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Cover page

Title:

Disentangling public preferences for health gains at end-of-life: Further evidence of no support of an end-of-life premium

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Disentangling public preferences for health gains at end-of-life: Further evidence of no support of an end-of-life premium

Abstract:

In many countries, it has been publicly debated whether health gains for patients at end-of-life (EoL) should be valued higher than health gains for other patients. This has led to a range of stated preference studies examining the justification for an EoL premium on the basis of public preferences - so far with mixed findings. In the present study, we seek to extend this literature. We apply a simple stated preference approach with illustrative binary choices to elicit both individual and social preferences for several types of health gains. More specifically, we investigate whether health gains at EoL, resulting from either an improvement in quality of life (QoL) or life expectancy (LE) are valued differently from similarly sized health gains from preventive treatment and treatment of a temporary disease. Furthermore, we examine whether social preferences are affected by the age of beneficiaries. A web-based survey was conducted in 2015 using a random sample of 1,047 members of the general public in Denmark. Overall, we do not find evidence to support an EoL premium compared to other health gains, neither when preferences are elicited from a social nor an individual perspective. Furthermore, our results demonstrate that the type of the health gain received matters to preferences for treatment at EoL with more weight given to gains in QoL than gains in LE. Finally, we find heterogeneity in preferences according to respondent characteristics, perspectives and age of beneficiaries.

Word count: 236

Keywords: End-of-life, Stated preferences, Public preferences, Social value, Elicitation perspective, Priority setting, Health economics

Introduction

Worldwide publicly funded health care sectors are challenged by rising expenditures, which has led to an increased focus on the optimal use and allocation of health care resources. Economic evaluation methods, including cost-utility analysis (CUA), are useful tools to inform decision makers about cost-effective use of health care resources. The CUA is recommended by health authorities in many countries, as it integrates the impact of mortality and morbidity into a single health measure known as quality adjusted life years (QALYs). Consequently, QALYs allow for trade-offs between quality and quantity of life, which facilitates comparison of cost-effectiveness across treatments. The principle of maximising QALYs is based on utilitarianism and relies on the distributive neutral judgement that 'a QALY is a QALY is a QALY' (Dolan, 2000). However, the public may consider some health gains more valuable than others, implying that QALYs may not reflect all the aspects of value that society generates from the health gain of a new treatment (Tsuchiya, 2012, McCabe et al., 2016). In many countries, access to expensive treatments at end-of-life (EoL) has received attention in the public policy debate, including the issue of whether treatments at EoL should be given priority over other treatments. In the UK, The National Institute of Health and Care Excellence (NICE) introduced an EoL premium in the evaluation of new treatments targeting EoL patients. The EoL premium is specified to add extra value to health gains if treatments fulfil the criterion of extending life expectancy by a minimum of three months for patients with a remaining life expectancy of 24 months or less (NICE, 2009). The EoL premium is based on the rationale that the public values health gains from treatments at EoL more than similar non-terminal health gains (Chalkidou, 2012, NICE, 2009, Shah et al., 2018). Not surprisingly, this has led to a series of academic studies that seek to explore public preferences for health gains received at EoL with the majority of studies using stated preference (SP) techniques (Shah et al., 2018). So far the results are mixed. Whereas some SP studies find support for an EoL premium (Pinto-Prades et al., 2014, Rowen et al., 2016, Pennington et al., 2015, Shah et al., 2014), other SP studies find no or weak preferences for an additional EoL premium (Linley, Hughes, 2013, Olsen, 2013, Skedgel et al., 2015, Gyrd-Hansen, 2018, Shiroiwa et al., 2013, Shah et al., 2015). According to Gyrd-Hansen (2018), these mixed results may be due to substantial differences in both the SP designs and the use of different comparators (i.e. type of health gain, patients and illness). The overall aim of the present study is to contribute with new insight into preferences for an EoL premium. In an SP study, we set out to systematically elicit preferences for treatment at EoL premium by examining factors that can potentially affect preferences for an EoL premium.

In terms of elicitation methods, the majority of SP studies use variants of choice experiments (including person trade-off), where respondents are asked to choose between different health gains (Gyrd-Hansen 2018, Linley, Hughes 2013, Olsen 2013, Shah et al., 2014, Pinto-Prades et al., 2014, Shah et al., 2015, Skedgel et al., 2015, Rowen et al., 2016). This allows for a comparison of the relative weighting of the alternatives and the defined attributes. Other studies (Pennington

et al., 2015, Pinto-Prades et al., 2014, Shiroiwa et al., 2013) have elicited willingness to pay (WTP) estimates for different types of health gains. Although WTP allows for an individual measure of the strength of preferences, the use of WTP in the EoL context is not without problems, as a comparison of WTP for different health gains rests on the critical assumption that marginal utility of income is unaffected by remaining LE. If opportunity costs decrease as LE approaches zero (Philipson et al., 2010), this will result in higher WTP estimates for health gains at EoL, all else being equal.

Most SP studies (Shah et al., 2015, Rowen et al., 2016, Shah et al., 2014) have focused on the extent to which the public prioritise patients with fewer remaining life years over patients with more life years to test the justification of NICE's EoL definition of a LE of 24 months or less. In a recent review, Shah et al. (2018) call for more research to establish better evidence of an EoL premium, including extension of the limited literature on the relative weighting of health gains from treatment at EoL and health gains from other types of treatments, such as prevention. Based on a single choice set, Gyrd-Hansen (2018) examines preferences for a gain in LE at EoL relative to a health gain in LE from prevention and finds a preference for preventive treatments over EoL treatments. Pinto-Prades et al. (2014) find preferences for treatment at EoL over treatment of temporary health problems. Like health gains from EoL treatment, health gains resulting from preventive treatment occur mainly towards EoL. However, the timing of preventive treatment is very different, as preventive treatment is introduced prior to the potential occurrence of the specific disease. In contrast, a health gain from treatment of a temporary disease allows for a direct comparison with similar sized health gains at EoL, with remaining (known) LE being the only difference.

So far, the preferences for health gains resulting from either quality of life (QoL) or life expectancy (LE) has only been studied to a limited extent in the EoL literature. In their review, Shah et al. (2018) argue that more research is needed on the decomposition of preferences for health gains at EoL to justify NICE's restriction of an EoL premium to gains in LE. In a recent study testing preferences for general treatment choices in priority setting, McHugh et al. (2018) find indications of preferences for QoL over LE at EoL, though without controlling for the size of health gain. Using SP experiments with defined QALY gains, Pinto-Prades et al. (2014) and Shah et al. (2014) also find evidence of higher valuation of gains in QoL compared to gains in LE at EoL, whereas Shah et al. (2015) find the opposite preference for a gain in LE over QoL. Unfortunately, Pinto-Prades et al. (2014) do not control for initial QoL, which may have affected the results, giving priority to patients with higher severity in terms of lower initial QoL (e.g. Baker et al., 2010, Shiroiwa et al., 2013). Moreover, Shah et al. (2014) include health gains in QoL, which fully restore the health (i.e. 100% QoL), implying that they are not able to isolate the effect of a generic gain in QoL from the potential effect of being cured.

Public preferences for health gains can be elicited from either an individual or a social perspective. Which one is the appropriate perspective, depends on normative considerations and the policy context in which preferences should be

applied. As different elicitation perspectives capture different values (Dolan et al., 2003, Tsuchiya, Watson, 2017), the variation in elicited preferences for health gains at EoL may be explained by the applied elicitation perspective. In the individual perspective, elicited preferences are based on the person's preferences for own health gains, whereas in a social perspective preferences comprise motives such as altruism and fairness considerations. Still, only a few studies (Pinto-Prades et al., 2014, Gyrd-Hansen 2018, Shah 2017) have investigated the impact of perspective on preferences in an EoL setting. Pinto-Prades et al. (2014) find preferences for an EoL premium when applying both a social and an individual perspective. As the authors apply different methodologies with different metrics (WTP in the individual perspective and person trade-off in the social perspective), they cannot separate the impact of perspective from the potential confounding effect of the methodology applied. In Gyrd-Hansen (2018), respondents are asked in a one-choice task to choose between treatments (preventive vs. EoL treatment extending LE) in either a private health care insurance programme (individual perspective) or a national health care programme (social perspective). Replicating one choice task, Shah (2017) examines whether preferences for giving a one-year prolongation of life to a patient with a remaining LE of either one or five years differ across an individual and a social decision maker perspective. In contrast to Pinto-Prades et al. (2014), Gyrd-Hansen (2018) and Shah (2017) do not find preferences for an EoL premium from any of the two perspectives. However, their results indicate a relatively stronger preference for LE health gains at EoL in the social than in the individual perspective.

Dating back to the fair innings argument (Williams, 1997), it has been debated whether patients' age should be given weight in general when setting priorities for treatments. In countries such as Norway and New Zealand the emphasis is on the size of health losses, which implicitly means prioritising young patients (Olsen, 2013). This view has been supported by previous SP findings that younger beneficiaries should generally be prioritised over older beneficiaries (Shah et al., 2018, Gu et al., 2015). So far only two studies have attempted to separate the effect of age from preferences for EoL treatment (Gyrd-Hansen 2018, Shah et al., 2014). Whereas Shah et al. (2014) find no effect of age of beneficiaries on preferences for treatment at EoL, Gyrd-Hansen (2018) finds a preference towards prioritising younger beneficiaries over older ones. To date, Shah et al. (2014) is the only study that has examined whether the age of beneficiaries affects public preferences regarding the type of the health gain at EoL. They find no effect of age but note that their results are uncertain due to a small sample size.

This study seeks to provide new insight on public preferences for EoL treatment. Applying a SP experiment, we aim to address four unresolved issues in the SP literature. First, we examine whether preferences for health gains in LE or QoL from treatment at EoL differ from similarly sized health gains resulting from treatment of temporary disease and preventive health care. Second, we disentangle preferences for different types of health gains at EoL, comparing treatments resulting in improvement in QoL as opposed to LE. Third, we investigate whether preferences elicited in the

individual perspective differ from preferences elicited in the social perspective. Fourth, we examine whether information on the age of beneficiaries influence the preferences for treatment at EoL. Finally, as a robustness check, we examine the extent to which our results are sensitive to the severity of health state in terms of the initial health status provided.

Method

The survey

The research questions were addressed using a web-based survey with a SP experiment. Respondents were asked to prioritise between two new treatments resulting in different types of health gains but of a similar size in terms of QALYs. The treatments were characterised according to a number of characteristics that varied within and/or across respondents. The sample was blocked in four versions according to the applied perspective and characteristics of the beneficiaries. Except for this, the choice sets were identical across versions. Table 1 shows the four survey versions.

The social perspective (used in versions 1, 3 and 4) was framed in accordance with recommendations in the literature (Dolan et al., 2003, Pinto-Prades et al., 2014) as follows:

Box. 1: Social perspective

"Imagine two identical patients, patient A and patient B.

There is a possibility that the patient's course of illness can be improved with new and better treatments. Both treatments cost the same, but there is not enough money to give both patients the new and better treatment.

Imagine that you are the person who has to decide which patient should receive the new treatment.

Would you prefer to give an improvement to patient A or patient B?"

In versions 3 and 4, information about the age of the patients was added in the form of the following text: *"Imagine two identical patients, patient A and patient B. They are both ["18-35"]/["65+"] years old. There is a possibility…"*

The individual perspective (version 2) was constructed as an *ex ante* insurance perspective, implying that respondents were asked to make their decision without knowing whether or which of the health gains they would need in the future. The framing of the individual perspective was constructed as follows:

Box. 2: Individual perspective

"Imagine that you have a small risk of getting one of the following two diseases in the future. One disease is incurable and hence will end your life. The other disease is curable and will occur in the middle of your life. There is an equal probability of getting the diseases.

Imagine that there are new and better treatments, which can improve both disease paths. Both treatments cost the same, but there is not enough money to make both treatments available to you.

Which of the new treatments would you prefer to have access to, if needed in the future?"

The scenarios

In the design, we included four different types of health gain scenarios: a) an improvement in QoL resulting from treatment of a temporary disease (QoL-T), b) an improvement in LE for treatment at EoL (LE-EoL), c) an improvement in QoL for treatment at EoL (QoL-EoL), and d) an increase in LE from a preventive treatment (Prevention). All four health gain scenarios are illustrated in Figure 1.

The QALY terminology was not used in the survey, and the respondents were shown graphic representations of all the gains. The QoL dimension was described in terms of a visual analogue scale ranging from 0-100% (from dead to perfect health). By focusing on changes in QoL instead of changes in specific health status, the design controlled for variations in the valuations of health/use of scale. In order for the respondents to become familiar with the QoL scale, they were asked to evaluate their own health and a fictive person's health (described by EQ5D-3L attributes) on the visual analogue scale.

The health gain scenarios were carefully designed so that results from choice sets could be interpreted as preferences for one type of health gain over the other, controlling for the size of health gains, severity in terms of initial QoL and whether or not current treatment was available. We applied equally sized health gains of 0.2 QALYs in all the scenarios. For scenario a, b and c, this corresponded to a gain of 40% QoL for a period of six months. The health gain resulting from the preventive treatment (d) was described as an uncertain gain in LE in perfect health (Pennington et al., 2015, Gyrd-Hansen, 2018). Specifically, it was stated that one out of 10 would get the disease but if treated would experience a health gain of two years in full health due to prevention of the disease. From an *ex ante* perspective, this corresponds to an expected health gain of 0.2 QALYs per treated person, which is similar to the magnitude in scenarios a, b and c. Initial

EoL health states (scenarios b and c) were described as health states with a LE of six months. In contrast, LE with current treatment for the health state of the temporary disease was left unspecified, as the temporary disease had no effect on LE. We specified the temporary disease to affect QoL for a period of six months. The initial level of QoL with current treatment was set to the same level of 40% in scenarios a, b and c, which ensured that elicited preferences would not be affected by severity effects from QoL (Nord et al., 1999). The initial level of 40% QoL in combination with the gain of 0.2 QALYs was chosen in relation to levels applied in Pinto-Prades et al. (2014) and on the basis of realism with actual QoL of patients suffering from terminal illness and reasonably obtainable QALY gains from treatment (Wisløff et al., 2014, Färkkilä et al., 2014). Moreover, this combination was chosen due to the design presenting the size of the health gains at EoL (b and c) and for the temporary disease (a) as visually identical (marked by the blue areas in Figure 1 for a, b and c), making the design less cognitively complex to handle for respondents. Furthermore, health gains a, b and c were designed so that the health gain doubled the level of QoL or LE relative to the initial health profile. We operated with a maximum attainable QoL of 80%. This was done to control for the potential distinctive preferences for 'perfect health' (QoL of 100%), which could otherwise potentially bias the results. Finally, all scenarios were described in terms of improvement in *existing* treatments to ensure that choices were not affected by the availability of treatment.

In order to test preferences for health gains at EoL over other health gains and preferences for health gains at EoL, we combined the four specified health scenarios in pairs of two, which gave five choice sets. An overview of the combinations is provided in Table 2, and an example of a choice set (scenario a vs. c, version 1) is presented in Figure 2. We did not compare the two non-EoL health gains (scenario a vs. d) due to the focus on EoL premium. Prior to the choice sets, respondents were carefully introduced to the scenarios and were given the information that there was no right or wrong answer. Furthermore, we included an additional choice set, choice set 6, to test preferences for LE over QoL at EoL in another context. We presented the respondents with a choice between a treatment resulting in a life expectancy of six months and 50% QoL and another treatment, which resulted in a remaining LE of 12 months but at the cost of a low QoL due to side effects. In both cases the remaining life would correspond to 0.25 QALY. Hence, this choice set represents a simple trade-off situation, where respondents must choose whether or not they want to give up QoL for LE at the EoL. Figure 3 presents the visual components in choice set 6.

As a robustness test of the impact of severity on elicited preferences, we included three follow up choice sets for choice sets 1, 2 and 3 (1b, 2b and 3b), where the initial QoL level was altered to 25%. After answering each of the three choice sets with an initial QoL of 40%, respondents faced the same choice but with an initial QoL of 25%. Respondents were informed that it was the same choice, except that the initial level of QoL had changed. These QoL-gains also resulted in a doubling of the QoL level (now from 25% to 50%) for a period of six months, leading to an absolute gain of 0.125 QALY. The gain in LE was described as an extension of life of six months at the initial QoL of 25% also leading to a gain

of 0.125 QALY. In total, each respondent faced nine choice sets (choice sets 1-6 and follow up choice sets for choice sets 1-3). A translated version of the SP experiment is available in the Appendix (for the social perspective).

Survey structure

Table 2 provides an overview of the choice set scenarios, order and randomisation. The choice sets were divided into four sections: section A) QoL-T vs. EoL, section B) EoL, section C) Prevention vs. EoL, and section D) Side effects.

To limit the complexity of the choice task and thus the cognitive burden on the respondent, we decided only to randomise the order of the choice sets in section A and C (randomising choice set 1 and 2; and choice set 4 and 5) and not to randomise the position of the alternatives in each choice set (right vs. left). This ensured that the scenarios were introduced successively and that the EoL scenario was always placed to the right (when compared to a non-EoL scenario).

Prior to choice sets, respondents were asked questions about their own health. Subsequent to all choice sets, respondents were asked to state how certain they were about their answers. Finally, the questionnaire included standard socio-demographic questions on age, gender, education, people in the household, children in the household and whether they have family or friends that were currently terminally ill.

Piloting

We conducted a pilot study based on a convenience sample of 30 respondents. The pilot was followed up by interviews with an emphasis on the understanding of the SP experiment. There was a specific focus on respondents' understanding of the health gain from the preventive treatment and the trade-off scenario in choice set 6. Respondents in the pilot expressed no concerns regarding any of the design issues. A few improvements in the individual perspective were implemented after the pilot study. Specifically, we changed the wording of the choices in the individual perspective to ensure that respondents understood that the choice sets were about choice of preferred health *gain* and not preferred health *state*. This change was retested successfully.

Analytical strategy

Data for each choice set are analysed separately using the proportion test (z-test). Specifically, we test whether health gains at the EoL are preferred to health gains from other treatments (choice sets 1, 2, 4 and 5) and whether the type of health gain affects preferences for treatment at EoL (choice sets 3 and 6). Furthermore, for each choice set we test whether preferences differ in versions with different perspectives (version 1 vs. 2) and age of beneficiaries (version 3 vs. 4) using a proportion test on two samples (z-test). The robustness test of impact of initial QoL level is performed by comparing choice sets 1-3 to their follow up choice sets (1b, 2b and 3b) using a proportion test (z-test). As further

robustness checks, we also analyse our data excluding 1) respondents answering *uncertain/very uncertain* to the certainty question and 2) respondents with response times either below 5 minutes or above 30 minutes.

In addition, to test variation in the overall preference across choice sets we conduct a series of conditional logit regressions. The four different health gains (QoL-T, LE-EoL, QoL-EoL and Prevention) can be described by three generic health gain dimensions: *EoL* takes on the value 1 if the health gain is given in EoL and otherwise 0; *QoL* takes on the value 1 if the health gain is an improvement in QoL and otherwise 0; *Prev* takes on the value 1 if the health gain is prevention and otherwise 0. In version 1 (social) and 2 (individual), we test whether the overall preference differs across respondent characteristics. This is done by including all respondent characteristics as dummy variables (subgroups) and interacting them with the three generic health gain dimensions. We test preferences across gender (1=men), age (1=+65), education (1=high education), self-reported health (1=good health) and whether respondents have a terminally ill friend or family member (1=terminal relation). Correspondingly, the model then becomes;

$$y = \beta_1 EoL + \beta_2 Qol + \beta_3 Prev + \beta_4 EoL * subgroup + \beta_5 QoL * subgroup + \beta_6 Prev * subgroup \quad (1)$$

Using the same model approach, we also test the impact of perspective (social versus individual) and beneficiaries' age on the overall preference (young versus elderly beneficiaries). More specifically, we run the conditional logit regressions with similar interaction terms defined by the three health gain domains and a binary perspective variable indicating 1 for the individual perspective (version 2) and 0 for the social perspective (version 1). Similarly, we run the conditional logit regression with interaction terms defined by the three health gain domains and a binary age variable indicating 1 for elderly beneficiaries (version 4) and 0 for young beneficiaries perspective (version 3).

The sample comprised adult members of a web-panel of a Danish market research agency. A stratification strategy was used to ensure that all four version samples were representative with respect to the age, gender and geographical distribution of the Danish adult population (above the age of 18). Moreover, respondents were randomised to the four survey versions. Respondents were compensated with reward points, which could be redeemed for gift vouchers.

Results

The survey was conducted in October 2015, and a total of 2,564 individuals were invited by email to participate in the survey of which 1,047 completed the survey. The survey was closed shortly after reaching the target sample of 1,000 individuals (250 in each version), giving a response rate of 41%. Due to a successful stratification strategy, the sample is representative of the Danish population in terms of gender, age and geography (see Table 3). In terms of education, those with higher education are slightly overrepresented. The randomisation of the four version samples was successful, implying that there are no statistically significantly differences in either age, gender, income or education across the four samples.

Are health gains at EoL preferred over other health gains?

Results from the choice sets in the social perspective (version 1) and the individual perspective (version 2) are presented in Table 4. Looking into the differences in choice sets comparing EoL treatment with treatment of temporary disease and prevention (choice sets 1, 2, 4 and 5), it becomes apparent that health gains obtained from treatment at EoL are generally not preferred to other health gains. The only exception is in choice set 5 in version 1 (social perspective), in which we find a preference for a QoL health gain at EoL over a preventative health gain. Results from the conditional logit regressions (Model 1 and 2, Table 8) confirm our finding, that the EoL dimension has a negative effect on the overall preference for health gains and thus is not preferred to other health gains. The results of our subgroup analysis show minor variation in the preferences for EoL. In the individual perspective (version 2), the size varies across gender, EoL relation and education. Although there is still a negative net impact of EoL, we see a significantly positive interaction effect for women, respondents with a relation to a terminally ill patient and highly educated persons (Model 4, 8 and 12, Table 8). Most notably, we see positive EoL coefficients for women and respondents with a relation to a terminally ill patient in the social perspective (Model 3 and 7, Table 8).

Focusing specifically on the health gain from treatment of the temporary disease, our results from the choice sets indicate a preference for treatment of temporary diseases over EoL treatment, which is most pronounced in the individual setting and for the lower level of QoL at 25% (see Tables 4 and 6). The only health gain from treatment of the temporary disease that is not preferred to EoL is QoL-T to QoL-EoL. The results are less clear for the choices between prevention and EoL treatments. When the choice set involves a preventative health gain versus a gain in LE at EoL, there is a tendency to prefer prevention (significant in the individual perspective), whereas the results are more mixed for the choice set between prevention and gain in QoL at EoL. In the social perspective (version 1), QoL-EoL is preferred to the preventative health gain, but in the individual perspective (version 2) we do not find preference for one over the other.

What is most important at EoL: quality or quantity?

For the choice sets directly comparing different health gains at EoL (choice sets 3 and 6), we find a clear preference for gain in QoL over gain in LE. This is observed across perspectives and for both initial QoL levels (Table 4). Comparing the preferences across initial QoL, we find the strongest preference for QoL at the lowest initial QoL level of 25% (Table 6). The preference for QoL at EoL is especially pronounced for the trade-off in choice set 6, where the vast majority (more than 84% in all versions) prefer treatment A without side effects and thus are not willing to trade QoL for prolongation of life in treatment B. These results are supported, when we test for differences across choice sets 1 vs. 2 and 4 vs. 5 (see Table 7). For both comparisons, one scenario is kept constant (QoL-T or Prevention), implying that the only change across the paired choice sets is whether the gain at EoL is in terms of QoL or LE. Here, we also see a clear pattern of improvements in QoL being more preferred relative to improvements in LE, when these two health gains are

compared to other non-EoL health gains. Furthermore, the conditional logit regressions confirm that the QoL dimension is found to be a positive main driver of the overall preferences for health gains (Model 1 and 2, Table 8). However, this is not isolated to EoL.

Does perspective influence preferences?

Focusing on choice sets 1 and 2 (see Table 4), we find some significant differences in preferences between the social and the individual perspective (version 1 vs. version 2). QoL-T is more preferred in the individual perspective compared to EoL, which means that, relatively, more respondents prefer a health gain at EoL to a gain in QoL from treatment of a temporary disease in the social perspective. This is irrespective of whether the gain at EoL is in terms of QoL or LE. For the choice sets involving prevention against improvements at EoL (choice sets 4 and 5), we see a similar shift in preferences towards EoL treatment in the social perspective relative to the individual perspective, although this is not significant. For choice sets 3 and 6, we see no difference in preferences for EoL treatments across the two perspectives. QoL is preferred in both choice set 3 and 6 in both perspectives. Based on the conditional logit regression including interactions for perspective (Model 13, Table 9), we see that the EoL dimension affects the overall preference negatively in the individual perspective compared to the social perspective. Furthermore, from the conditional logit regressions, we find differences across perspectives when we look at subgroups (Table 8). In the social perspective, women have an overall positive preference for EoL, whereas the opposite is the case in the individual setting (Models 3 and 4, Table 8). The same pattern is observed for respondents with a relation to a terminally ill patient. They too have a positive social preference for EoL and a negative individual preference for EoL (Models 7 and 8, Table 8).

Does the age of beneficiaries matter?

Table 5 presents the results from versions with young beneficiaries (version 3) and older beneficiaries (version 4). Comparing the preferences, we find few significant differences in the distribution of preferences for health across the two defined age groups. For the choice sets testing preferences for an EoL premium (choice sets 1, 2, 4 and 5), we observe a slightly stronger preference for improvements in QoL from treatment of the temporary disease as opposed to improvements in LE at EoL, when beneficiaries are elderly than when they are young (choice set 2). This effect is significant at a 0.1 level. The conditional logit regression including interactions (Model 14, Table 9) capturing differences in preferences across the two versions shows an overall stronger preference for prevention treatments targeting younger beneficiaries. Furthermore, the regression results show an overall tendency of a small but positive preference for health gains at EoL for younger patients (significant at a 0.1 level). For choice sets testing preferences for health gains at EoL, we observe a significantly stronger preference for a QoL gain at EoL relative to LE, when the beneficiaries are young (follow-up question for choice set 3 with initial QoL of 25%).

Robustness checks

Finally, we also carried out two robustness checks excluding 1) respondents answering *uncertain* (n=248)/*very uncertain* (n=36) to the certainty question, and 2) respondents with recorded response times either below 5 minutes (n=35) or above 30 minutes (n=66). For all four versions, and across perspectives, we find that the exclusion criteria do not alter the observed choice patterns and consequently do not have an impact on our main findings.

Discussion

Overall, we do not find evidence in support of an EoL premium. This is irrespective of whether preferences are elicited from a social or from an individual perspective and irrespective of type of health gain at EoL. The only exception is a preference for QoL gain at EoL over gain from preventive treatment in the social perspective. These findings are robust across different levels of initial QoL and apply regardless of whether the group of beneficiaries is defined as young or old patients. We see the largest difference in choice probabilities for choice set 2 with more than 70% of respondents choosing a gain in QoL for treatment of temporary disease over a gain in LE for treatment at EoL in the individual perspective. Our finding provides valuable input to the ongoing policy debate concerning public health care system's priority setting criteria and questions the justification of prioritising treatments at EoL over other treatments as recommended by NICE on grounds of public preferences. In relation to the other SP studies comparing EoL health gains to health gains from treatment of temporary diseases or a preventive treatment, our findings are in keeping with Gyrd-Hansen et al. (2018), who find no preference for a gain in LE at EoL over a health gain from prevention, but contradict Pinto-Prades et al. (2014), who find preference for EoL health gains over health gains from a temporary disease. Our study design is inspired by Pinto-Prades et al. (2014) but differs on several important dimensions. We use a between subject design, whereas they use a within-subject design applying different methodologies (WTP and person trade-off) and perspectives (social and individual). Moreover Pinto-Prades et al. (2014) describe the initial EoL health states as health states without treatment, whereas patients initially receive treatment in the comparable health scenario (temporary health problems). It is likely that this difference in access to treatment, if considered important by the respondents, could bias the results and thus serve as an explanation of the higher valuation of health gains at EoL found by Pinto-Prades et al. (2014).

Furthermore, our study also highlights that the type of health gains at EoL impacts the elicited preferences. We find evidence of a non-constant proportional trade-off in QoL and life years, as assumed in the QALY model, demonstrating that a QALY gain resulting from a change in QoL is valued significantly higher than an equally sized gain in LE at EoL. We find an even stronger preference for QoL gains for the lower level of initial QoL of 0.25, indicating that severity in

terms of health state also matters for the public valuation of health gains at EoL (Nord, 1995). Although the relative size is kept constant (100% increase in QoL), we cannot rule out that some of the effect of QoL severity could be driven by a change in the absolute size of a health gain, with larger health gains being obtainable in the scenarios with an initial level of 0.25 QoL. The preference for QoL gains at EoL is also confirmed by the preference for gain in QoL from EoL treatment over the life-extending gain from preventive treatment. Our results confirm previous results by Shah et al. (2014), Pinto-Prades et al. (2014) and McHugh et al. (2018), suggesting a tendency in the public to prioritise QoL gains over LE gains in the allocation of public health care resources to treatments at EoL. A finding that contradicts NICE's guidelines of prioritising life-extending treatments at EoL over other treatments including treatments that generate a QoL gain at EoL. Moreover, our results provide valuable input to medical decision making about individual preferences for treatment at EoL, including palliative care. In terms of shared decision making, it is vital that patients' preferences for life-prolonging treatments are taken into consideration, especially when treatment comes at the cost of a decrease in QoL (Henselmans et al., 2017). This dilemma is apparent in choice set 6, which demonstrates a strong aversion among respondents against trading off QoL for LE at EoL. When asked directly about the choice between a treatment that prolongs life but lowers QoL (due to side effects) compared to a standard treatment (without side effects), 85% of respondents chose the standard treatment. We recognise that the visualisation could have induced some status quo bias and thus impacted on our results. Yet, we would argue that the scenario is very realistic in terms of the treatment decisions that many EoL patients face. This includes patients in late-stage cancers, where chemotherapy is used as palliative care but with the risk of severe side effects. Placing our results in this context suggests that most individuals, if fully informed, would refuse this type of palliative chemotherapy when asked *ex ante*.

Besides being related to health status, a concern for severity can also relate to the patient's age at the time of treatment (Norheim et al., 2014). Due to our design setting we cannot rule out that a potential preference for EoL could be confounded by a preference for prioritising health gains to patients with more severe diseases, resulting in shorter LE. This distinction is important as age represents a separate distributional concern. A decomposition of preferences for EoL and shorter LE would require the two dimensions to be varied independently. In order to be able to compare preferences across perspectives, we deliberately decided not to control for LE. In the individual perspective, such a decomposition would imply that the same respondent is faced with different life expectancies (prior to illness), which we argue would be unconceivable and increase the complexity of the choices. However, based on our two versions with defined age of beneficiaries, we are able to examine the impact of age on beneficiaries, and thus remaining LE, on preferences for EoL. According to our results, we see a slightly positive preference for EoL treatment when the patients are younger compared to older (significant at the 0.1 level), which could be driven by the larger impact on LE of younger patients with a terminal illness (Model 14, Table 9). In priority settings, it has been debated whether younger age groups should be given priority over older age groups. Such an argument can be justified either on the grounds of the size of the expected

health gain due to their longer life expectancy (consistent with the QALY maximization rule), the potential productivity gain or the fair innings argument (Dolan et al., 2005, Tsuchiya, 1999). As the health gains in our study are identical for the younger and the older age group at EoL, and as it is realistic to assume that neither are active on the job market due to their severe health condition, this suggests that age impacts on public valuation of treatment at EoL in accordance with the fair innings argument. Despite this potential confounding effect of age, we find that, overall, non-EoL gains are preferred over EoL gains. Consequently, controlling for shorter remaining LE would only strengthen our findings of no preferences for an EoL premium.

We find a minor, yet interesting, impact on perspective of the elicited preferences. When comparing a gain in QoL in temporary diseases to EoL health gains, we find a relative stronger (less negative) preference for health gains at EoL when preferences are elicited from a social perspective compared to an individual perspective, suggesting that the perspective from which preferences are elicited - at least to some degree - matters. Our findings are in keeping with Shah (2017) and Gyrd-Hansen (2018), indicating that value judgments differ across perspectives, which implies that altruistic motivation and/or fairness considerations differ from narrow self-interest. From the regression analysis including respondents' characteristics it becomes apparent that the change in preference pattern across perspectives is primarily driven by women and respondents with a relation to a terminally ill person. Specifically, we see that these two groups have a significantly positive preference for EoL in the social perspective, whereas the opposite applies in the individual setting. This indicates an expressive alteration in value judgment among women and further suggests that social distance to beneficiaries significantly affects preferences. Unfortunately, we are not able to say what drives these motivational changes. Results from experimental economics suggest that women are more altruistically motivated than men (Brañas-Garza et al., 2018) and that altruism varies inversely with social distance between giver and receiver (Rachlin, Jones, 2008, Bohnet, Frey, 1999). If respondents believe that other people value EoL treatment more than they themselves do, then altruistic motivation would cause a change in preferences towards a relatively stronger preference for EoL in the social compared to the individual perspective. Hence, an explanation for the preference shift across perspectives observed for women may be due to women being more altruistic towards EoL patients than men. Furthermore, altruism would also be a natural driver for the presence of a positive preference for EoL for respondents with a relation to a terminally ill person. However, more research is needed to study value judgments and the impact of perspective on preferences for different type of health gains as recently proposed by (Tsuchiya, Watson, 2017).

There are limitations to the study that need to be acknowledged. We apply forced choices and therefore do not include an indifference option. Shah (2017) finds that inclusion of an indifference point has an impact on preferences. However, he finds that inclusion of an indifference point does not favour an EoL preference. Accordingly, we would argue that an indifference option most likely would not have changed our overall findings. Also, not including an indifference option is in

line with standard practice in the choice experiment literature (Bateman et al., 2002). As we did not mirror the choice sets across respondents (i.e. change the position of the alternatives within a choice set), we cannot rule out that our results could be subject to some right-left bias and that not providing the respondents with an indifference option could have amplified this. As a robustness check we limited our analysis to include only those individuals who took more than 5 minutes to answer the survey as these individuals are more likely to have engaged in the task (and thus less likely to have been subject to left-right bias). Reassuringly, this does not change our conclusions. Another way to test the potential right-left bias would have been to have included another version of the survey that mirrored the left and right position of the alternatives in all choice sets. Furthermore, it should be noted that the choice sets were grouped into sections, and thus we did not randomise the order of the choice sets completely. Moreover, the application of an incomplete randomisation strategy of choice set and alternatives within the choice set is in line with the study designs applied by Shah et al. (2014) and Pinto-Prades et al. (2014). Another additional limitation is that we decided to include only one gain in length of life (6 months). As we did not test for the impact of different LE gains or durations of illness, we cannot rule out that our findings are confined to this setting.

Moreover, our study results are limited to ordinal rankings and should thus only be interpreted as such. Consequently, we are not able to estimate the individual strength of preferences (measured in terms of willingness-to-pay, for instance) of a preferred health gain. Still, and in line with previous studies with similar designs (Shah et al., 2014, Gyrd-Hansen, 2018, Linley, Hughes, 2013), we use the propensities as an estimate for the overall preference intensity. Nevertheless, it could be argued that the appropriate analysis criterion should be whether the propensity is below or above 0.5 in accordance with majority rule voting and thus in line with traditional public referendums. Whereas this criterion limits the number of analyse that can be conducted (testing for differences in size across perspectives and choice sets), it does not change the major findings of our study.

We operate with two initial levels of QoL of 25% and 40%, and it could be argued that both these levels, despite being realistic QoL levels for terminally ill patients and comparable to levels applied by, for instance, Pinto-Prades et al. (2014), were considered very poor by the respondents. If this is true, it would imply that gains in length of life are considered to be of low value to respondents, which could have intensified the non-favouring of gains in LE at EoL Unfortunately, we are unable to extrapolate our results beyond the benchmark of 40%, so that this question remains unresolved. More research is needed that examines the impact of QoL severity on the trade-off between quality and length of life at EoL.

Conclusion

Growing health care expenditures is a challenge to public health care systems worldwide. Consequently, this has led to a vibrant discussion of the rationale behind prioritisation including whether some types of health gains can be considered more valuable to the individual than others, and whether society prefers some distributions of health to others. This study sets out to examine the public's preferences for health gains at EoL compared to other health gains, elicited using different perspectives and for different age groups. Overall, we do not find support for a higher priority to health gains received from treatment at EoL and thus an EoL premium. This is irrespective of the type of the health gain although there is a stronger preference for gains in QoL than for gains in LE at EoL. Moreover, we find some heterogeneity in preferences for health gains across age of beneficiaries and perspectives. Preferences for an EoL premium is found to be affected by age of beneficiaries demonstrating that treatment at EoL matters more when beneficiaries are younger. In a social decision maker perspective, women and respondents with a relation to an EoL patient have a positive preference for treatment at EoL but preferences are reversed in an individual perspective. Further research should investigate the values beyond self-interest that comprise public preferences for treatment at EoL, including the impact of altruistic motivation.

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Tables

Table 1 – The different survey version.

	Version 1: Social	Version 2: Individual	Version 3: Young	Version 4: Elderly
Perspective	Social	Individual	Social	Social
Characteristics of beneficiaries	Generic (not defined)	Generic (not defined)	Aged 18-35	Aged 65+

Table 2 – Overview of choice sets in the applied design and ordering of the choice sets in the survey.

Section	Choice set	Comparison		Figure
A QoL-T vs. EoL	1	QoL-T[1]	vs. QoL-EoL[2]	a + c
	1b	*Same as choice set 1 with initial QoL 25%[4]*		
	2	QoL-T[1]	vs. LE-EoL[3]	a + b
	2b	*Same as choice set 2 with initial QoL 25%[4]*		
B EoL	3	QoL-EoL[2]	vs. LE-EoL[3]	c + b
	3b	*Same as choice set 3 with initial QoL 25%[4]*		
C Prevention vs. EoL	4	Prevention	vs. LE-EoL[3]	d + b
	5	Prevention	vs. QoL-EoL[2]	d + c
D Side effects	6	No side effects	vs. LE and side effects	Figure 3

Notes: [1]QoL gain from treatment of temporary disease (non-terminal); [2]QoL gain in EoL; [3] LE gain in EoL; [4]Follow-up questions testing initial QoL level. Same choice but with lower initial QoL (and QALY size).

Table 3 – Descriptives for versions 1-4, the full sample and the Danish population.

	Population	Full Sample n=1,047	Social (version 1) n = 262	Individual (version 2) n = 261	Young (version 3) n = 262	Old (version 4) n = 262
Gender						
Male	0.49	0.49	0.48	0.49	0.48	0.48
Female	0.51	0.51	0.52	0.51	0.52	0.52
Age						
18-39	0.34	0.35	0.34	0.36	0.35	0.35
40-59	0.35	0.36	0.35	0.35	0.35	0.36
60+	0.31	0.29	0.30	0.30	0.29	0.29
Mean		48.4	49.0	48.0	47.3	49.1
Median		50	51.5	50	48.5	50
Education						
Low education	0.38	0.15	0.16	0.14	0.17	0.15
Medium education	0.53	0.68	0.69	0.68	0.67	0.69
High education	0.08	0.17	0.15	0.18	0.16	0.16

11 *Table 4 – Results from social and individual perspective (versions 1 and 2). Reported in proportions.*

Choice set		Initial QoL 40%			Follow up questions: Initial QoL 25%		
		Version 1: Social	Version 2: Individual	Difference (version 1 vs. 2)	Version 1: Social	Version 2: Individual	Difference (version 1 vs. 2)
1	QoL-T	0.48	0.63	*-0.15****	0.55	0.66	*-0.11***
	QoL-EoL	0.52	0.37		0.45	0.34	
	Difference	*-0.04*	*0.26* ***		*0.09*	*0.31* ***	
2	QoL-T	0.61	0.71	*-0.11***	0.72	0.81	*-0.09***
	LE-EoL	0.39	0.29		0.28	0.19	
	Difference	*0.21* ***	*0.43* ***		*0.44* ***	*0.62* ***	
4	Prevention	0.53	0.58	*-0.05*			
	LE-EoL	0.47	0.42				
	Difference	*0.06*	*0.16* **				
5	Prevention	0.43	0.50	*-0.07*			
	QoL-EoL	0.57	0.50				
	Difference	*-0.14* **	*0.00*				
3	QoL-EoL	0.60	0.63	*-0.03*	0.74	0.72	*0.01*
	LE-EoL	0.40	0.37		0.26	0.28	
	Difference	*0.21* ***	*0.26* ***		*0.47* ***	*0.45* ***	
6	No side effects	0.89	0.85	*0.05*			
	LE and side effects	0.11	0.15				
	Difference	*0.79* ***	*0.69* ***				
		n=262/246[a]	*n=261*		*n=262*	*n=261*	

Notes **** p<0.01; ** p<0.05;* *p<0.1

Reported differences are based on non-rounded proportions.

Differences between two proportions within the same survey (vertical difference) are tested using proportion test on one sample (z-test). Differences between two proportions across perspective (horizontal) are tested using proportion test on two samples (z-test).

a – Due to a technical error few respondents in version 1 (social perspective) did not receive the two choice sets with preventive health gain. Here n = 246.

12

13 *Table 5 - Choice of treatment across young and elderly beneficiaries (versions 3 and 4) reported in proportions.*

Choice set		Initial QoL 40%			Follow up questions: Initial QoL 25%		
		Version 3: Young	Version 4: Elderly	Difference (version 3 vs. 4)	Version 3: Young	Version 4: Elderly	Difference (version 3 vs. 4)
1	QoL-T	0.45	0.47	*-0.02*	0.48	0.51	*-0.03*
	QoL-EoL	0.55	0.53		0.52	0.49	
	Difference	*-0.09*	*-0.06*		*-0.03*	*0.02*	
2	QoL-T	0.49	0.57	*-0.08* *	0.66	0.67	*-0.02*
	LE-EoL	0.51	0.43		0.34	0.33	
	Difference	*0.02*	*0.15* **		*0.31* ***	*0.34* ***	
4	Prevention	0.50	0.48	*0.02*			
	LE-EoL	0.50	0.52				
	Difference	*-0.01*	*-0.05*				
5	Preventionn	0.41	0.37	*0.05*			
	QoL-EoL	0.59	0.63				
	Difference	*-0.18* ***	*-0.27* ***				
3	QoL-EoL	0.57	0.56	*0.02*	0.72	0.63	*0.09* **
	LE-EoL	0.43	0.44		0.28	0.37	
	Difference	*0.14* **	*0.11* *		*0.44* ***	*0.26* ***	
6	No side effect	0.84	0.84	*0.00*			
	LE and side effects	0.16	0.16				
	Difference	*0.67* ***	*0.67* ***				
		n=262	*n=262*		*n=262*	*n=262*	

Notes *** p<0.01;** p<0.05;*p<0.1

Reported differences are based on non-rounded proportions.

Differences between two proportions within the same survey (vertical difference) are tested using proportion test on one sample (z-test). Differences between two proportions across versions (horizontal) are tested using proportion test on two samples (z-test).

14

15 *Table 6 – Test of impact of initial QoL (40% vs. 25%)*

			40% initial QoL vs. 25% initial QoL						16
Choice set	Initial QoL		Version 1: Social		Version 2: Individual		Version 3: Young		Version 4: Elderly
1 QoL-T vs. QoL-EoL	*40%*	*QoL-T*	*0.48*		*0.63*		*0.45*		*0.47*
	25%	*QoL-T*	*0.55*		*0.66*		*0.48*		*0.51*
		Difference	*0.06*		*0.03*		*0.03*		*0.04*
2 QoL-T vs. LE-EoL	*40%*	*QoL-T*	*0.61*		*0.71*		*0.49*		*0.57*
	25%	*QoL-T*	*0.72*		*0.81*		*0.66*		*0.67*
		Difference	*0.11*	*	*0.10*	*	*0.17*	***	*0.10*
3 QoL-EoL vs. LE-EoL	*40%*	*QoL-EoL*	*0.60*		*0.63*		*0.57*		*0.56*
	25%	*QoL-EoL*	*0.74*		*0.72*		*0.72*		*0.63*
		Difference	*0.13*	**	*0.10*		*0.15*	**	*0.08*

Notes: *** p<0.01;** p<0.05;* *p<0.1

Numbers indicate the numeric difference between proportions for choice set 1, 2, 3 and their follow up questions (initial QoL 25%). Reported differences are based on non-rounded proportions.

A positive number indicate a stronger preference for QoL-T in choice set 1 and 2 and indicate a stronger preference for QoL-EoL in choice set 3 as the initial QoL changes from 40% to 25%.

Differences between choice sets with 40% and 25% QoL are tested using proportion test within one sample.

Table 7 – Test for differences in preference for health gains at EoL vs. either QoL-T or prevention (choice sets: 1 vs. 2 and 4 vs. 5)

Initial QoL		EoL vs. QoL-T (choice set 1 vs. 2)		EoL vs. Prevention (choice set 4 vs. 5)	
		Version 1: Social	Version 2: Individual	Version 1: Social	Version 2: Individual
40%	*QoL-EoL*	*0.52*	*0.37*	*0.57*	*0.50*
	LE-EoL	*0.39*	*0.29*	*0.47*	*0.42*
	Difference	*0.13* **	*0.08*	*0.10*	*0.08*
25%	*QoL-EoL*	*0.45*	*0.34*	*N/A*	*N/A*
	LE-EoL	*0.28*	*0.19*	*N/A*	*N/A*
	Difference	*0.18* ***	*0.16* ***	*N/A*	*N/A*

Notes: *Reported differences are based on non-rounded proportions. The differences represents the difference in the preference strength for a health gain in QoL at EoL compared to a prolongation of life at EoL, when the two health gains are compared separately to either QoL-T or Prevention.*

A positive difference indicates a stronger relative preference for QoL-EoL than for LE-EoL compared to QoL-T or Prevention.

Differences between proportions in choice sets are tested using proportion test within one sample.

22 *Table 8 – Results from conditional logit regressions on health and respondent characteristics.*

	Base model		Gender (male=1)		Health (good health=1)		Relation to terminal patient (=1)		Age (old respondent=1)		Education (high education=1)	
	Model1 Social	Model 2 Individual	Model 3 Social	Model 4 Individual	Model 5 Social	Model 6 Individual	Model 7 Social	Model 8 Individual	Model 9 Social	Model 10 Individual	Model 11 Social	Model 12 Individual
EoL	-.049	-.563***	.308***	-.444***	-.018	-.501***	-0.145*	-.693***	-.011	-.522***	-.145	-.764***
QoL	.639***	.628***	.892***	.762***	.348***	.550***	.603***	.617***	.661***	.629***	.591***	.446***
Prev	.187	-.084	.436**	-.205	.177	-.147	.230	-.003	.204	-.063	.066	-.252
EoL*male			-.745***	-.241*								
QoL*male			-.517***	-.264								
Prev*male			-.506*	.250								
EoL*good health					-.051	-.089						
QoL*good health					.484***	.113						
Prev*good health					.017	.090						
EoL*terminal							.297**	.336**				
QoL*terminal							.116	.037				
Prev*terminal							-.143	-.216				
EoL*65+									-.183	-.231		
QoL*65+									-.111	-.001		
Prev*65+									-.082	-.119		
EoL*high educ											.232	.388***

QoL*high educ	.115	.358***
Prev*high educ	.292	.324

P-values: *<0.1 ;**<0.05; ***<0.01. Regressions are run using clogit with robust standard errors in Stata.

Table 9 – Effect from perspective and beneficiaries' age from conditional logit regressions.

	Perspective Model 13 Versions 1 and 2	Age Model 14 Versions 3 and 4
EoL	-.049	-.013
QoL	.639***	.431***
Prev	.187	-.117
EoL*individual	-.515***	
QoL*individual	-.010	
Prev*individual	-.271	
EoL*young		.181*
QoL*young		.075
Prev*young		.351**

P-values: *<0.1 ;**<0.05; ***<0.01.

Regressions are run using clogit with robust standard errors in Stata.

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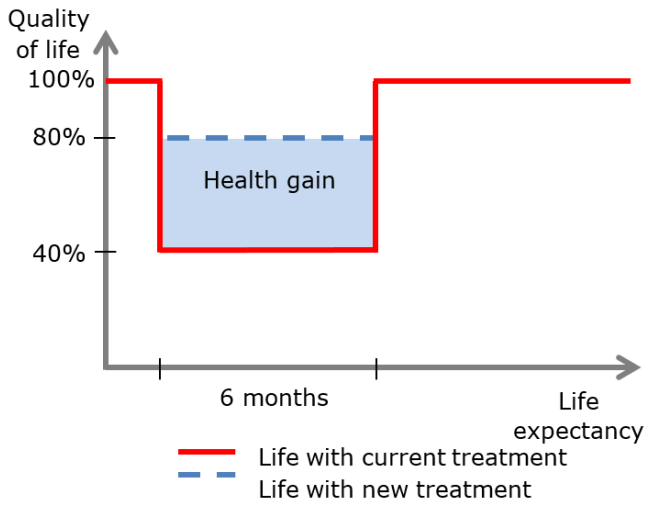
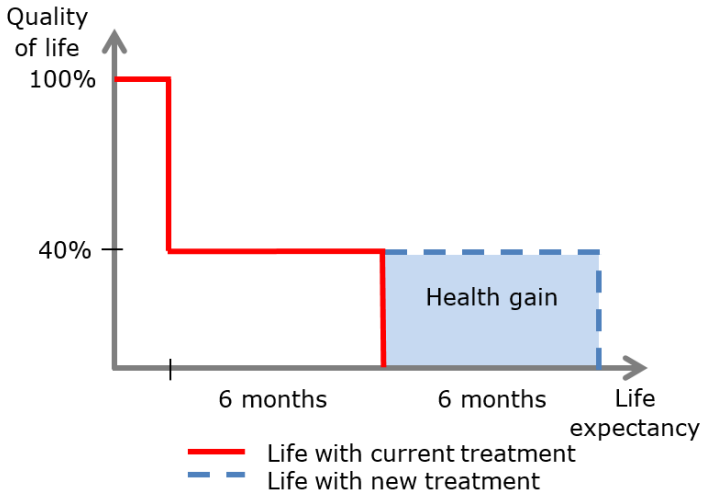
Figures

Figure 1 – Visual presentation of the four health scenarios: a) gain in QoL from treatment of temporary disease (QoL-T) b) gain in LE at EoL (LE-EoL), c) gain in QoL at EoL (QoL-EoL) and d) gain from preventive treatment (Prevention).

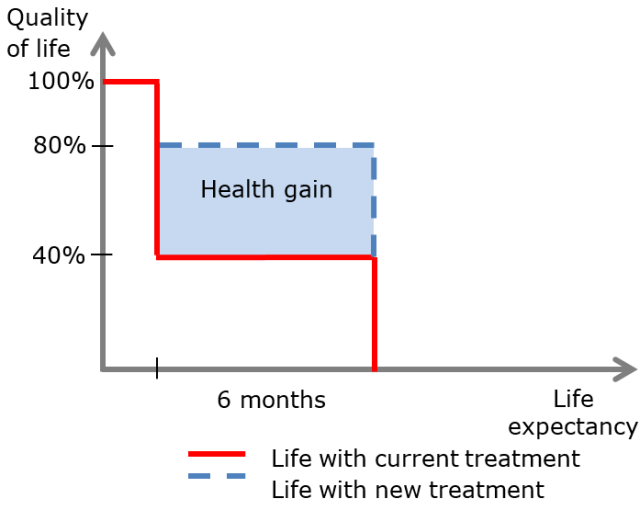
a) QoL-T



b) LE-EoL



c) QoL-EoL



d) Prevention

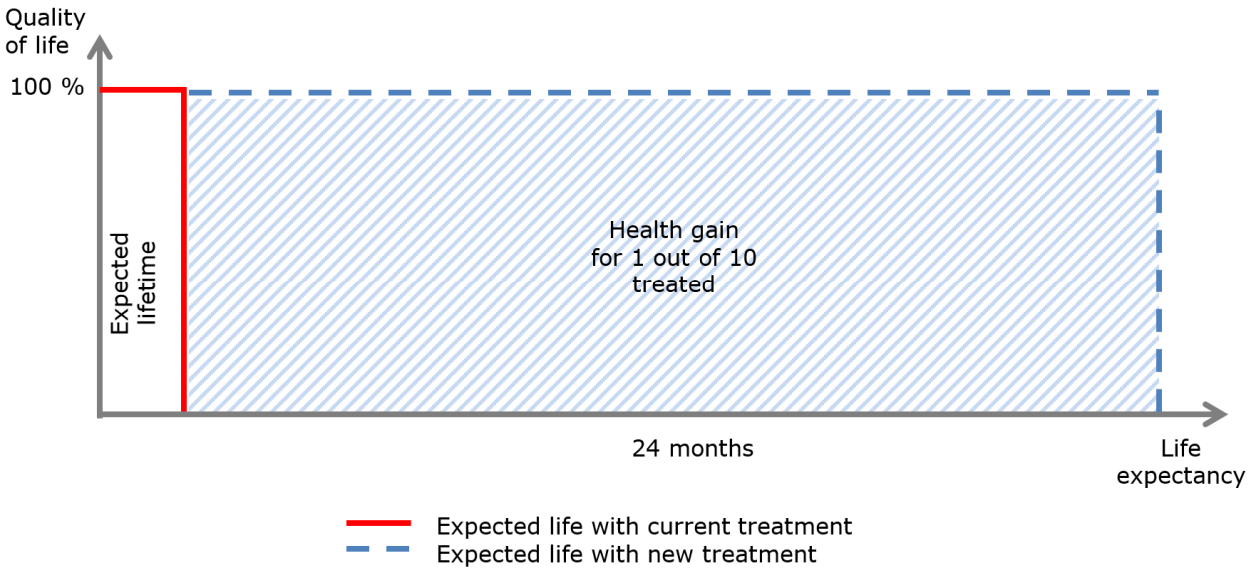
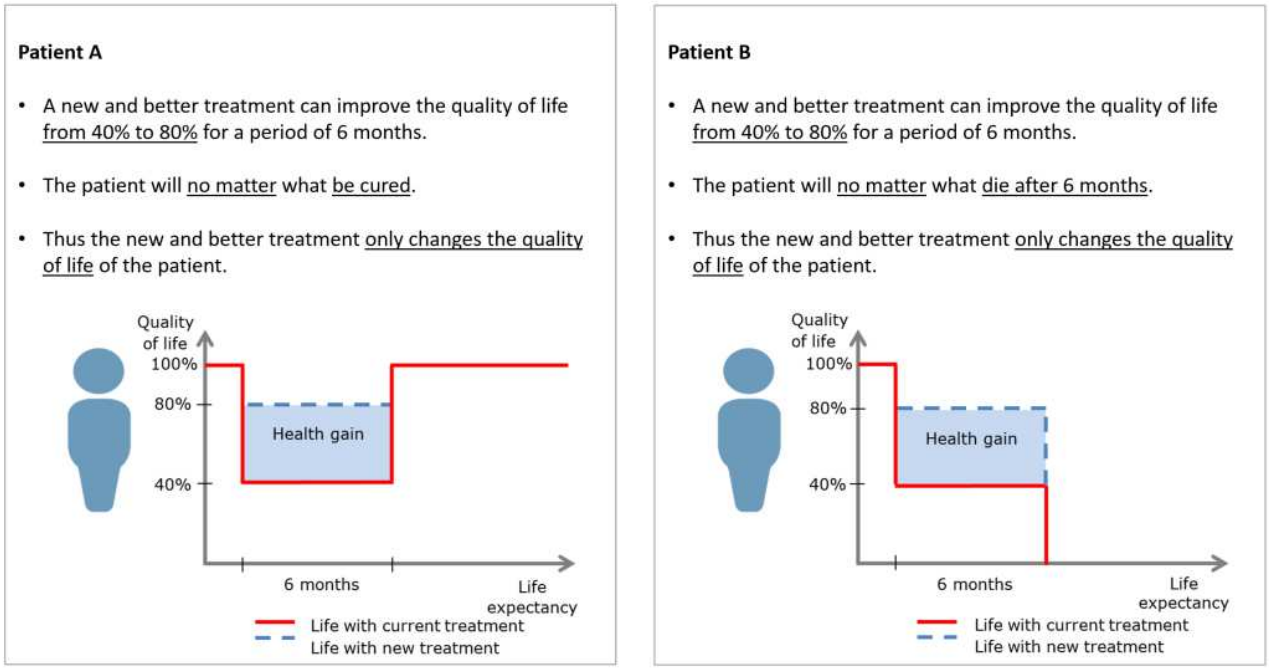


Figure 2 – Example of a choice set (scenario a vs. c in version 1)

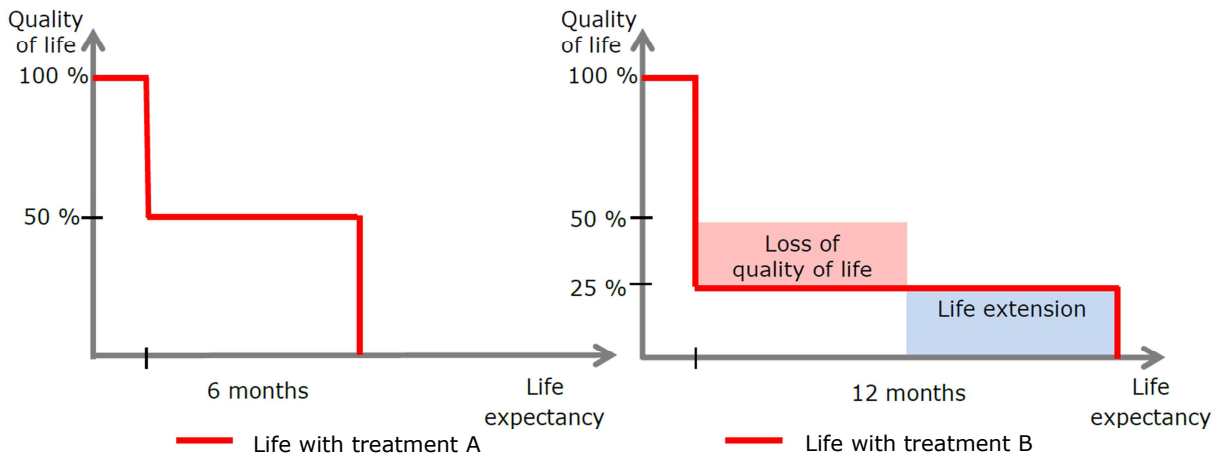
Would you prefer to give an improvement to patient A or patient B?

(Before answering, please look carefully at the figures)



61 *Figure 3 – Visual representation of the two scenarios in choice set 6 representing a trade-off situation, where*

62 *respondents must choose whether or not they want to give up QoL due to side effects for a gain in LE.*



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Highlights:

- No evidence to support an end-of-life premium
- Type of health gain impacts on preferences for treatment received at end-of-life
- Gains in quality of life are preferred to gains in life expectancy at end-of-life
- Some differences are observed across the individual and social perspective
- Impact of beneficiaries' age on preferences is minor