VALUING HEALTH AT THE END OF LIFE

SUMMARY REPORT BY THE DECISION SUPPORT UNIT

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A paper published in *Social Science & Medicine* contains updated analyses of the data from this discrete choice experiment. This is available to download free-of-charge from:

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SUMMARY OF KEY FINDINGS

- The choices made by general public survey respondents about which patient to treat are dominated by the sizes of the health gains achievable from treatment.

- There is no evidence that respondents on average are willing to sacrifice aggregate health gains in order to give priority to the treatment of end of life patients.

- Most respondents choose to treat the patient who is closest to their end of life only when the benefits of treating that patient (in terms of QALYs gained) are similar to or greater than the benefits of treating the non-end of life patient.

- Whilst both types of gain appear to be important, the results from the regression analysis suggest that life-extending treatments are valued more highly than quality of life-improving treatments that offer similar gains in terms of QALYs.

- All else being equal, respondents are more likely to choose to treat a patient who has just found out about their illness than one who has known about their illness for some time.

1. INTRODUCTION

In 2009, NICE issued supplementary advice to its Appraisal Committees to be taken into account when appraising life-extending 'end of life' treatments.[1] The advice indicates that under certain circumstances it may be appropriate to recommend the use of such treatments even if they would not normally be considered to be cost effective. The current criteria[2] are:

1. The treatment is indicated for patients with a short life expectancy, normally less than 24 months;
2. there is sufficient evidence to indicate that the treatment offers an extension to life, normally of at least an additional three months, compared to current NHS treatment; and
3. the treatment is licensed, or otherwise indicated, for small patient populations.

The advice also states that the Appraisal Committees should be satisfied by the robustness of the estimates and assumptions used in the economic modelling.

The purpose of the project summarised here was to assess whether there is public support for giving higher priority to life-extending end of life treatments; and if so, how much additional weight should be attached to such treatments. The project focuses only on criteria 1 and 2 of the supplementary guidance.

1.1. PRELIMINARY STUDIES

We began by conducting an exploratory pilot study using a sample of 21 postgraduate students and members of non-academic staff at the University of Sheffield. In face-to-face interviews, we tested different ways of asking respondents about how they would set health care priorities. We used detailed probing questions to understand the rationales behind respondents' choices and to obtain feedback about different aspects of the study design.

Findings from the exploratory study provided the basis for a second study which used a more representative sample. Fifty members of the general public completed a priority setting survey in face-to-face interviews conducted by trained interviewers.

The sample was recruited by knocking on the doors of homes in randomly allocated postal areas in London and Kent. The survey questions asked respondents to indicate which of two hypothetical patients they would prefer to treat. The patients differed in terms of their life expectancy without treatment, amongst other things. In all cases the benefit from treatment was equivalent to half of a quality adjusted life year, or QALY.

In the second study we found some evidence of support for giving priority to the patient with shorter remaining life expectancy, but also observed that some respondents expressed the opposite view. Substantial preference for quality of life improvement over life extension for end of life patients was observed. We also found that respondents' preferences for giving priority to end of life patients were often reported to be driven by concern about how much time these patients have to 'prepare for death'.

Based on these findings, we conducted a larger scale study in order to estimate how much priority people are prepared to give to end of life treatments; and the extent to which people are willing to sacrifice overall health benefits in order to give priority to end of life treatments (the design of the first two studies did not permit this type of analysis since all of the questions involved choosing between treatments offering equal-sized benefits). The remainder of this report focuses on that larger scale study.

2. METHODS

There are a variety of techniques that can be used to elicit people's preferences for health care.[3] We chose to use the discrete choice experiment (DCE) technique on the basis that it is in widespread use in disciplines such as economics and market research; has substantial acceptance in the health economics community;[4] and has been used by several researchers to examine social preferences about health care (i.e. preferences about priority setting) in recent years.[5] Other choice-based methods such as time trade-off and standard gamble are suitable for assessing how people value different health states, but have not been used to elicit social values arising from health benefits for different people across society.

DCEs are typically implemented in surveys comprising a series of questions asking respondents to choose which of two alternatives they prefer. In our study, the choice is between treating two hypothetical patients described in terms of their prognosis (life expectancy without treatment and quality of life without treatment) and the benefits they could achieve from treatment (life expectancy gain and quality of life gain). The life expectancy attributes were included because these form the basis for criteria 1 and 2 in the current NICE guidance. The inclusion of quality of life attributes was driven by our previous findings that many people appear to favour the prioritisation of quality of life-improving treatments over life-extending treatments. The levels included, 100% and 50%, represent no problems (full health-related quality of life) and relatively severe problems, respectively. Table 1 lists the attributes and levels used in the study. Other potential attributes, such as the patient's age or past health, were considered but eventually omitted from the final study design in order to restrict the complexity of the choice tasks. We chose to focus on the attributes that are most salient to the policy context for NICE. Each respondent can only be expected to answer a small number of DCE questions (10 in our case) but by asking different questions to a large number of respondents, we can gather enough information to estimate the statistical relationships between the various attributes.

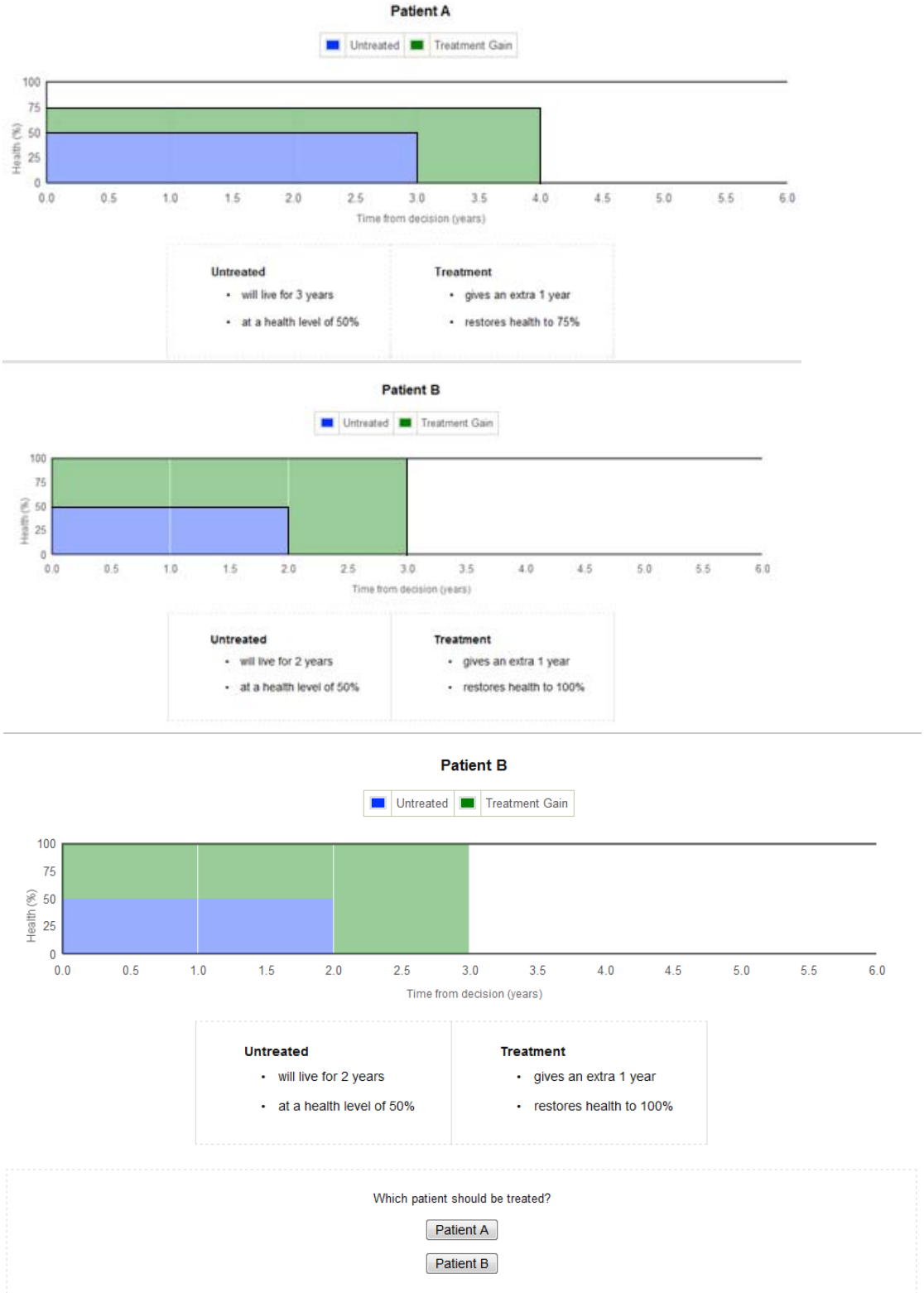
Table 1 Attributes and levels used in the study

Attribute	**Unit**	**Levels**
Life expectancy without treatment	months	3, 12, 24, 36, 60
Quality of life without treatment	%	50, 100
Life expectancy gain from treatment	months	0, 1, 2, 3, 6, 12
Quality of life gain from treatment	%	0, 25, 50

A web-based survey was developed in partnership with a software development company, EpiGenesys. The survey draws heavily on the design used in the social weightings study being conducted by the Department of Health EEPRU (currently in progress) and was piloted extensively before we confirmed the final design. Using a horizontal scale to represent life expectancy and a vertical scale to represent quality of life (described in the survey as 'health'), we constructed diagrams of the sort shown in Figure 1. Respondents were asked to indicate which of the two patients (patient A or

patient B) they thought should be treated, assuming that the health service has only enough funds to treat one of the two.

Figure 1 Example DCE task



The decision to use questions involving forced choices without a 'neither A nor B' option was driven by our concern that such an option may be used by respondents as a default ('opt-out') choice, thus providing a way to avoid taking time to make difficult decisions. The study design allowed us to control for the possibility of respondents reverting to a default choice, such as the patient presented first, every time they are unable or unwilling to choose between the patients. The patients, illnesses and treatments were described in generic terms (e.g. 'patient A', 'patient A's illness', 'treatment for patient A') due to concern that the use of labels (e.g. 'cancer') would induce biased responses based on respondents' personal experiences and interpretations.

We included two 'extension' tasks at the end of each set of 10 questions. The extension tasks were designed to examine whether respondents' choices are influenced by information about how long the patients have known about their illness (the results of our earlier studies had suggested that this may be a key factor in determining people's preferences regarding end of life scenarios).

Web-based surveys offer a cost-effective means of collecting a large amount of data in a very short period of time. They can be custom-designed to present information and collect choice data in a clear, user-friendly manner. Interviewer-led survey administration is often preferred because the interviewer can explain the instructions more fully if required,[6] and respondents may be more likely to give their full attention to the survey whilst under supervision. However, the use of interviewers can lead to forms of bias such as the interviewer giving subtle clues that influence the respondent towards certain preferences or choice strategies. With web-based surveys, the questions and instructions are presented in the same manner to all respondents.

The survey was administered on a sample of adult members of the general public in England and Wales, all of whom were members of a panel of a market research agency, ResearchNow. Respondents were compensated by way of 'reward points' which can be redeemed for gift vouchers or charity donations. A targeted invitation strategy (combined with quotas) was used to ensure that the sample was representative of the general population in terms of age, gender and social grade.[7,8]

Whilst most households in the UK now have access to the Internet,[9] there remain legitimate concerns about the genuine representativeness of any sample made up of members of an online panel. However, this issue is not specific to web-based data collection. The types of individuals who are willing to complete postal surveys or to allow interviewers into their homes for face-to-face interviews are similarly unlikely to be representative of the general population.

3. RESULTS

The survey was completed by 3,969 respondents. The response and completion rates were consistent with those of similar web-based surveys using online panels. By design, the sample was highly representative of the general population in terms of age, gender and social grade.

There are 110 possible combinations of the attributes and levels set out in Table 1 – that is, 110 different ways of describing a patient's prognosis and gains from treatment. We estimated the relative probability of choosing each of the 110. This enabled us to compare the combinations with higher probabilities (those which are likely to be most preferred overall) with the combinations with lower probabilities (those which are likely to be least preferred overall).

We found that the most preferred combinations all involve substantial health gains – a life expectancy gain of 12 months and/or a quality of life gain of 50%. Correspondingly, the least preferred combinations mostly involve a small life expectancy gain (one or two months) and no quality of life gain. The picture is clear – the larger the size of the QALY gains associated with a given combination, the more likely that combination is to be chosen. By contrast, there is no clear relationship between the number of QALYs without treatment in a given combination and the likelihood of that combination being chosen.

Table 2 Summary (average attribute levels) of the most and least preferred combinations

	LE without treatment (mths)	**QOL without treatment (%)**	**LE gain (mths)**	**QOL gain (%)**	**QALYs without treatment**	**QALYs gained**
10 most preferred	27	55	11	38	1.14	1.76

combinations						
55 most preferred combinations	27	57	7	31	1.27	1.22
55 least preferred combinations	27	65	2	10	1.49	0.29
10 least preferred combinations	28	50	1	3	1.18	0.06

Table 2 provides a summary of the most and least preferred combinations. This indicates that there is little/no difference between the highest and lowest ranked combinations in terms of life expectancy without treatment (i.e. the extent to which the combination describes the situation of an end of life patient). The difference between the highest and lowest ranked combinations is driven by differences in the sizes of the health gains from treatment.

In some of the DCE questions, both patients had the same level of quality of life without treatment and would benefit equally, in QALY terms, from treatment. Of the 994 respondents who encountered this type of scenario, 65% indicated that the patient with shorter life expectancy without treatment should be given priority over the patient with longer life expectancy without treatment. This is consistent with the results of our earlier studies in which QALY gains were held constant across the two patients.

Other questions involved choosing between giving a small life extension to a patient with short life expectancy without treatment and a larger life extension to a patient with relatively longer life expectancy without treatment (with no difference between the patients in terms of quality of life with or without treatment). Of the 1,995 respondents who encountered this type of scenario, 74% indicated that the patient with longer life expectancy should be treated (thereby implicitly implying a preference for larger health gains over giving priority to end of life treatments).

These general findings were supported by more sophisticated multivariate regression analyses. Furthermore, we defined a selection of respondent subgroups whose choices

may be expected to differ from those of the rest of the sample, such as those with experience of close friends or family with terminal illness; and those with responsibility for children. We found no substantial differences between the regression results for any of these subgroups and those for the full sample.

Results from the extension tasks showed that including information about the amount of time that patients have known about their prognosis has a clear impact on preferences – specifically, holding everything else constant, respondents are less likely to choose to treat a patient if they have known about their illness for two years than if they have only just found out about their illness.

4. DISCUSSION

Several previous studies have reported evidence of people being willing to sacrifice overall health gain in order to pursue objectives such as the prioritisation of those who are severely ill. However, many of these studies used small, non-random samples and involved elicitation methods that were not choice-based.[10,11] Furthermore, the empirical literature more commonly defines severity in terms of quality of life than in terms of life expectancy or proximity to death. To the best of our knowledge, our study is the first large scale examination of the preferences of the general public regarding end of life scenarios.

On the whole, the results indicate that choices about which patient to treat are influenced more by the sizes of the health gains achievable from treatment than by patients' life expectancy or quality of life in absence of treatment. Concern about the extent to which the patient is at the end of life appears to have a negligible effect. Whilst both types of gain appear to be important, the regression analysis indicates that life-extending treatments are valued more highly than quality of life-improving treatments that offer similar gains in terms of QALYs (in contrast to the results of our earlier study).

One caveat to these results is that all of the hypothetical scenarios depicted in this study involve relatively poor prognoses. Across all combinations, the patient who is

'best off' without treatment would still die within five years. It is not possible from these data alone to infer whether similar results would have been found had we asked respondents to compare very short life expectancies with much longer life expectancies that clearly cannot be described as 'end of life' (e.g. 20 years). Nevertheless, it is telling that according to the regression coefficients, the likelihood of choosing a given combination is much the same regardless of whether the patient's life expectancy without treatment is three, 24 or 60 months (the latter of which falls well beyond the definition of an end of life treatment according to the current criteria). This further emphasises the relative lack of importance that respondents place on end of life concerns compared to the size of the health gains offered by treatment.

The results from the extension tasks are consistent with findings from the earlier studies which suggested that the observed tendency to give priority to the end of life patient may be driven by concerns about the patient's ability to 'prepare for death' rather than the amount of time they have left to live *per se*. Further investigation of this issue is recommended.

Overall, the findings of this study suggest that the general public does not support giving higher priority to end of life treatments than to other types of treatments if the treatments being de-prioritised offer more substantial health gains. Since the supplementary advice was issued, some end of life treatments with incremental cost effectiveness ratios well in excess of the usual NICE threshold have been recommended for use in the NHS.[12] Based on the results of this study, we would question whether such a policy can be justified on grounds of social preferences and suggest that approving these technologies may result in a net loss to the NHS.

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