The former study by Kroll and Davidovitz (2003) uses children and chocolate bars, and shows that the children prefer an equal distribution of chocolate bars, but they do not want to give up their own bars in order to achieve this distribution. The latter study by Carlsson et al. (2005) estimates individual risk aversion and inequality aversion separately in an experiment where respondents made pairwise choices between either hypothetical lotteries or societies. Their main findings suggest

² People opt for treating others in accordance with their own needs when put behind a ‘veil of ignorance’ since the distribution is known but which share they will get is unknown (McPake et al., 2002).

³ There will only be an increase in social welfare if the welfare of the worst-off individual increases (McPake et al., 2002)

that people prefer equality *per se*, and that relative risk aversion and inequality aversion differs between genders, where female respondents tend to be more risk and inequality averse on average. They also find that technology and business students are less risk and inequality averse than other students.

That individuals exhibit both risk averse and risk seeking behavior at the same time in regards to health care is suggested by Loomes and McKenzie (1989). Individuals might prefer prioritizing treatments that are lower in efficiency but that help many patients, over treatments with high efficiency for fewer patients. That is, the treatment that gives a higher probability of being treated is preferred, which indicates that individuals are risk averse. On the other hand, they argue that individuals are risk seeking as they also might have a high demand for health insurances covering treatments they are unlikely to need, such as heart transplants.

2.4 Summary

In summary, previous studies have found that people have strong preferences for helping severely ill patients over less severely ill patients. Men, younger individuals, and individuals with higher education are associated with a higher acceptance of priority-setting in health care in general compared to opposing groups. It has also been showed that the framing of questions in surveys can greatly affect the results, in particular for questions of high ethical difficulty. Given the perspective a respondent is asked to consider, this can influence the way he or she wants to prioritize. Moreover, females are on average more inequality and risk averse than men, and students studying technology or business exhibit lower levels of aversion in the same scenarios.

3. Methodology

In April 2014, a web based survey was constructed through a survey tool called ‘SurveyGizmo’. The survey in its entirety can be found in appendix II, and the reader is encouraged to study the survey carefully before reading any further.

3.1 Sample selection

Email addresses to students were requested from eight randomly selected universities in Sweden. Table 1 below illustrates the composition of the sample, which consists of 3,086 students in total. The email addresses are equally divided between the two different types of

questionnaires, the private and the public. This division was made in order to see if the results differ between perspectives, since previous studies suggest that an individual's priority-decision can depend on the perspective he or she faces. To increase the response rate, students who completed the entire survey could win headphones or cell phone cases.

Table 1 : Number of email addresses in the sample

University	Private perspective	Public perspective	Total
Lund	243	246	489
Södertörn	187	179	366
Luleå	249	249	498
Borås	50	50	100
Karlstad	99	101	200
Mid Sweden	236	237	473
Karolinska institutet	239	236	475
Royal institute of technology (KTH)	247	238	485
Total	1,550	1,536	3,086

3.2 Construction of the survey

One approach for this kind of study could be to ask for respondents' willingness to pay (WTP) for pharmaceuticals for different scenarios. It has been shown in previous studies, however, that respondents have difficulties stating WTP. For instance, a respondent can state a similar WTP to avoid a small risk (e.g. 1:1000) as to avoid a much higher risk (e.g. 1:100) (Zweifel, Breyer, & Kifmann, 2009). With this in mind, this study will not perform estimations of WTP for helping patients of different health states. Instead, the study is a type of Person Trade-Off (PTO) approach, which makes it possible to estimate what social value people attribute to different health care interventions. In PTO questions, people are asked to state how many outcomes of a given kind they consider equivalent, in terms of social value, to X outcomes of another given kind (Nord, 1995). The social values that people then holds for these particular outcomes are given from the X that they state. When allocation decisions are made in health care, Nord (1995) argues that actually person trade-offs are made. Thus, the use of this technique in the survey could simulate actual decisions.

3.3 Survey design

The creation of the survey has to a certain extent followed the steps suggested by Whitehead (2006). The survey consists of four parts: the respondent's own health status (part 1), the valuation of severity of illness in terms of pain and immobility (parts 2 and 3), and background questions concerning the respondent's socioeconomic status (part 4).

Part 1

This part consists of ‘warm-up’ questions in order to prepare the respondent for the more difficult questions, which comprises questions about the health state of respondents, and former health state in terms of pain and immobility. The stages in the first question about immobility are based on the seven steps developed by Nord (1993) from Sintonen’s scale of severity first introduced in 1981, since each step is demonstrated to be equally large. The five steps in the third question about pain are freely developed from Sintonen’s five levels of health status and the standardized measurement for health outcomes, EQ-5D⁴. A concrete way of measuring pain is yet to be found, as pain can be very subjective and hard to describe.

At the end of the first part, respondents are asked to indicate the level of their own health status on a vertical scale from 0 to 100. This is to help respondents understand the severity levels of the patient groups in parts two and three. In these parts as well, vertical arrows pointing upwards illustrated the health improvements on a scale from 0 to 100.

Parts 2 and 3

The second and third parts are the main parts of the questionnaire and consist of questions regarding severity of illness, in terms of pain and immobility. In order to avoid anchoring bias and force the respondents to reflect over their true preferences, open-ended questions are used. This type of question makes it possible to use ordinary least squares (OLS) since point estimates of the responses are obtained. Closed-ended questions would instead result in interval estimations. Furthermore, open-ended questions enable the search for outliers and protest responses.

For simplicity, patient groups A(C) are always more severely ill than patient groups B(D)⁵. A patient’s pre-treatment health state, i.e. the starting point, is the most popular method to define severity in the literature (Shah, 2009). Therefore, this is the definition used in this study. Also, the level of pain and immobility is referred to in terms of health status since a higher level on the health status scale should always represent an improvement. The health status scale used in these questions was developed from EQ-5D. If the seven levels of mobility are “transferred” to our health status scale, then level 0 corresponds to being

⁴ EQ-5D is a standardized instrument extracted from a questionnaire about health status designed for self-completion. EQ-5D yields a single index value for health status, which makes health conditions and treatments comparable (EuroQol Group, 2014).

⁵ Patient groups A and B in the questions regarding pain and C and D in the questions regarding immobility.

permanently bedridden and level 100 to being able to walk without any difficulties. For pain, level 0 would correspond to having extreme pain and 100 to having no pain at all.

Each part consists of three questions concerning patient groups with different levels of pain or three questions concerning patient groups with different levels of mobility. Half of the respondents got questions 1 and 3 for both pain and immobility, whilst half of the respondent got questions 2 and 4. In addition, a third random question out of questions 5-9 is included as robustness check. After each three question set, respondents were encouraged to comment on their way of reasoning. In order to avoid always getting fatigue answers for either pain or mobility, the order of these two parts is randomized so about half of the respondents got the mobility part first and vice versa. The questionnaire for the private perspective has exactly the same formation as the public perspective except for one sentence stating the perspective. The main question posed in the public perspective survey was “*Assume that you are a policymaker asked to choose which one of these two pharmaceuticals the state should finance*⁶. *Imagine that the pharmaceutical for group A(C)*⁷ *can help 10 patients. At least how many patients in group B(D) need to be helped by their pharmaceutical in order for you to choose to finance pharmaceutical B(D) instead of A(C)?*”

In total, nine trade-offs between different health improvements of the severity levels are included. In order to extract the evaluation for the different levels, the changes in severity in questions 1-4 are the most important to include since these four comprise the whole health status scale from 0-100 (Table 2). Questions 5-9 work as robustness checks of the consistency of the answers. If the prospective health improvements for the two groups follow consecutively after each other on the health scale, the comparisons are known as local (gray-shaded boxes). When there is a difference between the health status that the worst-off patient group can achieve, and the *initial* status of the better patient group, the comparisons are referred to as global. Global comparisons are made in questions 5-9. The starting point differences in terms of health levels are 20 for the local comparisons (questions 1-4), 40 for questions 5-7, and 60 for questions 8-9.

⁶ Private perspective: Assume that there is a big risk that you will suffer from illness A(C) or B(D) in the future.

⁷ A and B in the questions regarding pain and C and D in the questions regarding immobility

Table 2: Severity levels of patient group A(C) and B(D) in the survey questions

		Patient group A(C)				
		0-20	20-40	40-60	60-80	80-100
Patient group B(D)	80-100	.	9	7	4	.
	60-80	8	6	3	.	.
	40-60	5	2	.	.	.
	20-40	1
	0-20

Note: The numbers in the boxes correspond to a question number.

The 10th alternative, which is the most extreme case where patient group A(C) start at level 0 and patient group B(D) at level 80, was excluded from the questionnaire due to practical limitations.

Part 4

The fourth part of the questionnaire consists of background questions to facilitate the identification of sub-groups. Examples are questions regarding gender, age, and level of education. At the end of the questionnaire, respondents could leave general comments.

3.3.1 Pilot studies and focus groups

Throughout the construction process of the questionnaires, several pilot studies and focus group meetings were conducted with both students and non-students. The dominant issue the participants had was the difficulty in answering the main questions in parts two and three. Even after efforts to simplify the questionnaire, it was pointed out by respondents that there is a risk that respondents arbitrarily select a number without reflecting on if it is their true preference or not, due to complex ethical dilemmas. The main method is therefore supplemented with a second method, called laboratory settings. If the results vastly differ between the two methods, it could possibly be due to the actual methods in question.

3.3.2 Laboratory setting

For the laboratory setting we invited patient organizations and students from different universities to participate. The patient organizations were offered to take part in the survey after one of their meetings, whereas the students were invited to a computer room. In total, 17 respondents participated in this setting. Five participants represent a patient organization (fibromyalgia), five respondents study business and economics, and seven participants study health-related subjects. Participants were randomly selected to get either the private or the public perspective, but the number of participants conducting each of the questionnaires was

controlled. Before the respondents were allowed to start, one of us read a predetermined script out loud explaining the main questions in parts two and three. The same researcher conducted this procedure to ensure extra consistency in the way the information was presented. Any questions that the respondents might have had were answered according to the predetermined script. Participants were not allowed to discuss and no comments were made outside the script.

3.4 Econometric specification

The total value that a respondent has stated for all his/her questions is the dependent variable, *value*. The response variable consists of the following explanatory variables:

$$value_i = value(levels_{m-n}, p_i, f_i, hs_i, exp_i, inc_i, hes_i, z_i)$$

The subscript i indicates individual, and $levels_{m-n}$ corresponds to the levels considered in each question where m and n indicate the interval. The dummy variables public perspective (p_i), female (f_i), experience of pain and/or immobility (exp_i), and whether studying health (hes_i) are factors believed to be positively related to $value_i$, e.g. the expected marginal effect for females is $(\partial value_i / \partial f_i) \geq 0$. This implies that if the individual is female, the independent variable $value_i$ is expected to increase on average. Health status (hs_i) and household income (inc_i) are expected to have the opposite marginal effect, e.g. $(\partial value_i / \partial hs_i) \leq 0$. The higher the self-reported health status or income, the smaller the independent variable $value_i$ is estimated to be. Age and household composition are examples of control variables that are incorporated in z_i . No specific hypotheses are expressed for these characteristics.

Since the data is skewed to the right with some outliers in each question (Figures 1 and 2, Appendix D), the data is logged to obtain a more normal distribution (Figures 3 and 4, Appendix I). This can also be seen by the antilog of the mean logged data, being closer to the median than the mean from the unlogged data (Table 4, Appendix I). Hence, performing OLS regressions with logged data is justified.

3.5 Method criticism

One of the main problems when creating the survey has been to make it simple without losing the context. Even in the final version, complexity remains. It is difficult to give information in the hypothetical scenarios in a sufficiently neutral way so as not to encourage a particular

interpretation. Also, the survey ended up being longer than what is desirable, but it was essential that the respondents fully understood the context.

Further, an issue with the open-ended questions is that it is more difficult to answer these than closed-ended questions or questions with payment cards. People are more used to making a decision at an already given level, e.g. a price, than to choosing a level themselves. In closed-ended questions or payment cards, respondents merely have to answer yes/no or choose a specific number already suggested. In general, respondents are open to suggestions when answering unfamiliar questions (Whitehead, 2006), and this could bias the responses. Besides, reasonable response categories are difficult to suggest in the closed-ended questions or on a payment card and it is harder to distinguish protest responses and outliers.

Other possible critiques are selection bias and the unfamiliarity of thinking in these terms. For example, students that are more interested in the health care and pharmaceutical sector are more likely to complete the survey. Also, since we had a lottery with headphones and cell-phone cases, it is possible that some participants completed the survey without reflecting over the questions because they wanted to win a prize. Thus, there is a risk that some respondents have stated a number randomly and not given it any thought. However, this is impossible to control without having personal interviews with each respondent.

It could also be the case that respondents feel that they have to answer in a certain way, e.g. always stating a higher number than 10 due to the framing of the questions, or to buy ‘moral satisfaction’⁸. Another issue is the possible problem of anchoring bias, i.e. when respondents get “attached” to the number stated in the survey and think that the “correct” answer is probably close to the suggested number, which would be 10 in our case. Questions of this ethical difficulty are sensitive to framing, and other results could possibly be obtained if the questions are slightly rephrased. The results from this study should therefore be approached with caution.

⁸ When expressing support for good causes, respondents may receive a “warm glow”. This is what Kahneman and Knetsch (1992) call purchase of moral satisfaction.

4. Data

In total 387 students completed the questionnaire out of the total 3,086 students. This corresponds to a response rate of 12.5 %. The links to the questionnaires were emailed twice, meaning that participants were reminded one time. 26 respondents were dropped from the sample for different reasons. For example, some respondents stated that they did not understand the questions or admitted that they randomly stated a number. Another example is respondents stating extremely high numbers or zero. These responses are considered to be protest responses. The 10 % largest numbers in each question were considered outliers and are therefore not included in the analysis. However, these respondents are not dropped from the sample as respondents might have stated a high number in only one of the questions. The results and analysis are based on the remaining 90% of the sample. This sample consists of 361 respondents. Table 3 below illustrates the descriptive statistics. 45% of the respondents answered the private version, about 61% are females, and the mean age is 27 years in this sample. The mean level of health corresponds to 81 (on a scale ranging from 0 to 100). About a quarter of the respondents study health-related subjects, and almost a third study engineering of some kind. Furthermore, there is no statistically significant difference between the respondents who were given the private or the public perspective, with respect to average age, gender distribution, average household income and distribution of study areas.

Table 3: Descriptive statistics

	Obs.	Mean	Std.Dev	Min	Max
<i>Public</i>	361	0.55	0.50	0	1
<i>Health status</i>	361	81.46	14.95	12	100
<i>Experience of immobility</i>	361	0.12	0.33	0	1
<i>Experience of pain</i>	361	0.22	0.42	0	1
<i>Female</i>	361	0.61	0.49	0	1
<i>Age</i>	361	27.39	6.75	20	58
<i>Number of adults</i>	361	1.79	0.86	1	6
<i>Number of children</i>	361	0.35	0.80	0	4
<i>Work experience health</i>	361	0.39	0.49	0	1
<i>Family member work experience health</i>	361	0.57	0.50	0	1
<i>Household income</i>	361	2.18	1.27	1	5
Study area	Obs.	%			
<i>Health-related education⁹</i>	88	24.38	.	.	.
<i>Business and Economics students</i>	26	7.20	.	.	.
<i>Bachelor or Civil Engineering</i>	116	32.13	.	.	.
<i>Other education</i>	131	36.29	.	.	.

⁹ e.g. doctor, nurse, physiotherapist

5. Results and analysis

The results are obtained from nine pair-wise comparisons between different health improvements where the initial severity levels differ. First, the results from the questions about immobility are presented, followed by the results from the pain questions.

5.1 Immobility

For the questions regarding immobility, the local comparisons yielded the lowest number of patients required. For the global comparisons the numbers of patients are higher, where the highest numbers can be found in question 5, 8 and 9, as seen in Table 4 below. In both question 5 and 8, patients have the lowest possible level of mobility (level 0), which is equivalent to being permanently bedridden, according to the severity scale by Nord (1993). This level of mobility seems to have triggered respondents to state high numbers. In all the questions the means are higher than 10, i.e. the patients with the highest level of severity are prioritized. This is in line with previous findings; see e.g. Jacobsson et al., (2005) and Cookson and Dolan (1999).

In general, the means do not differ much between the two perspectives, and the only statistically significant difference between them can be found in question 9 ($p < 0.05$). This implies that those with the private perspective stated higher numbers on average, but only in this particular question. Furthermore, the individual variations in the questions are high. For instance, in question 4, one respondent has stated that at least one D-patient has to be cured if 10 C-patients can be cured by their pharmaceutical, and another has stated 500 in the same question (Table 4). Similar ranges can be found for all questions, for both perspectives.

Table 4: Mean values in questions about immobility, separated by perspective

Question number	Immobility		Private		Public		No. of observations
	C	D	Range	Mean	Range	Mean	
1	0-20	20-40	3-100	36	1-100	37	168
2	20-40	40-60	1-100	32	1-100	30	157
3	40-60	60-80	1-200	41	1-100	37	168
4	60-80	80-100	1-500	52	1-500	47	156
5	0-20	40-60	1-5,000	400	1-1,000	136	58
6	20-40	60-80	5-700	84	3-200	42	64
7	40-60	80-100	5-1,000	211	1-1,000	128	70
8	0-20	60-80	1-1,000	228	1-5,000	345	62
9 ^a	20-40	80-100	6-10,000	1,486	5-1,000	198	75

^a Statistically significant difference between private and public $p < 0.05$

There are large differences between the mean and the median in each question. This indicates that the results are not evenly distributed around the mean. Consequently, using the median can be justified. Table 5 below illustrates the medians divided by 10. This is done to get a one-to-one patient comparison, since there were always 10 patients in the worse-off group in the trade-offs. The gray-shaded boxes display the local comparisons and the median valuation of different health improvements. In the left box, showing the public perspective, all local health improvements are valued similarly. For example, helping one C-patient to go from level 0 to 20 is valued equally to helping two D-patients to go from 20 to 40. By the same reasoning for the global comparisons, helping one patient from group C to go from level 20 to 40 is valued equally to helping seven patients from group D to go from level 80 to 100. In the private perspective to the right, the median numbers are slightly higher than in the public perspective at large.

Table 5: Medians in questions about immobility, split by perspective

		<i>Public perspective</i>							<i>Private perspective</i>				
		Patient group C							Patient group C				
		0-20	20-40	40-60	60-80	80-100			0-20	20-40	40-60	60-80	80-100
Patient group D	80-100	.	7	4	2	.	Patient group D	80-100	.	10	5.5	3	.
	60-80	6	2.5	2.5	.	.		60-80	8	3.5	3	.	.
	40-60	5	2	.	.	.		40-60	3.1	2	.	.	.
	20-40	2		20-40	2
	0-20		0-20

From the four local comparisons, a utility function of being at a certain level of health in terms of immobility can be estimated by using the median values which is done in the following section. This is done separately for the public and the private perspective but the procedures are the same for both.

5.1.1 Estimating utility functions

$U(x)$ is the utility of being at a certain level of immobility, where $x \in \{0,100\}$, and immobility decreases with a higher number of x . For instance, the utility of going from level 20 to level 40 is valued half as much as going from 0 to 20 in the public perspective (see the gray-shaded boxes in Table 5 above). From this median the following equation results:

$$2(U(40) - U(20)) = U(20) - U(0) \quad [1]$$

The same logic yields the remaining three equations for the other gray-shaded boxes:

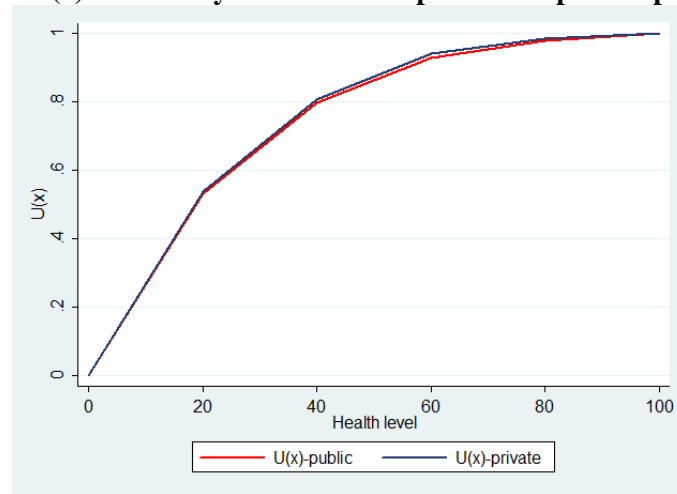
$$2(U(60) - U(40)) = U(40) - U(20) \quad [2]$$

$$2.5(U(80) - U(60)) = U(60) - U(40) \quad [3]$$

$$2(U(100) - U(80)) = U(80) - U(60) \quad [4]$$

This gives 6 unknown levels of utility and 4 equations. By normalizing $U(100)$ equal to one, and $U(0)$ equal to zero this system of equations is solved (for calculations see Appendix III). From this system of equations, the utility of being at a particular level of mobility is obtained. The utility levels are presented in Figure 1 below, for both the public and the private perspective.

Figure 1: $U(x)$ of mobility from both the public and private perspective



The utility functions are concave with diminishing returns to utility of increased mobility. That is, the utility from increased mobility is larger the lower the starting point is. Applying the levels of mobility that were developed in the first part of the questionnaire, this implies that going from being permanently bedridden (level 0) to being partly bedridden, but being able to sit up if assisted (about level 15) gives the largest marginal improvement in utility. In the same line of thinking, going from being able to walk, but having troubles walking longer distances (about level 85) to being able to walk completely without troubles (level 100), gives the smallest marginal improvement in utility.

The private perspective implied that the respondents themselves could end up in one of the two patient groups in the future. Thus, the concave shape of the utility function shows that the respondents in the private perspective are risk averse. This indicates that they want more resources to be spent on patients with higher levels of severity, than on conditions of milder severity, as a way of insuring themselves if ending up in the worst possible condition. Quantifying the level of risk aversion in the same manner as one would calculate a Gini-

coefficient; a coefficient of aversion of 0.51 is obtained (see Table 1 in Appendix I)¹⁰. Similar to the interpretation of the Gini-coefficient, a coefficient of 0 would imply no risk aversion (risk neutrality) and a coefficient of 1 would imply the highest possible level of risk aversion. Thus, the coefficient of 0.51 confirms this fairly high level of risk aversion for the average respondent.

For the public perspective, the respondents are tasked with deciding from a policymaker's point of view which pharmaceutical should be financed. Since the shape of this utility function is concave, this implies that the respondents are inequality averse. This curve is identical to the one for the private perspective. This means that the "public" respondents do not want any patients to be in the severest conditions, and that they prefer financing pharmaceuticals to those worse-off in terms of health compared to those who are better-off. The coefficient of aversion is equal to 0.48, which also confirms the rather high level of inequality aversion. In brief, the respondents in the private setting are equally risk averse as the respondents in the public setting are inequality averse. These results go against the findings of Nord (1995) and Nord et al. (1996), who find that the priority decisions and line of thinking differ between the two perspectives.

5.2 Pain

In the questions for pain, the lowest means are found in the local comparisons and the highest in the global, exactly as in the immobility questions. Again, question 5, 8 and 9 yielded the highest number of B-patients, as seen in Table 6 below. As for immobility, the most severely ill patients are prioritized, as all the means are higher than 10. The mean ranges are similar and there are no significant differences between the two perspectives (Table 6). The individual variations in both the perspectives are high. For example, in the private perspective in question 5, at least one respondent has stated that one B-patient is required, whereas another has stated that 10,000 B-patients are required.

¹⁰ A Gini-coefficient is usually used for measuring how the distribution of income in a country among individuals differs from a perfectly equal distribution. The Gini-coefficient is a measure of how far the distribution is from the perfect equality line, where 1 equals perfect inequality and 0 perfect equality (The World Bank, 2014)

Table 6: Mean values in questions about pain, separated by perspective

Question number	Pain		Private		Public		No. of observations
	A	B	Range	Mean	Range	Mean	
1	0-20	20-40	4-100	40	1-100	31	168
2	20-40	40-60	1-200	44	1-200	36	160
3	40-60	60-80	1-100	33	1-100	33	168
4	60-80	80-100	1-200	44	1-200	43	159
5	0-20	40-60	1-10,000	759	1-1,000	122	58
6	20-40	60-80	5-500	92	2-200	50	64
7	40-60	80-100	1-1,000	178	1-1,000	153	70
8	0-20	60-80	1-1,000	254	1-5,000	426	63
9	20-40	80-100	5-10,000	1,441	5-10,000	675	75

Table 7 below presents the median for all the questions regarding pain, divided by 10. The left box illustrates the public perspective, whilst the right illustrates the private. The means differ from the medians in all of the questions. Remarkably, all local health improvements in the left box are valued equally. Besides, the global comparisons are reasonably consistent with the local ones. The valuations from respondents within the private setting are in general similar to those within the public setting.

Table 7: Medians in questions about pain, split by perspective

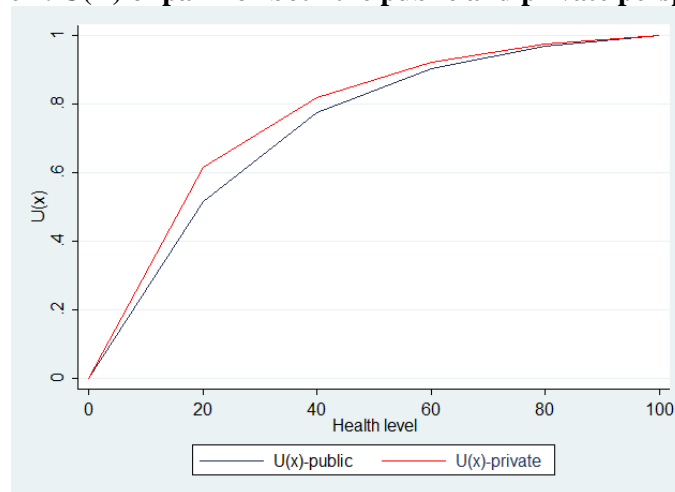
<i>Public perspective</i>						<i>Private perspective</i>					
Patient group A						Patient group A					
Patient group B						Patient group B					
	0-20	20-40	40-60	60-80	80-100		0-20	20-40	40-60	60-80	80-100
80-100	.	7	4	2	.	80-100	.	10	5	2	.
60-80	5	4	2	.	.	60-80	9	4	2	.	.
40-60	5	2	.	.	.	40-60	3.6	2	.	.	.
20-40	2	20-40	3
0-20	0-20

5.2.1 Estimating utility functions

The medians from the local comparisons can be used to estimate a utility function for a certain level of health, in terms of pain. The utilities are calculated in the same manner as in the immobility section, and the results are plotted in Figure 2 below. Again, the functions are concave, meaning that respondents value the utility from getting improvements in health lower, the better the initial health status and the lower the level of pain. Going from the most extreme levels of pain (level 0) to less severe pain (level 20) gives the largest marginal increase in utility. Here, it appears as if those with the public perspective are slightly less inequality averse than those with the private perspective are risk averse. The coefficients capturing these aversions are 0.53 for the private (risk aversion) and 0.47 for the public

(inequality aversion), confirming that there is a slight difference between them (Table 1, Appendix I). Thus, when respondents themselves are facing a risk of staying in the worst possible health state, in terms of pain, they value the pharmaceutical directed to patients at this level higher compared to respondents that are acting as policymakers. Besides this difference, the utility functions are alike.

Figure 2: U(X) of pain for both the public and private perspective



5.3 Comparison between pain and immobility

In regards to differences between the questions for pain and immobility, the number of patients required in order to finance the pharmaceutical for patient groups B or D differs significantly for questions 2 and 3, if aggregating all respondents (Table 3, Appendix I). In question 2 the numbers are on average higher for pain than for immobility, implying that helping patients with severe pain is valued higher than helping patients with severe immobility. The opposite is found in question 3, i.e. when the patient groups are midway on the health scale, helping patients with immobility is valued higher than helping patients with pain. However, there is no significant difference in most of the questions. This means that respondents are equally risk averse (or inequality averse depending on perspective) against high levels of pain as against low levels of mobility. This can also be seen from the coefficients of aversion that are very similar to each other. Hypothesis I, that people would assign a higher social value to helping patients with severe pain over patients with severe immobility, does not hold as these types of patients are valued equally.

5.4 Comparison between the private and public perspectives

As already mentioned, the only significant difference between the private and the public perspectives can be found in question 9 for immobility, where those with the public perspective in general stated a lower number than those with the private perspective. Other than that, it appears as if either the framing of the questions has not impacted the way that participants respond to the questions, or the preferences actually are the same regardless of perspective. This lack of difference stands in contrast to the results of both Nord (1995) and Nord et al. (1996) who got different results from the two different framings with which they confronted their respondents. According to Hypothesis II, those with the public perspective were expected to maximize resources to a larger extent than those in the private perspective, and they are not expected to be equally inequality averse as the respondents with the private framing are risk averse. By studying the utility functions in Figures 2 and 4, it is clear that the differences between the perspectives are negligible, especially in the case of immobility where the functions are essentially identical. Also, from the coefficients of aversion (Table 1, Appendix I) it can be seen that there are very small differences between the two perspectives. For example, for immobility they differ by 0.03 and for pain by 0.06. Consequently, from now on no distinction between the public and the private setting will be made. Instead, all responses are aggregated into one sample.

5.5 OLS estimations

The following model is estimated to find the values that respondents hold for being at a particular level of pain or immobility:

$$Value_i = \beta_1 level_{i_{0-20}} + \beta_2 level_{i_{20-40}} + \beta_3 level_{i_{40-60}} + \beta_4 level_{i_{60-80}} + \varepsilon \quad [5]$$

where *value* is the total value that a respondent has stated for all his/her questions, *i* is the individual, β_1 to β_4 are the coefficients for each question, $level_{i_{0-20}}$ is a dummy for when a respondent has valued going from level 0 to level 20, and the other level dummies work in the same manner. ε is the error term. One question corresponds to one dummy in the local comparisons, and several dummies in the global comparisons. For example, when responding to question 2, a respondent only considers levels 20-40, but when responding to question 5, a respondent considers both levels 20-40 and 40-60, thus both these corresponding level dummies will be equal to 1.

In Table 8, columns 1-3 concern immobility estimations, and columns 4-6 represent the estimations for pain. Columns 1 and 4 show the estimation for the local comparisons, i.e. for question 1 to 4, which is the benchmark case. Columns 2 and 5 illustrate the global comparisons, and column 3 and 6 present the local and the global comparisons pooled together. These estimations are used as robustness checks for the consistency in responses. The coefficients estimate the value that the average respondent holds for an increase in health, by a decrease in immobility or pain, and are all statistically significant at the 1% significance level.

Table 8. OLS estimations

	Immobility			Pain		
	Local	Global	Local+global	Local	Global	Local+global
VARIABLES	(1) <i>value</i>	(2) <i>value</i>	(3) <i>value</i>	(4) <i>value</i>	(5) <i>value</i>	(6) <i>value</i>
Level 20 to 40	3.100*** (0.298)	1.723*** (0.222)	2.884*** (0.292)	3.559*** (0.294)	1.546*** (0.233)	2.533*** (0.311)
Level 40 to 60	2.486*** (0.462)	1.600*** (0.221)	3.552*** (0.339)	3.638*** (0.345)	1.837*** (0.234)	3.910*** (0.335)
Level 60 to 80	3.438*** (0.297)	1.387*** (0.229)	3.351*** (0.392)	2.818*** (0.302)	1.356*** (0.240)	3.305*** (0.382)
Level 80 to 100	3.920*** (0.465)	2.053*** (0.212)	2.869*** (0.286)	2.814*** (0.351)	2.061*** (0.224)	2.847*** (0.285)
Observations	361	361	361	361	361	361
R-squared	0.943	0.859	0.926	0.934	0.851	0.918

Robust standard errors in parentheses, *** $p < 0.01$, ** $p < 0.05$, * $p < 0.1$

5.5.1 Utility functions

Given the above OLS estimates, the utilities of being at a particular health level in terms of pain and immobility can be calculated in the same manner as the utilities in equations [1]-[4]. Figures 3 and 4 plot the estimated utilities for the local, global and local-plus-global estimates. As before, the functions are concave and the utilities derived from the local estimates and the local-plus-global estimates are more or less identical. The greatest change in utility is found if going from level 0 to level 20 in all estimations. However, the global estimations indicate a considerably lower level of risk averseness. Going from 80 to 100 gives almost no improvement in utility in both the local and the local-plus-global estimations, in contrast to the utilities derived from the global estimates where the increase is slightly larger. These results hold for both immobility and pain, and the two graphs are virtually identical.

Figure 3. U(x) of immobility

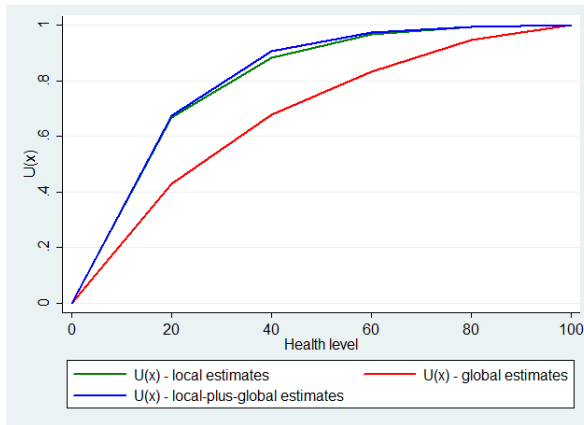
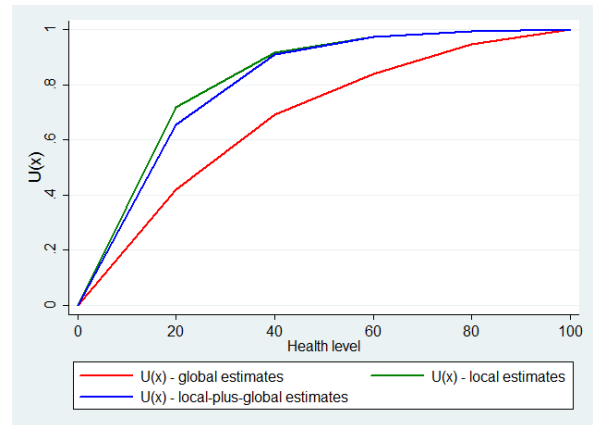


Figure 4. U(x) of pain



The coefficients of aversion for immobility are 0.60 for the local estimates, 0.35 for the global and 0.62 for the local-plus-global estimates. The coefficients of aversion for pain are 0.64 for the local comparisons, 0.36 for the global and 0.61 for the local-plus-global comparisons (Table 2, Appendix I). Thus, the aversion in the global comparisons differs hugely from the other two, implying that respondents are less risk or inequality averse, depending on perspective, when making the global comparisons for both immobility and pain. It could be the case that respondents do not consider the health states of the worst-off patients to be as terrible as in the local comparisons, since a lower number of B or D patients are needed in the trade-offs on average. Accordingly, the respondents' preferences are not completely consistent in the local and the global comparisons. In the global comparisons, some people stated low numbers with the justification that it would be more "efficient" for society to help those who could achieve perfect health, rather than those at the bottom, who would still need more resources in order to be "beneficial" for society. This could be one explanation why going from 0 to 20 gives a lower increase in utility in the global estimates than compared to the others. Besides the global comparisons, the OLS estimations are in line with the utilities obtained from the median calculations (see Figures 1 and 2 above).

5.5.2 Sub-groups

Our model takes the following form when control variables are included;

$$Value = \beta_1 level_{0-20} + \beta_2 level_{20-40} + \beta_3 level_{40-60} + \beta_4 level_{60-80} + \beta_z Z + \varepsilon \quad [6]$$

Z is a vector of control variables such as gender, age, income and type of education etc. None of the control variables are significantly different from zero at the 5% significance level in any of the estimations (Table 5, Appendix I). This implies that regardless of the socio-economic background the students belong to, their responses do not differ significantly in any

way. One could of course argue that students are a homogeneous group, but nonetheless there may be differences between genders or between those who have experienced severe pain or low mobility during a longer period, for example. This is a surprising result that is not in line with Hypothesis IV, which states that respondents with previous experience of illness, low-income individuals or females are more prone to state a high value. This also goes against previous findings such as the findings of Ryyänen et al. (1999) and Carlsson et al. (2005) who find differences in preferences between genders and education levels or type of education. Additionally, it is not the case that studying health related subjects affects the responses, as stated in Hypothesis III. From a graphical inspection (Figure 5 to 11, Appendix D), the distributions of answers in different sub-groups are generally the same. For some questions, mainly question 5 and 9, the answers can differ in magnitude. However, the differences are not statistically significant.

5.6 Different viewpoints

Respondents were encouraged to leave comments to explain their reasoning in parts two and three in order to easily identify if they had understood the task. From these comments, some similar patterns can be extracted. The comments can be categorized into four general viewpoints, and one miscellaneous. Almost 62% of the 361 respondents did leave a comment explaining their reasoning, out of which 216 comments were sufficiently understandable in order to categorize them. The four main philosophies of resource distribution of pharmaceuticals found are as follows: (1) helping the worse-off patients (Rawlsian), (2) reducing inequalities in health (Equity), (3) maximizing overall health (Utilitarian) and (4) considering what should be the most efficient solution for society (Efficiency). The efficiency viewpoint was to a greater extent supported by engineering students ($p < 0.001$) compared to other types of students, which is in line with the findings of Carlsson et al. (2005), that technology students are less risk and inequality averse. The Rawlsian philosophy was rather supported by medical students. Examples of typical comments categorized in each perspective can be found in Table 7 in Appendix I.

5.7 Large variance

It seems as if the framing in terms of answering the private or the public perspective neither had an impact on the stated numbers, nor on the way of reasoning on average. However, the individual variance is high, and hence it is evident that there are large differences in risk aversion (and inequality aversion) between respondents. For instance, in question 9 for pain,

the lowest stated number is 5 and the highest 10,000. The respondents stating these two numbers have very different levels of risk aversion where the respondent stating 10,000 is extremely risk or inequality averse compared to the respondent stating 5. Nevertheless, as previous studies for WTP has shown, people generally cannot separate different risk levels such as (1:100) and (1:1,000). This could be one explanation to the high variance within the sample in this case as well. Further, it might be problematic from an insurance-perspective that there exist high variations in responses between individuals. People cannot actually choose how much they are willing to pay for “insurance” in terms of pharmaceuticals, as it is a state agency that determines how costly a pharmaceutical will be. When TLV determines which pharmaceuticals to include in the pharmaceuticals benefits scheme, they look at the costs, benefits and the effectiveness of the pharmaceutical. It is probable that patients have a higher WTP than TLV decides is rational to pay for a particular treatment, which can result in a discrepancy between people’s preferences and what the state is willing to provide.

5.8 Laboratory setting

As a part of robustness check of the main method, the web surveys were conducted in a laboratory setting as well. The results from those are presented in Table 6 in Appendix I. When comparing these results with the results from the web survey, it is found that the numbers stated seem lower in general. There are not any zeroes stated in this sample (which was the case in the main method), and there also seems to be a greater difference between the numbers stated for pain and the numbers stated for immobility in this sample. This implies that respondents make a larger difference between being in a state of severe pain and being in a state of low mobility compared to the results in the web survey. About 75% of the respondent explained their reasoning, compared to about 62% in the other method. However, it is hard to say exactly how much of these differences come from the change in method and how much is specific to this sample. Further, it was observed that participants found it difficult to give a precise number to the first question in part. After answering a couple of questions, respondents chose more quickly. This was probably also the case in the web survey, and some respondents might have closed the survey before getting up to speed.

6. Discussion

The scenario in our study is hypothetical and a simplified example of actual situations that policymakers face. Nevertheless, it is an attempt to simulate the difficulty of ethical dilemmas that arises during prioritization processes. In Sweden, people generally do not have experience in purchasing health care services since the state-financed insurance and subsidy system is well developed. This can make it difficult for Swedes to estimate costs and to understand the concept of limited resources in health care. One could therefore argue whether the resource allocation within the health care sector should take the public's preferences into account at all. Some respondents stated extremely high numbers of patients and some very low, leading to a high variance.

6.1 The survey

It is difficult to know how much information that should be provided in a survey. There is a trade-off between the benefit of having a lot of informative text so respondents are fully informed and the risk of losing impatient participants before the main parts begin. Also, previous studies have shown that questions of high ethical difficulty can be very sensitive to framing, and this study is probably no exception. A slight change of wording might impact the respondents to reply differently. It could be the case that the framing of the questions steered the respondents into thinking that they should state a number greater than 10. In the main parts of the questionnaire, there are 10 patients in the trade-offs, in order to give respondents the possibility to state preferences in two directions, i.e. by stating a number lower than or greater than 10. In other studies where similar questions have been asked, comparisons have been made between one patient in a certain state, and X patients in another state. The indicated X should correspond to the respondent's equivalence number. We believe that this frames the respondents to state a higher number than one, as a number lower than one would not make much sense. Our framing does not exclude the possibility to state preferences for the "better-off" patients, and in fact, some respondents have stated numbers lower than 10.

Additionally, there is always a risk that respondents randomly state responses throughout the survey without really giving their answers a second thought. Answers that seemed to be inconsistent, i.e. very high numbers, zeroes throughout, or random, were dropped from the sample. This risk could perhaps increase when there is an incentive to complete the survey,

e.g. when there is the possibility of winning a prize, as is the case in this survey. Since it is easier to state a very high number when the context is hypothetical, a phenomenon known as hypothetical bias, the 90% lowest responses are used in the results and analysis sections. If the respondents would have been able to see in some way how many people a thousand patients, for example, actually is, the likelihood that they would state such a high number is possibly lower. There is also the probability that respondents get a feeling of “warm glow” when stating high numbers. Kahneman and Knetsch (1992) argue that the purchase of moral satisfaction (or “warm glow of giving”) is increasing with contributions to a public good. In our case, respondents might get moral satisfaction from stating a high value, i.e. when showing much sympathy for the worse-off patient group.

The overall low response rate of about 12.5% is troublesome, but it is hard to say where this low response rate comes from. The biggest obstacle seems to be to make the respondents even open the web survey in the first place. Then, out of those who started the web survey, but did not complete it, close to 50% did not reach the main part but closed the survey before that. Thus, the contacted students seem to be impatient and unwilling to allocate time to surveys. In general, the background questions should always come last in a questionnaire, but in retrospect it would have been useful to put more background questions in the beginning to make it possible for a proper “fall-out” analysis.

6.1.1 The sample

Since the sample only consists of Swedish students, the results are not transferable to that of the Swedish population, and cannot be generalized. The overall health levels of the respondents are high (81 out of 100), and only a few have experienced previous illness. However, the aim of this study is explorative, and for this purpose, a student sample works well. There is also the concern about selection bias, i.e. those who for some reason are interested in prioritization in health care or pharmaceuticals, for example, decided to reply to our web survey. The same line of thinking goes for those who chose to participate in our laboratory setting survey. This is a common problem in surveys, and it is difficult to fully control who took part and for which reason they did so. It is impossible to say exactly which effects a possible selection bias could have in this study.

ManUnfortunately, the sample from the laboratory setting was not as large as expected. With only 17 respondents, the results cannot be generalized and the sample size is too small to distinguish whether this approach is preferable to the web survey.

6.2 Results

None of the four hypotheses were confirmed by our results. Some explanations could be that preferences among individuals do not vary as much as expected or that the sample is too homogenous to find any large differences. The findings in this study indicate that no substantial difference is made between severe pain and low levels of mobility, or between the public and the private perspectives. Overall, the mean and median in both types of questions and in both perspectives did not differ significantly. Therefore, Hypothesis I that pain should be valued higher than immobility, does not hold. Also, Hypothesis II, that the numbers stated in the private perspective were predicted to be lower than in the public perspective, is incorrect. Thus, individual self-interested preferences seem to be the same for distributive justice.

Hypothesis III, that respondents that study health and social care will value the “worse-off” patient group higher than respondents that study other subjects, does not hold. Since nurses and doctors probably meet patients with severe pain and low levels of mobility in their daily work, one could argue that they might have a greater empathy for patients in worse states. However, this is not the case according to the results. Hypothesis IV, that females and individuals with low income or low health status together with those who have previous experience of pain or low mobility will value the worst-off patients higher, is not confirmed by the results. The results regarding the students studying engineering are in line with findings from Carlsson et al. (2005) that technology and business students seem to have lower values for relative risk aversion and inequality aversion than other students. However, we do not find any support for their results that females have higher values for relative risk and inequality aversion.

Further, the high variation in individuals’ responses raises the question about whether the public should be involved in setting priorities in health care or not. And if yes, whose views should count and where should one draw the line? Should ‘extreme’ preferences be accepted if it corresponds to the preferences of the median respondent? Reasons not to pursue greater public engagement are that, for example, the public is not objective or well informed, the

processes will be prolonged, and the members do not identify themselves as the right persons to make those decisions (Bruni et al., 2008). Some counterarguments are that incorporating the public's views into prioritizations would lead to a higher quality and acceptance of decisions, and that there are no reasons to believe that the opinions of the decision-makers are less objective (Bruni et al., 2008). It has also been argued that the most relevant perspective to take into account is the private perspective, i.e. when respondents might themselves end up in one of the two groups, as this would establish guidelines that provide resources in line with Rawlsian justice (Nord et al., 1996). Nevertheless, the results from this survey indicate that the decisions people make out of self-interest in our sample are the same decisions that people make when they are asked to consider the interests of society.

One can also discuss whether it makes sense to have a single national system of health insurance when the variance in individual preferences is high. Perhaps this indicates that a system of private health insurances is preferred by individuals. However, a system of only private health insurance would go against the egalitarian foundation of the Nordic health care systems, where everyone should have equal access to health care. If individuals have to insure themselves by their own means, equal access will never exist, as people have different abilities to purchase health care.

7. Conclusion

The aim of this study has been to obtain the values that Swedish students hold in regards to patients with different levels of severe pain and immobility. In this study, it is found that Swedish students do value helping severely ill patients over less severely ill patients. In terms of how much, the general results seem to be that a more severe condition is valued twice as much as a less severe condition. Further, there are no differences between those who were asked to take on the *ex-ante-insurance perspective* of an individual, and those who were asked to take on the *ex-post distribution perspective* of a decision-maker. The risk aversion of the "private individuals" is similar to the inequality aversion of the "decision-makers". Also, no statistical differences are found between the values stated for the patients with pain and low level of mobility. Further, there are no differences between sub-groups with respect to age, gender, household income and type of education. The results also indicate that there are high variations in individuals' responses. However, when there is a large group of people, random errors at the individual level can be evened out when aggregated. Also, there are

other contexts where collective decisions have to be made, where the problem of variations in individuals preferences are solved by the use of majority voting.

Lastly, one could argue how useful it actually is to quantify the social values that people hold in terms of numbers. However, since difficult decisions have to be made in health care on a daily basis, we would argue that being able to quantify exactly how much people value improvements from one health level to another is more straightforward than the existing guidelines, stating that those with the most severe conditions should be prioritized. What numerical guidelines would do is to give *an indication* of how much more the most severe conditions should be prioritized, and thus aid decision-makers with difficult evaluations. It could also enable some consistency in decisions over time. However, this does not mean that we believe decisions should be made solely on quantitative measures, but it could work as a complement when stuck in ethical dilemmas about how much resources should be allocated to patients with various levels of severity. If the study were to be replicated with a representative sample of the Swedish population, together with more extensive scenarios, the results obtained can be used as complements to the official guidelines.

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Appendix I – Tables and figures

Table 1. Level of risk aversion – from median values

Pain		Immobility	
Public	Private	Public	Private
0.465	0.533	0.484	0.507

Table 2. Level of risk aversion – OLS estimations

Pain			Immobility		
Global	Local	Local + Global	Global	Local	Local + Global
0.358	0.640	0.612	0.354	0.604	0.619

Table 3. Mean and median for each of the questions

Question number	Levels	Pain		Immobility		Difference Mean
		Mean	Median	Mean	Median	
1	0-20 vs 20-40	35	20	36	20	(-1.78)
2	20-40 vs 40-60	39	20	31	20	(5.21)***
3	40-60 vs 60-80	33	20	39	28	(-5.66)***
4	60-80 vs 80-100	43	20	49	23	(-1.90)
5	0-20 vs 40-60	429	50	264	40	(-24.22)
6	20-40 vs 60-80	69	40	61	30	(4.74)
7	40-60 vs 80-100	165	45	168	50	(-16.59)
8	0-20 vs 60-80	347	80	292	70	(52.80)
9	20-40 vs 80-100	972	80	713	80	(258.37)*

Note: *** p<0.01, ** p<0.05, * p<0.1

Figure 1. Distribution of answers – pain Q1

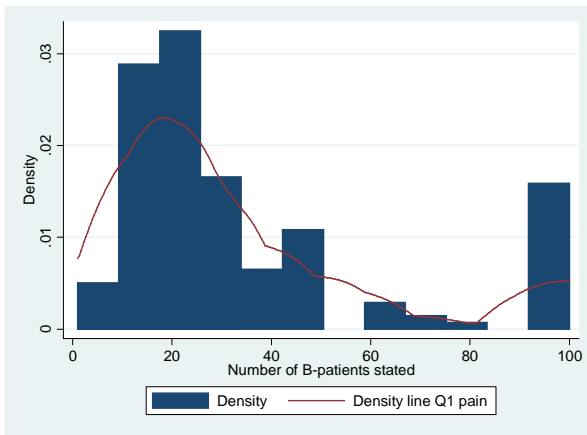


Figure 2. Distribution of answers – pain Q6

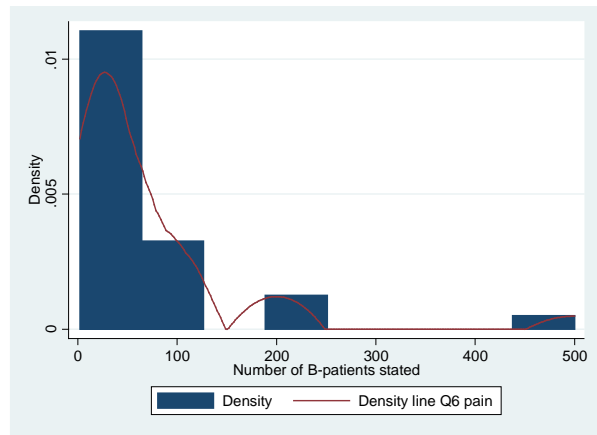


Figure 3. Distribution of answers – pain log(Q1)

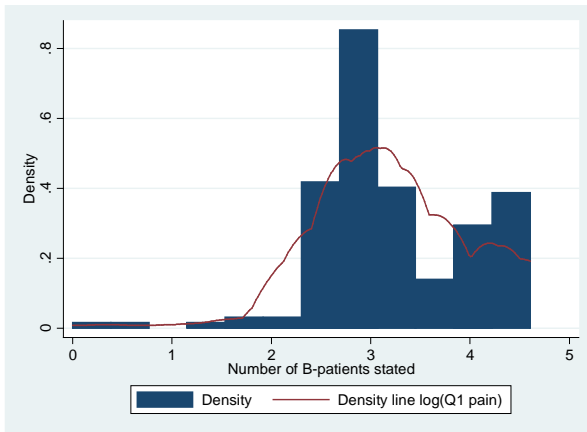


Figure 4. Distribution of answers – pain log(Q6)

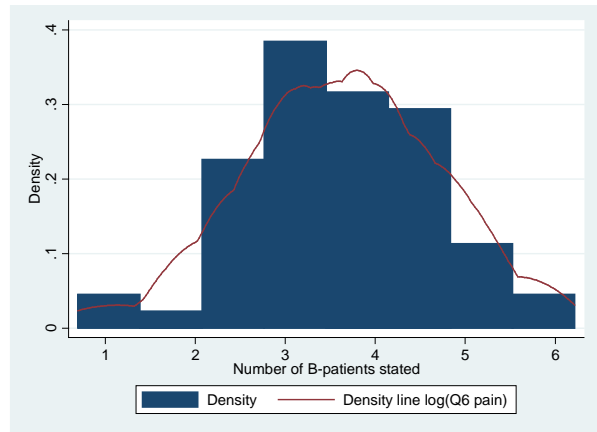


Table 4. Mean and median for pain Q1-Q4, unlogged and antilogged

Pain	Mean from unlogged data	Median from unlogged data	Anti-log of mean	Immobility	Mean from unlogged data	Median from unlogged data	Anti-log of mean
Q1	35	20	25.608953	Q1	36	20	25.681862
Q2	39	20	25.556977	Q2	31	20	22.019645
Q3	33	20	24.034781	Q3	39	28	28.20629
Q4	43	20	27.07487	Q4	49	23	29.141492

Table 5. OLS estimations for immobility and pain with control variables

VARIABLES	Immobility			Pain		
	Local (1) value	Global (2) value	Local+global (3) value	Local (4) value	Global (5) value	Local+global (6) value
Level 20 to 40	2.856*** (0.261)	1.488*** (0.220)	2.497*** (0.303)	3.276*** (0.323)	1.324*** (0.233)	2.067*** (0.336)
Level 40 to 60	2.180*** (0.426)	1.390*** (0.232)	3.077*** (0.370)	3.408*** (0.325)	1.631*** (0.254)	3.314*** (0.365)
Level 60 to 80	3.179*** (0.271)	1.143*** (0.248)	2.831*** (0.433)	2.603*** (0.301)	1.143*** (0.257)	2.708*** (0.430)
Level 80 to100	3.719*** (0.428)	1.848*** (0.210)	2.440*** (0.306)	2.534*** (0.321)	1.845*** (0.226)	2.316*** (0.307)
Health Status	-0.000829 (0.00427)	0.00393 (0.00462)	0.00126 (0.00783)	0.00476 (0.00527)	0.00694 (0.00457)	0.0132 (0.00989)
Public	-0.0509 (0.161)	-0.244 (0.166)	-0.203 (0.295)	-0.0851 (0.180)	-0.205 (0.182)	-0.152 (0.317)
Experience of immobility	0.255 (0.276)	-0.229 (0.271)	0.202 (0.533)	0.0155 (0.331)	-0.0777 (0.379)	-0.0763 (0.646)
Experience of pain	-0.144 (0.220)	-0.0103 (0.226)	-0.228 (0.421)	-0.235 (0.245)	-0.302 (0.259)	-0.480 (0.449)
Age	0.0162 (0.0120)	0.00367 (0.0132)	0.0389* (0.0227)	0.00622 (0.0165)	-0.00429 (0.0136)	0.0157 (0.0290)
No. of Adults in HH	-0.126 (0.119)	-0.0125 (0.127)	-0.0755 (0.228)	0.0163 (0.132)	-0.0460 (0.127)	0.111 (0.238)
Female	0.158 (0.174)	0.00978 (0.190)	0.0699 (0.339)	0.104 (0.189)	0.0521 (0.199)	0.0583 (0.357)
No. of children in HH	-0.218* (0.113)	-0.0109 (0.144)	-0.381 (0.234)	-0.247* (0.143)	-0.0844 (0.135)	-0.439* (0.259)
Work exp. in health sector	-0.154 (0.216)	-0.0707 (0.214)	-0.337 (0.387)	0.130 (0.237)	0.104 (0.238)	0.227 (0.421)
Fam.work.exp. health sector ¹¹	0.0217 (0.157)	0.0736 (0.168)	0.0210 (0.291)	-0.309* (0.168)	0.172 (0.178)	-0.270 (0.300)
HH income	0.153* (0.0818)	0.0407 (0.0907)	0.202 (0.170)	0.0686 (0.0900)	0.0287 (0.0981)	0.114 (0.174)
Health-related studies ¹²	0.132 (0.230)	0.390* (0.216)	0.632 (0.397)	-0.0435 (0.239)	0.385 (0.245)	0.366 (0.408)
Studies in engineering	0.0922 (0.200)	0.397* (0.222)	0.556 (0.407)	0.0106 (0.201)	0.185 (0.219)	0.285 (0.395)
Observations	361	361	361	361	361	361
R-squared	0.945	0.865	0.929	0.937	0.858	0.923

Robust standard errors in parentheses, *** p<0.01, ** p<0.05, * p<0.1

¹¹ Family member with work experience in the health care sector.

¹² For example, medical studies, nurse education and physiotherapy education.

Figure 5 : Pain and immobility - mean number of B(D)-patients

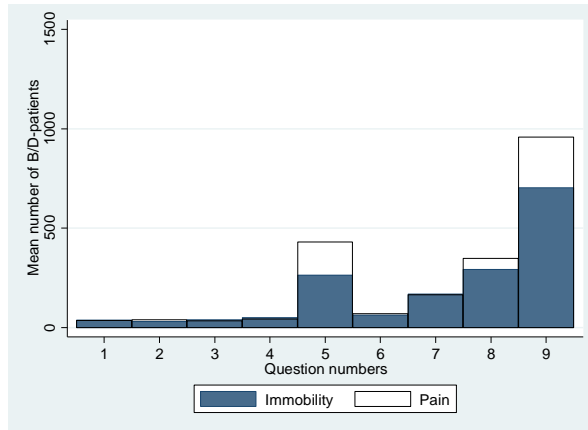


Figure 6: Pain (B-patients) - split by gender

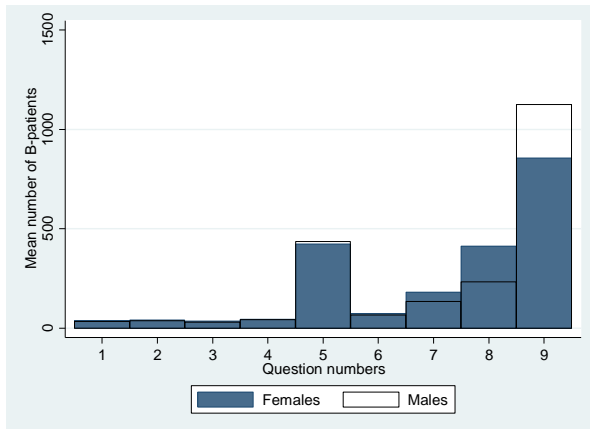


Figure 7: Immobility (D-patients) - split by gender

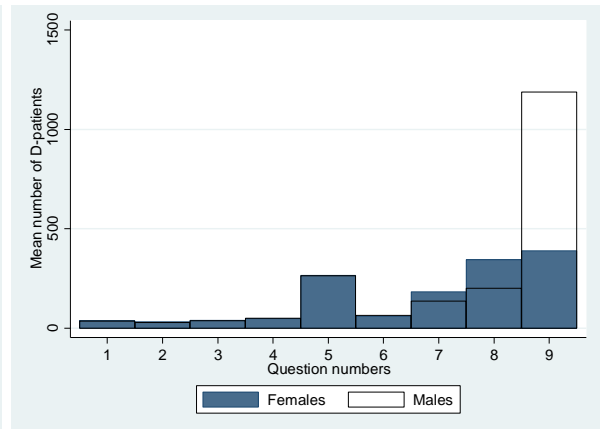


Figure 8: Experience of pain – pain questions

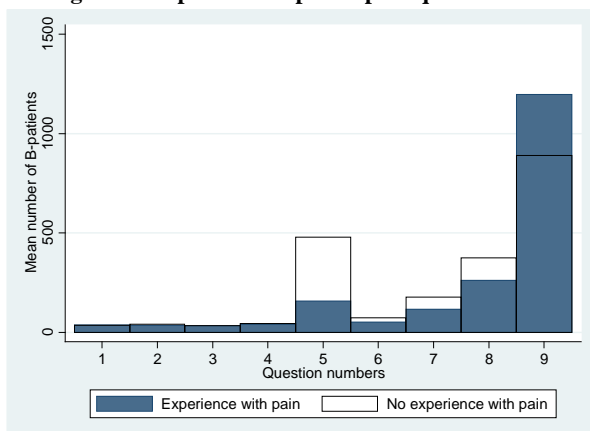


Figure 9: Experience of pain – immobility questions

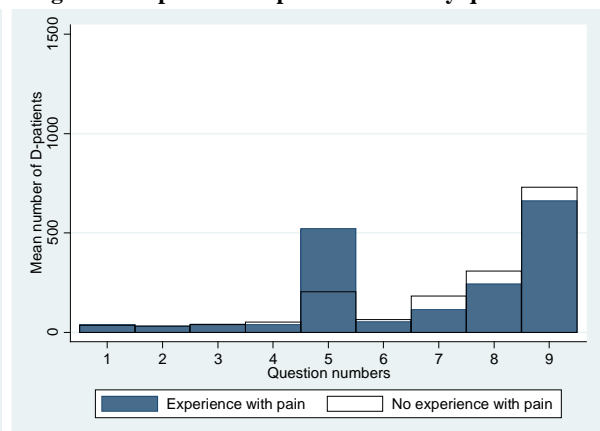


Figure 10: Experience of immobility – pain questions

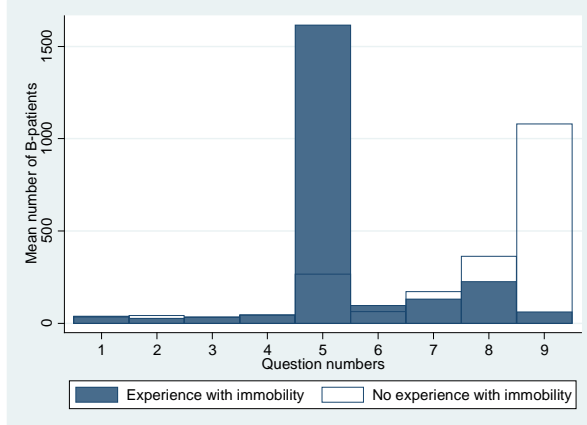


Figure 11: Experience of immobility – immobility questions

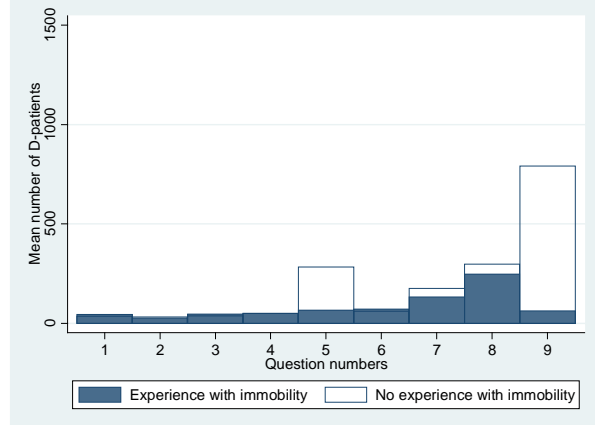


Table 6. Laboratory setting

Question	Levels		Observations	Pain		Immobility	
				Mean	Median	Mean	Median
	A/C	B/D					
1	0-20	20-40	8	36	22	65	31
5	0-20	40-60	3	110	100	117	100
8	0-20	60-80	4	161	67	140	25
2	20-40	40-60	8	80	35	48	25
6	20-40	60-80	6	70	65	43	33
9	20-40	80-100	1	1,000	1,000	50	50
3	40-60	60-80	8	41	40	71	40
7	40-60	80-100	2	28	28	85	85
4	60-80	80-100	8	74	75	57	60

Table 7. Comments split by the perspective

	Rawlsian	Equity	Utilitarian	Efficiency
Public	<p>“Individuals with the most severe pain should be prioritized. The higher the level of pain, the more they should be prioritized.”</p> <p>“The patient group with a low level of pain could perhaps live their lives reasonably normal, while those with much pain become hindered by it. Therefore, I think those with more pain should be given priority even if that patient group is smaller.”</p> <p>“People with a lot of pain should, be helped before people with less pain. The higher up the other patient group is, the more patients is required to shift focus away from those with more pain.”</p>	<p>“Primarily, the pharmaceutical should even out differences between the patient groups.”</p> <p>“It feels better to strive for an equitable health where those who are worst off are getting better than to aggravate the gap.”</p> <p>“I think those with a worst health status should be able to reach the same level as those in group B/D. When everyone is on the same level, then pharmaceuticals that help all should be developed.”</p> <p>“It is better if ALL people are feeling okay then if some are feeling great and some are feeling awful.”</p>	<p>“If you can help more people to get into better health, it’s always worth it. There will always be people who are worse or better. If the cost it the same it shouldn’t matter, then help the largest group.”</p> <p>“The largest patient group should be financed.”</p> <p>“I considered the difference between the two groups more. If there are two groups that do NOT have perfect health, we should strive for some equity between them.”</p>	<p>“As a decision maker, I would take what helps the society at large into account. If people have a high mobility, the lower is the risk of getting other types of diseases. This will save money for the state.”</p> <p>“In those cases where B could get a good health with treatment, I think more of them can work and make more money to the state. They can then later help to contribute to the pharmaceutical for group A.”</p> <p>“If a person can go from relatively poor health to relatively good health it means that this person can contribute to society in a different way than a person who has worse health. The sicker person should of course not be left behind, but we need people who are able to work.”</p>
Private	<p>“The worst-off patient group deserves more help.”</p> <p>“Primarily prioritize those in most need if there is not enough money to finance both projects. (...) I believe that there is a great charitable value in helping those in most need. This value is almost impossible to estimate in economic terms.”</p> <p>“I believe that economics and ethics often go completely different ways. For me, it is always the case that those who are the most disadvantaged should be helped first. (...) The quality of life is important.”</p>	<p>“I think that it's better to have more people with a little bit of pain than to have both extremes with some people completely healthy and others in really bad pain.”</p> <p>“Rather a large part of the population on the same health level than too large differences.”</p> <p>“Helping someone e.g. become 20 “steps” more mobile means as much for someone who starts at 10 as someone who starts at 50.”</p>	<p>“The healthier patient group must contain at least one more patient in order to receive the subsidized pharmaceutical.”</p> <p>“The increase in health status is equal. I assumed that it also implies a similar increase in quality of life. If the increase in quality of life is the same, it is sufficient if one additional person gets help in order to make it more valuable.”</p> <p>“I summed up health scores for the two pharmaceuticals, which resulted in the same amount of health points. Then, I added one more patient in order to make it worthwhile to finance the other pharmaceutical.”</p>	<p>“If taking the societal return into account, it would be more profitable to give pharmaceuticals to the healthiest so they are perfectly healthy and can work fulltime.”</p> <p>“It is better for society to help people from “sick list” to join the workforce. The state can then profit more by putting resources on almost healthy people to become healthy so they can start working again.”</p>

Appendix II – the questionnaires

a) Swedish version – public perspective



UNIVERSITY OF GOTHENBURG
SCHOOL OF BUSINESS, ECONOMICS AND LAW

Den här enkäten är gjord av två masterstudenter i nationalekonomi från Handelshögskolan i Göteborg och den kommer vara en del i vår uppsats. Vi uppskattar om du svarar på alla frågor och fullföljer hela enkäten. Kom ihåg att det inte finns något rätt eller fel svar och att dina svar är anonyma.

Vi tackar för att du ger oss möjlighet att få veta svaret på några viktiga frågor.

Har du frågor angående enkäten är du välkommen att höra av dig till oss.

Emelie Pauli & Julia Widén

MSc in Economics

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Del 1: Din hälsa

Markera ditt svar genom att kryssa i den ruta som bäst beskriver din hälsa. De här frågorna behövs för att se om svaren skiljer sig åt för människor med olika erfarenheter av smärta och/eller försämrad rörlighet.

1) Rörlighet*^{13, 14}

- Jag går utan svårigheter.
- Jag går utan svårigheter, men har svårt att gå längre sträckor.
- Jag går utan svårigheter i hemmet, men har svårt att gå i trappor och utomhus.
- Jag kan gå med viss svårighet i hemmet, men behöver assistans i trappor och utomhus.
- Jag kan sitta, men behöver assistans att gå – både i hemmet och utomhus.
- Jag är till viss del sängliggande, men kan sitta delar av dagen om jag får assistans att komma upp.
- Jag är sängliggande.

2) Har du tidigare erfarenhet av långvarig begränsad rörlighet?

(Långvarig betyder längre än 3 månader)*

- Ja
- Nej

3) Smärtor utan eventuell medicin.*

- Jag har inga smärtor.
- Jag har lite smärtor.
- Jag har måttliga smärtor.
- Jag har svåra smärtor.
- Jag har fruktansvärda smärtor.

¹³ Tvingande frågor är markerade med stjärna (*).

¹⁴ Frågor där man kan rangordna koder som 1 ifall första svarsalternativet är valt, 2 ifall andra svarsalternativet är valt etc.

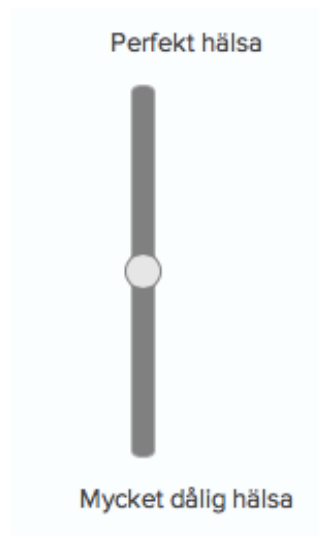
4) Har du tidigare erfarenhet av långvariga smärtor?

(Långvarig betyder längre än 3 månader)*

Ja

Nej

5) Markera hur bra eller dålig din hälsa är, som du själv bedömer det, genom att flytta cirkeln på skalan nedan. Perfekt hälsa är markerat med 100 och mycket dålig hälsa är markerat med 0.



Ett exempel

Följande förutsättningar gäller de 6 kommande frågorna som handlar om smärta och rörlighet för olika patientgrupper.

* Det finns fyra olika sjukdomar där fyra patientgrupper (A, B, C och D) har uppgett hur mycket smärta eller begränsad rörlighet de har på grund av sina sjukdomar.

* Det finns nya läkemedel tillgängliga för alla fyra patientgrupper som skulle lindra deras livslånga smärta eller deras livslånga begränsade rörlighet.

* Läkemedlen kostar lika mycket att framställa.

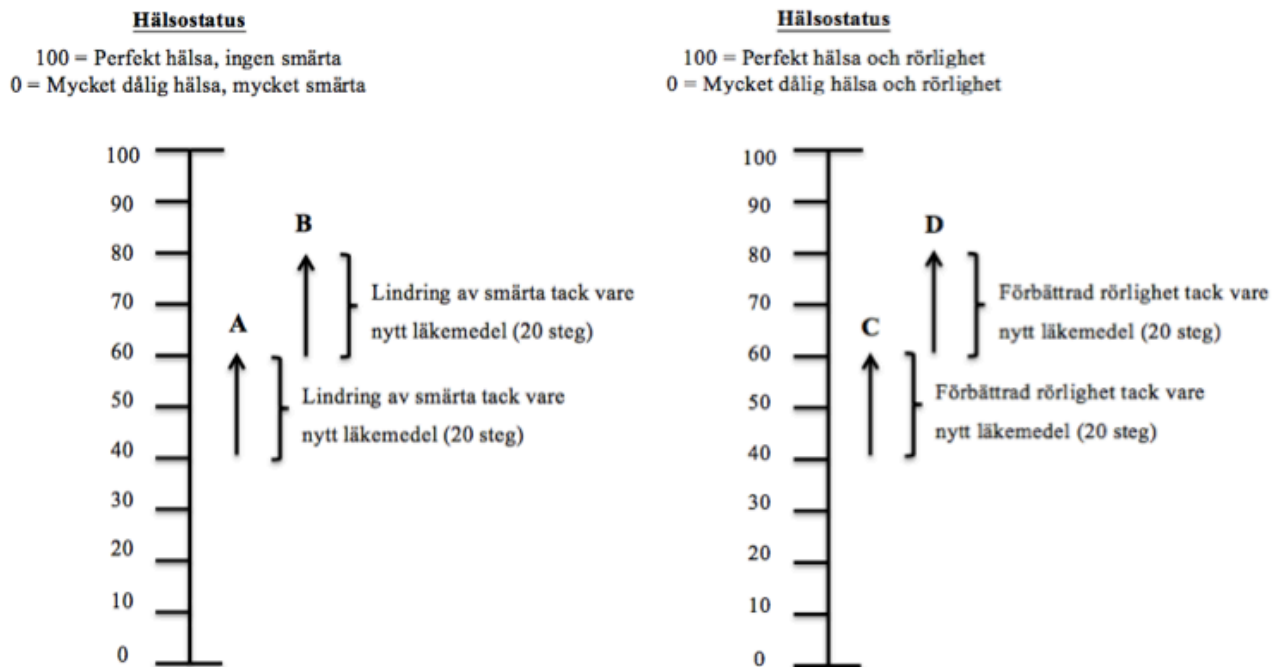
* Det är ingen skillnad mellan grupperna förutom deras smärtonivåer eller rörelsenivåer.

*** Staten har endast resurser att finansiera två av dessa läkemedel, ett som lindrar smärta för patientgrupp A eller B och ett som förbättrar rörlighet för patientgrupp C eller D.**

Fortsättning Exempel

I bilden nedan visas patientgruppernas hälsostatus i form av smärta eller rörlighet. Ju högre hälsostatus man har, desto lägre smärta respektive bättre rörlighet. Pilarna visar hur stor ökning i hälsostatus patienterna skulle få med sina nya läkemedel. Om patienterna inte får läkemedlet är hälsostatusen oförändrad, det vill säga, 40 för patientgrupp A/C och 60 för patientgrupp B/D i detta exempel.

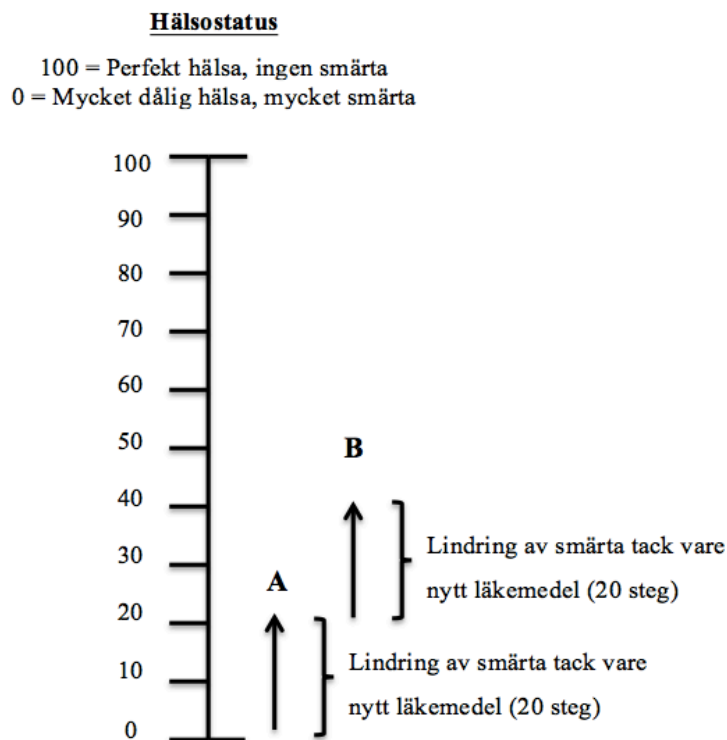
Även om frågorna kan kännas svåra, tänk på att myndigheter dagligen måste ta svåra beslut och att de ofta tvingas välja mellan olika alternativ.



6) SMÄRTA

Enligt bilden nedan så har grupp A en hälsostatus på 0 medan grupp B har en hälsostatus på 20. Tänk enbart på hälsa i form av smärta och kom ihåg att du när som helst kan gå tillbaka och kolla på exemplet.

Anta att du är en beslutsfattare som måste välja vilket av dessa två läkemedel som staten ska finansiera.¹⁵ Föreställ dig att läkemedlet för grupp A skulle hjälpa 10 patienter. Hur många patienter i grupp B behöver minst bli hjälpta av sitt läkemedel för att du ska tycka att läkemedel B bör finansieras istället för A?



{Fråga 7 och 8: Likadana frågor som fråga 6 men med andra smärtonivåer}

¹⁵ Privata perspektivet: Anta att det är stor risk att du själv kommer att drabbas av sjukdom A eller B i framtiden.

9) Här får du gärna förklara hur du resonerade när du besvarade frågorna om smärta!

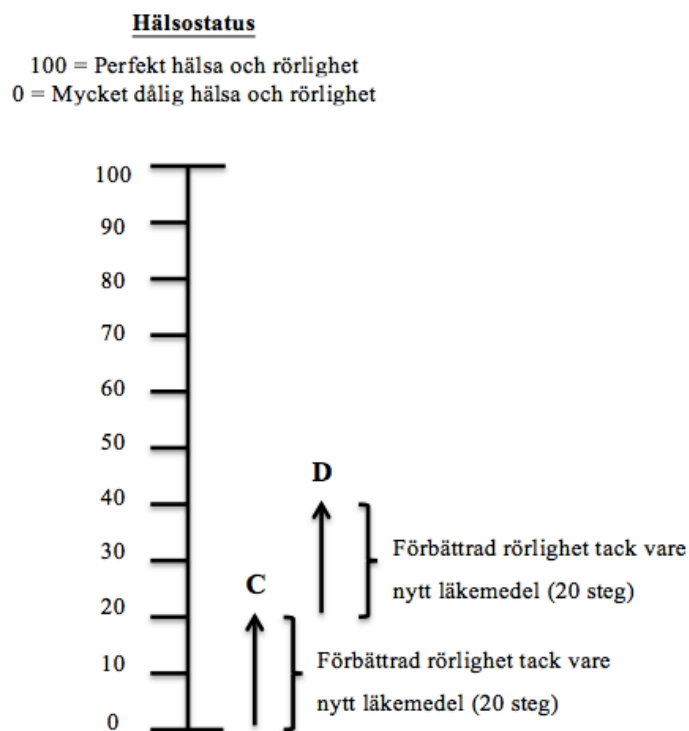
10) Hur upplevde du att frågorna om **smärta** var att besvara?

- Mycket svåra.
- Svåra.
- Varken svåra eller enkla.
- Enkla.
- Mycket enkla.

11) RÖRLIGHET

Enligt bilden nedan så har grupp C en hälsostatus på 0 medan grupp D har en hälsostatus på 20. Tänk enbart på hälsa i form av rörlighet och kom ihåg att du när som helst kan gå tillbaka och kolla på exemplet.

Anta att du är en beslutsfattare som måste välja vilket av dessa två läkemedel som staten ska finansiera.¹⁶ Föreställ dig att läkemedlet för grupp C skulle hjälpa 10 patienter. Hur många patienter i grupp D behöver minst bli hjälpta av sitt läkemedel för att du ska tycka att läkemedel D bör finansieras istället för C?



{Fråga 12 och 13: Likadana frågor som fråga 11 men med andra rörlighetsnivåer}

¹⁶ Privat perspektivet: Anta att det är stor risk att du själv kommer att drabbas av sjukdom A eller B i framtiden.

14) Här får du gärna förklara hur du resonerade när du besvarade frågorna om rörlighet!

15) Hur upplevde du att frågorna om **rörlighet** var att besvara?

- Mycket svåra.
- Svåra.
- Varken svåra eller enkla.
- Enkla.
- Mycket enkla.

Bakgrundsfrågor

Frågorna i denna del används för att se vem som har svarat på enkäten. Svaren går inte att knyta till dig personligen utan frågorna behövs för att se om svaren för olika grupper av människor skiljer sig åt. Kom ihåg att dina svar är anonyma.

16) Är du man eller kvinna?*

- Man
 Kvinna

17) Vilket år är du född?*

(ÅÅÅÅ)

18) Vilken är din högsta genomförda utbildning?*

- Grundskola
 Gymnasiet
 3-årig universitets- eller högskoleutbildning
 Mer än 3-årig universitets- eller högskoleutbildning
 KY / YH -utbildning
 Folkhögskola

19) Vilken är din huvudsakliga sysselsättning just nu?*

Studerar (ta det som stämmer bäst)

[[Lista över vanliga utbildningar plus flera övriga alternativ som kan specificeras i rutan nedan]]

Kommentar: _____

20) Hur många personer ingår i ditt hushåll inklusive dig själv?

Antal vuxna: _____

Antal barn (under 18 år) _____

21) Arbetar eller har **du** arbetat inom vård och omsorg?

- Ja
 Nej

22) **I din familj**, arbetar eller har någon arbetat inom vård och omsorg?

- Ja
 Nej

23) Hur stor är ditt **hushålls** ungefärliga sammanlagda **månadsinkomst före skatt**? Med inkomst avses lön från arbete, pensioner, bidrag i olika former t.ex. barn-, studie- och bostadsbidrag.*

- 0 - 14 999 kronor
- 15 000 - 29 999 kronor
- 30 000 - 44 999 kronor
- 45 000 - 59 999 kronor
- 60 000 kronor eller mer

Om du har några synpunkter på enkäten kan du skriva dem här:



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Tack för din medverkan!

Skicka ett mail till utlottning@outlook.com om du vill vara med i utlottningen av hörlurar från Urban Ears och mobilskal, båda sponsrade av Teligoo. Vi hör av oss senast 5/5 om du är en av de lyckliga vinnarna!

b) English version – public perspective



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This survey is created by two master students in Economics from the University of Gothenburg, School of Business, Economics and Law. It will be a part of our thesis and we appreciate if you answer to each question and complete the whole survey. Remember that there are no rights or wrong answers and that your response is anonymous.

We would like to thank you for giving us the opportunity to get the answer to important questions. Do not hesitate to contact us if you have any questions regarding the survey.

Emelie Pauli & Julia Widén

MSc in Economics

Email: websurvey@outlook.com

Part 1: Your health

Mark your choice by ticking the box you think most accurately describes your health. These questions are needed in order to see if the answers differ between people with different experiences of pain and/or low mobility.

1) Mobility*^{17, 18}

- I have no problems with walking.
- I can move about without difficulty anywhere, but has difficulties with walking more than a kilometer.
- I can move about with difficulty at home, but I have difficulties in stairs and outdoors.
- I move about with difficulty at home. I need assistance in stairs and outdoors.
- I can sit. Need assistance to move about – both at home and outdoors.
- I am partly bedridden but can sit if I get assistance.
- I am completely bedridden.

2) Do you have previous experience of prolonged periods of low mobility?

(Prolonged periods are longer than 3 months)*

- Yes
- No

3) Pains without any medication.*

- I have no pain.
- I have slight pain.
- I have moderate pain.
- I have severe pain.
- I have extreme pain.

¹⁷ Required questions are marked with a star (*).

¹⁸ Ranking questions are coded as 1 if the first option is chosen, 2 if the second option is chosen etc.

4) Do you have previous experience of prolonged periods of pain?

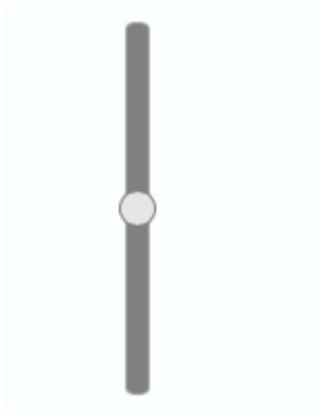
(Prolonged periods are longer than 3 months)*

Yes

No

5) Mark how good or bad your health is, according to yourself, by moving the circle on the scale below. Perfect health is marked with 100 and very bad health is marked by 0.

Perfect health, 100



Very bad health, 0

An example

The following circumstances hold for the upcoming 6 questions about pain and immobility for different patient groups.

* There are four different illnesses where four patient groups (A, B, C and D) have stated how much pain or immobility they have due to their illnesses.

* There are new pharmaceuticals available for all four patient groups that would alleviate their lifelong pain or their lifelong limited mobility.

* The pharmaceuticals are equally expensive to produce.

* No other differences than the level of pain or immobility can be found between the patient groups.

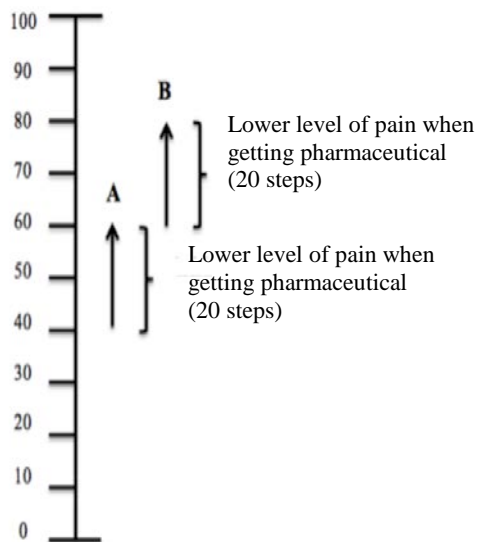
*** The state can only afford to finance two of these four pharmaceuticals, one that alleviates pain for patient group A or B, and one that improves mobility for patient group C or D.**

Example continued:

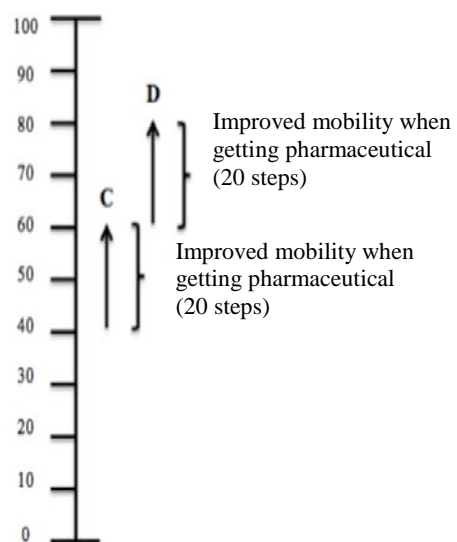
The figure below illustrates the health status of the patient groups in terms of pain or mobility. The higher health status, the lower is the level of pain or immobility. The arrows indicate how large the increase in health status would be with the new pharmaceutical. If the patients do not get the pharmaceutical, their health status will remain unchanged, namely 40 for patient group A/C and 60 for patient group B/D in this example.

Although the questions may seem difficult, remember that authorities daily have to make difficult decisions and that they are often forced to choose between different options.

Health status
100= Perfect health, no pain
0= Very bad health, very much



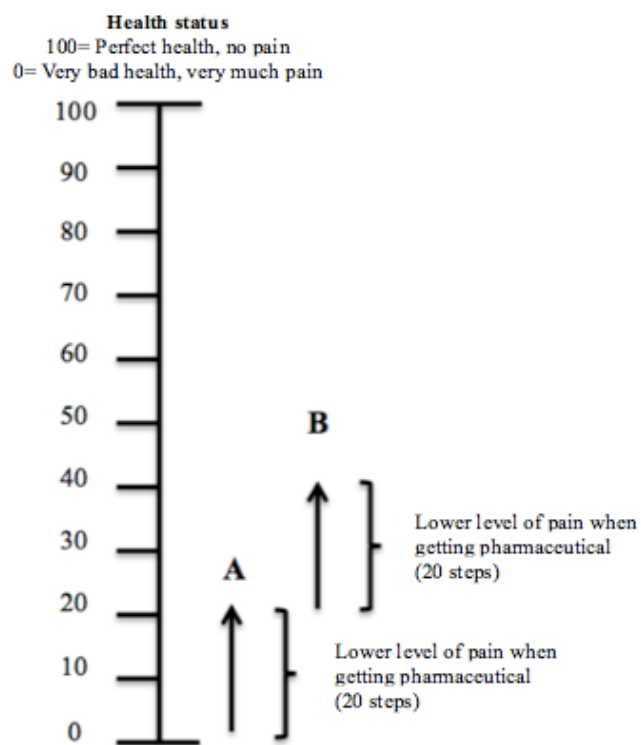
Health status
100= Perfect health and mobility
0= Very bad health and mobility



6) PAIN

According to the picture below, group A has a health status of 0 while group B has a health status of 20. Consider solely health in terms of pain and remember that you can go back and look at the example at any time.

Assume that you are a policymaker asked to choose which one of these two pharmaceuticals the state will finance¹⁹. Imagine that the pharmaceutical for group A can help 10 patients. At least how many patients in group B need to be helped by their pharmaceutical in order for you to choose to finance pharmaceutical B instead of A?



{Questions 7 and 8: Exactly the same as question 6 but with different levels of pain.}

¹⁹ Private perspective: Assume that there is a big risk that you will suffer from illness A or B in the future.

9) Please explain your way of reasoning while answering the questions about pain!

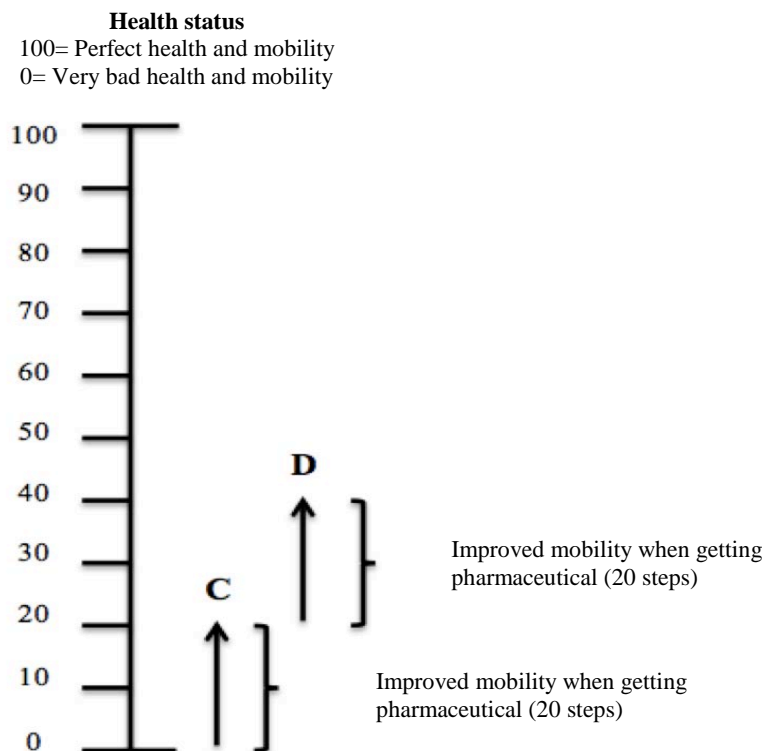
10) How was it to answer to the questions about **pain**?

- Very difficult.
- Difficult.
- Neither difficult nor easy.
- Easy.
- Very easy.

11) MOBILITY

According to the picture below, group C has a health status of 0 while group D has a health status of 20. Consider solely health in terms of mobility and remember that you can go back and look at the example at any time.

Assume that you are a policymaker asked to choose which one of these two pharmaceuticals the state will finance²⁰. Imagine that the pharmaceutical for group C can help 10 patients. At least how many patients in group D need to be helped by their pharmaceutical in order for you to choose to finance pharmaceutical D instead of C?



{Questions 12 and 13: Exactly the same as question 11 but with different levels of mobility.}

²⁰ Private perspective: Assume that there is a big risk that you will suffer from illness C or D in the future.

14) Please explain your way of reasoning while answering the questions about mobility!

15) How was it to answer to the questions about **mobility**?

- Very difficult.
- Difficult.
- Neither difficult nor easy.
- Easy.
- Very easy.

Background questions

The questions in this section are used to see who has responded to the survey. The answers will not be linked to you personally, but are needed to see if the responses of different groups of people differ. Remember that your responses are anonymous.

16) What is your gender?*

- Male
- Female

17) What is your year of birth?*

(YYYY)

18) What is your highest level of education?*

- Elementary school
- High school
- University or college, maximum 3 years
- University or college, more than 3 years
- KY / YH education
- Folk high-school

19) What is your current main occupation?*

Studying (choose what best corresponds to your study area)

[[List of common educations plus several other alternatives which could be specified below]]

Comment: _____

20) How many people live in your household including yourself?

No. of adults: _____

No. of children (below 18 years) _____

21) Do **you** work or have you worked in the health care sector?

- Yes
- No

22) **In your family**, does anyone work or has anyone worked in the health care sector?

- Yes
- No

23) Approximately, what is your household's total monthly income before taxes? Income refers to wages from work, pensions, and subsidies for e.g. children, studies or housing.*

- 0 - 14 999 SEK
- 15 000 - 29 999 SEK
- 30 000 - 44 999 SEK
- 45 000 - 59 999 SEK
- 60 000 SEK or more

If you have any comments about the survey, you can write them below:



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Thank you for your participation!

Send an e-mail to utlottning@outlook.com if you want to participate in the draw for headphones from UrbanEars and cell phone cases sponsored by Teligoo. You will hear from us no later than the 5th of May if you are one of the lucky winners.

Appendix III – Utility calculations

From the local comparisons, we can estimate a utility function of being at a certain level of health, in terms of immobility, by using the median values. Let $U(x)$ be the utility of being at a certain level of immobility, where $x \in \{0,100\}$, and where pain decreases with higher number of x .

We know that the utility of going from level 20 to level 40 is valued half as much as going from 0 to 20 for the public perspective (see the gray-shaded boxes above). From this we can set up the following equation:

$$2(U(40) - U(20)) = U(20) - U(0) \quad [1]$$

The same way of thinking will yield the remaining three equations for the other shaded boxes:

$$2(U(60) - U(40)) = U(40) - U(20) \quad [2]$$

$$2.5(U(80) - U(60)) = U(60) - U(40) \quad [3]$$

$$2(U(100) - U(80)) = U(80) - U(60) \quad [4]$$

This gives us 6 unknown levels of utility, and 4 equations. If we normalize $U(100)$ equal to 1, and $U(0)$ equal to zero, we can solve this system of equations.

This gives us:

$$2(U(40) - U(20)) = U(20)$$

$$2(U(60) - U(40)) = U(40) - U(20)$$

$$2.5(U(80) - U(60)) = U(60) - U(40)$$

$$2(1 - U(80)) = U(80) - U(60)$$

The first equation gives:

$$2U(40) = 3U(20)$$

$$U(40) = 1.5U(20)$$

The second equation gives:

$$2U(60) = 3U(40) - U(20) = 4.5U(20) - U(20) = 3.5U(20)$$

$$U(60) = 1.75U(20)$$

In the same manner we will get:

$$U(80) = 1.85U(20)$$

$$U(100) = 1.9U(20)$$

With these equations we can then get the utility at each level, given that $U(0)$ is normalized to 0, and $U(100)$ is normalized to 1.

$U(0) = 0$
$U(20) = 1/1.9=0.5263$
$U(40) = 1.5/1.9=0.7895$
$U(60) = 1.75/1.9=0.9211$
$U(80) = 1.85/1.9=0.9737$
$U(100) = 1$

The utility levels for immobility are calculated in exactly the same manner as those for pain.

The valuations are based on the median levels from Table 4.