HEDS Discussion Paper 11/17

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Published paper

Valuing health at the end of life: an exploratory preference elicitation study

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December 2011

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Abstract

Background: In January 2009, the National Institute for Health and Clinical Excellence (NICE) issued supplementary advice to its Appraisal Committees to be taken into account when appraising life-extending 'end of life' treatments. This indicated that if certain criteria are met, it may be appropriate to recommend the use of end of life treatments that offer an extension to life even if their reference case incremental cost effectiveness ratios exceed the upper end of the range normally considered acceptable. However, the public consultation carried out by NICE revealed concerns that there is little evidence to support the premise that society is prepared to fund life-extending end of life treatments that would not meet the cost effectiveness criteria used for other treatments.

Objective: The aim of this exploratory study is to design and pilot an approach to examining whether the policy of giving higher priority to life-extending end of life treatments (as specified by NICE) than to other types of treatment is consistent with the preferences of members of the general public.

Methods: The survey used five scenarios to address the research question posed, each of which involved asking respondents to choose which of two hypothetical patients they would prefer to treat, assuming that the health service has enough funds to treat one but not both of them. The various scenarios were designed so as to control for age- and time-related preferences, and to examine the trade-off between giving life-extending and quality of life-improving treatments to end of life patients. Follow-up questions were used to elicit additional information about the reasons for respondents' choices. The survey was administered using face-to-face interviews.

Results: Interviews were completed by a convenience sample of 21 members of non-academic staff and postgraduate students at the University of Sheffield. The majority of respondents chose to treat the patient who is closest to their expected death or whose disease progression has been most sudden. Very few respondents expressed indifference or unwillingness to choose between the two patients.

Discussion: The most common driver of respondents' choices was a concern about how much time patients have to 'prepare for death', which indicates, *prima facie*, support for NICE's end of life policy. However, the ways in which information on patient age and the timing of treatment affected responses was not straightforward and in some cases contrary to the authors' conjectured predictions. The results also suggest that improving quality of life is at least as, if not more, important than extending life in the end of life scenario.

1 Introduction

1.1. Background

The National Institute for Health and Clinical Excellence (NICE) is responsible for producing advice on the use of new and existing health technologies within the National Health Service (NHS) in England and Wales. NICE's Technology Appraisals are guided by clinical and cost effectiveness analyses, usually using the quality adjusted life year (QALY) (Weinstein and Stason, 1977) to measure health outcomes. Current guidelines used by NICE (2008a) define a 'reference case' position whereby all equal-sized health gains are of equal social value, regardless of to whom they accrue and the context in which they are enjoyed. As well as evaluating the scientific evidence, those responsible for formulating NICE advice also need to make social value judgements (NICE, 2008b). These are concerned with what is appropriate and acceptable for society in delivering health care across the NHS.

In January 2009, NICE issued supplementary advice to its Appraisal Committees (the independent committees responsible for formulating NICE guidance based on the available evidence) to be taken into account when appraising life-extending, 'end of life' treatments (NICE, 2009a). This advice constitutes an explicit departure from the reference case position described above. It indicates that if certain criteria are met, it may be appropriate to recommend the use of treatments for terminal illness that offer an extension to life even if their base case cost effectiveness estimates exceed the range normally considered acceptable by NICE (Rawlins and Culyer, 2004). Some aspects of the supplementary advice were revised following a five week public consultation exercise (NICE, x2009c). The current criteria (NICE, 2009c) are reproduced below; if met, the Appraisal Committee is asked to consider the impact of giving greater weight to the health gains achieved in the later stages of disease.

C1. The treatment is indicated for patients with a short life expectancy, normally less than 24 months;

C2. 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;

C3. 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, and that all calculations should consider the cumulative population for each licensed indication.

This policy of placing additional weight on survival benefits in a small number of patients with short life expectancy due to terminal illness could be considered a valid representation of society's preferences. This would be the case if society would prefer to assign greater weight to the (accurately measured) health benefits accruing to a minority of end of life patients than to equal-sized health benefits accruing to most other patients groups. Public preference studies can provide meaningful information about society's views on resource allocation issues if the methods used are scientifically defensible (Ryan, et al., 2001). Indeed, NICE's own position on what is acceptable for society is informed by the work conducted by its Citizens' Council, a panel of the general public who meet biannually to discuss questions related to social values within health care (NICE, 2010).

However, the consultation in 2009 revealed concerns that there is little evidence to support the premise that society is prepared to fund life-extending treatments that would not meet the cost effectiveness criteria used for other treatments (NICE, 2009b). A recent review undertaken by the UK Department of Health (2010) also notes that "there is currently no robust evidence in the literature to support a particular magnitude of weighting" of health gains accruing to patients who are severely ill or at the end of life. NICE has acknowledged a need for further exploration of the issues (NICE, 2009b).

1.2.   Objectives

The aim of this exploratory study is to design and pilot an approach to examining whether the policy of giving higher priority to life-extending end of life treatments (as specified by NICE) than to other types of treatment is consistent with the preferences of members of the general public. The study focuses on criteria C1 and C2 of the supplementary advice above. C3 is not being examined, as its inclusion was not driven by concerns about society's preferences but rather by NICE's responsibility to support the development of innovative treatments that are anticipated to be licensed for small groups of patients (NICE, 2009b).

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4 Methodology

4.1. Survey instrument

The survey included choice tasks based on five scenarios (S1-S5). All respondents considered all five scenarios, in the same order. Each scenario presented respondents with information about two hypothetical individuals (patient A and patient B) who have been diagnosed with illness. This information was presented using a written description and a diagram (the scenarios are included in full in the Appendix, and summarised in Table 1). The respondents were asked to indicate which patient they would prefer to treat, assuming that the health service has enough funds to treat one but not both of them.

In S1, S2 and S3, treatment would extend the life of either patient A or patient B by six months; the patients differed in terms of age and the amount of time between diagnosis and expected death. These scenarios did not examine quality of life – respondents were advised that the patients' illnesses were asymptomatic and that treatment would not affect their quality of life. In S4 and S5, the illnesses were described as having a negative effect on quality of life, with both patients experiencing their final year of life at 50% of full health. In these scenarios, treatment would restore patient A to full health (with no effect on life expectancy) or extend the life of patient B by one year (with no effect on quality of life). In all cases, patients' prognoses and gains from treatment were described as if they were known with certainty.

Under the conditions that two years in 50% health is equivalent to one year in full health, and that a health gain today is equivalent to an equal-sized health gain in the future, both patient A and patient B will gain exactly the same amount of health from treatment in all five scenarios – half of a QALY.

Table 1: Summary of scenarios used in the survey

	S1	S2	S3	S4	S5
Without treatment					
Patient A life expectancy	10 years	1 year	10 years	1 year	10 years
Patient A quality of life	100%	100%	100%	50%	50%
Patient B life expectancy	1 year	1 year	1 year	1 year	1 year
Patient B quality of life	100%	100%	100%	50%	50%
Health gain from treatment					
Patient A life expectancy	+6 months	+6 months	+6 months	No change	No change
Patient A quality of life	No change	No change	No change	+50%	+50% [a]
Patient B life expectancy	+6 months	+6 months	+6 months	+1 year	+1 year
Patient B quality of life	No change	No change	No change	No change	No change
Undiscounted QALY gain from treatment [b]					
Patient A	0.5 QALY	0.5 QALY	0.5 QALY	0.5 QALY	0.5 QALY
Patient B	0.5 QALY	0.5 QALY	0.5 QALY	0.5 QALY	0.5 QALY
Age of patients	A & B are same age	A & B are same age	B is 9 years older than A	A & B are same age	B is 9 years older than A
Timing of scenario (when does the treatment decision occur)	At time of A & B's diagnosis	9 years after A's diagnosis	At time of A & B's diagnosis	At time of A & B's diagnosis	At time of A & B's diagnosis

[a] Refers to the quality of life improvement in the patient's final year of life
[b] Note that respondents did not see this information (the term 'QALY' was not used at any point in the survey)

Scenario S1 provides a simple test of whether respondents wish to give higher priority to the treatment of end of life patients, as the only difference between the two patients at the start of the scenario is that patient B has a shorter amount of time left to live than patient A (one year would be classed as 'short life expectancy' under criterion C1, whereas 10 years would not).

However, the scenario design is such that there may be reasons other than favouring the treatment of end of life patients for choosing to treat patient B in S1. First, without treatment patient A will be nine years older when they die than patient B will be when they die. Hence, a preference to treat patient B may be driven by a social preference for giving priority to the young. A review by Dolan *et al*. (2005) suggests that there is some evidence of public support for age weighting based on equity concerns. To address this issue, scenario S3 replicates S1 except that patient B is nine years older than patient A at the start of the scenario, which means that both patients will die at the same age without treatment.

Second, the benefit from treating patient A would not take place until 10 years into the future (compared to one year into the future for patient B). Hence, a preference to treat patient B may be driven by a preference for enjoying benefits sooner rather than later. In general, it is assumed by health care decision makers in the UK that society has a 'positive time preference', which means that the further into the future benefits are accrued, the lower the value of those benefits. To address this issue, scenario S2 replicates S3 except that patient A was diagnosed with their illness nine years prior to the start of the scenario, which means that the benefits from treating patient A would now take place one year into the future – the same as for patient B. Thus both patients are at the 'end of life' in S2, but patient B's progression to this state has been more sudden than that of patient A.

Considerations of quality of life are introduced in scenarios S4 and S5. S4 involves choosing between giving priority to treatments that extend life and treatments that improve quality of life. NICE's end of life criteria accommodate life extensions but not quality of life improvements. Scenario S5 combines elements of S3 and S4, and involves making a trade-off between giving priority to quality of life-improving treatments and giving priority to end of life patients.

Table 2 summarises our conjectured explanations for different responses to selected key combinations of scenarios. Note that 'time preference' refers to a preference for enjoying benefits sooner rather than later; 'age preference' refers to a preference for favouring the treatment of younger patients; and 'end of life preference' refers to a preference for favouring the treatment of patients with short remaining life expectancy who have little time to prepare for death due to the suddenness of disease onset. We conjecture that a supporter of NICE's end of life policy would choose to treat patient B in all scenarios, except perhaps S2 where it is unclear whether the supplementary advice applies (the criteria do not distinguish between sudden and non-sudden onset or progression of disease).

Table 2: Conjectured explanations for responses to selected combinations of scenarios

Scenario	Choice	Scenario	Choice	Conjectured explanation
1	A	2	A	Preferences run counter to end of life criteria
1	A	2	B	Reverse time and/or age preference
1	A	2	no pref	
1	no pref	2	B	
1	B	2	A	Time and/or age preference
1	B	2	no pref	
1	no pref	2	A	
1	B	3	B	End of life preference
1	A	3	A	Preferences run counter to end of life criteria
1	A	3	B	Reverse age preference
1	A	3	no pref	
1	no pref	3	B	
1	B	3	A	Age preference
1	B	3	no pref	
1	no pref	3	A	
1	B	3	B	End of life preference and/or time preference
2	A	3	A	Preferences run counter to end of life criteria
2	A	3	B	Time preference
2	A	3	no pref	
2	no pref	3	B	
2	B	3	A	Reverse time preference
2	B	3	no pref	
2	no pref	3	A	
2	B	3	B	End of life preference
4	A	5	A	Preference for quality of life-improving treatments
4	A	5	B	Time preference
4	A	5	no pref	
4	no pref	5	B	
4	B	5	A	Reverse time preference
4	B	5	no pref	
4	no pref	5	A	
4	B	5	B	Preference for life-extending treatments
3	A	5	A	Preferences run counter to end of life criteria
3	A	5	B	Preference for life-extending treatments
3	A	5	no pref	
3	no pref	5	B	
3	B	5	A	Preference for quality of life-improving treatments
3	B	5	no pref	
3	no pref	5	A	
3	B	5	B	End of life preference and/or time preference

4.2. Administration of survey

The survey was administered using face-to-face interviews by one of the authors (KKS). Respondents were given a paper questionnaire and were asked to read the description for each scenario before informing the interviewer of their answer. The aim was to elicit considered responses, so respondents were encouraged to 'think aloud' and to discuss the reasons for their choices with the interviewer. They were also permitted to amend their responses to earlier scenarios if they changed their mind during the course of the interview. The interviewer emphasised that a 'no preference' response was acceptable.

After completing the final scenario, the respondents were asked a series of probing questions designed to elicit qualitative information about the thinking behind their responses. Finally, the respondents were asked to indicate their age, gender and experience of serious illness. All interviews were audio recorded with the permission of the respondents.

4.3. Sample

The survey was administered on a convenience sample of members of non-academic staff and postgraduate research students at the University of Sheffield (excluding those in the Faculty of Medicine, Dentistry and Health). The target sample size of 20 respondents was determined on the basis of available time and resources. The sample was recruited using two methods:

1. Email invitation to participate sent to administrative, facilities, specialist and technical staff and postgraduate research students at the University of Sheffield (excluding those in the Faculty of Medicine, Dentistry and Health).

2. Recruitment flyer posted in areas used by facilities staff at the University of Sheffield.

Respondents received a £5 gift voucher to thank them for their participation.

The survey was given ethics approval by the Ethics Committee of the University of Sheffield's School of Health and Related Research.

5 Results

Interviews were completed by 21 respondents. The sociodemographic characteristics of the sample are presented in Table 3. The sample includes a higher proportion of females than in the general population (source: 2001 Census: Standard Area Statistics (England and Wales)). The age distribution is broadly similar to that of the general population when only individuals of working age (18 to 65 years) are considered. The range of socioeconomic classes included is much narrower than in the general population – for example, the sample excludes individuals who are unemployed and those who are employed in a professional role.

Table 3: Socio-demographic characteristics of the sample used

	#	%
Total	21	100
Gender		
Male	6	29
Female	15	71
Age		
20-29	4	19
30-39	6	29
40-49	4	19
50-59	6	29
60+	1	5
Experience of serious illness		
in themselves	1	5
in their family	17	81
in caring for others	7	33
Work status [a]		
Staff	20	95
Student	2	10

[a] One respondent was included under both categories (part-time postgraduate student, part-time administrative staff)

All interviews lasted for between 20 and 35 minutes. All 21 respondents completed all five scenarios and answered all of the relevant probing questions. Data saturation was reached after approximately 15 interviews.

5.1. Response data

Table 4 reports aggregate response data for each of the five scenarios. Four respondents preferred to treat patient B in all five scenarios.

Table 4: Aggregate response data for all scenarios

	S1	S2	S3	S4	S5
Prefer to treat patient A	3 (14%)	0 (0%)	6 (29%)	12 (57%)	6 (29%)
No preference	2 (10%)	4 (19%)	3 (14%)	3 (14%)	2 (10%)
Prefer to treat patient B	16 (76%)	17 (81%)	12 (57%)	6 (29%)	13 (62%)
Total	21 (100%)	21 (100%)	21 (100%)	21 (100%)	21 (100%)

Tables 5 to 9 provide cross-tabulations of the response data for the combinations of scenarios shown in Table 2.

Table 5: Cross-tabulation – S1 versus S2

S2 S1	Prefer A	No preference	Prefer B	Total
Prefer A	0	0	3	3
No preference	0	2	0	2
Prefer B	0	2	14	16
Total	0	4	17	21

Most respondents preferred to treat patient B in both scenarios S1 and S2. In general, they claimed (both whilst thinking aloud and when answering the probing follow-up questions) that the rationale behind their choices was the same in both scenarios, but that the choice in S2 was more difficult.

Three respondents preferred to treat patient A in S1. The main argument given for this was that it was 'not worth' giving an extra six months to someone with as short a time to live as patient B – rather, the life extension would be more valuable if given to someone who has more time to participate in society and who has a better opportunity to get their life in order (and could therefore make the most out of the additional time offered by treatment). All three respondents then switched to choosing to treat patient B in S2. Despite interviewer probing, the respondents were unable to articulate clearly the reasons for this shift in choices.

Two respondents switched from choosing to treat patient B in S1 to having no preference in S2, arguing that although patient A would have had more time to prepare for death than patient B in S2, it would be unfair to assume that they will have made good use of that time.

Table 6: Cross-tabulation – S1 versus S3

S3 S1	Prefer A	No preference	Prefer B	Total
Prefer A	3	0	0	3
No preference	0	2	0	2
Prefer B	3	1	12	16
Total	6	3	12	21

Of the respondents who preferred to treat patient B in S1, most also preferred to treat patient B in S3, although one switched to having no preference and three switched to choosing patient A. The respondent who switched to having no preference seemed to be worried by the presence of specific information on patients' ages – whilst thinking aloud, he said to himself: "is it justifiable to take these things into account?" He eventually said that he was unwilling to choose between the patients because he did not feel that it was appropriate to make prioritisation decisions based on current age, but if he was forced to choose then he could not help but take age into account, given the prominence of the information about age in the scenario description. He chose not to amend his responses to the previous scenarios.

Of the three respondents who switched to preferring to treat patient A in S3, two said that their decision was based on a concern for treating the young ("gives the chance to the younger patient"). The fact that both patients would die at the same age without treatment was not considered important by these respondents – their concern was about how old the patients are *now*. The third respondent who made this switch said that he had imagined that the patients were children, and that his preference for treating patient A was based on a desire or duty to protect the very young.

It should be noted that although most respondents quickly recognised that the only difference between S1 and S3 was the ages of the patients, the two that did not immediately recognise this both switched from preferring to treat patient B in S1 to preferring to treat patient A in S3. However, both respondents displayed a good level of understanding after clarification had been provided by the interviewer, so their choices should not be interpreted as having been driven by misunderstanding.

Table 7: Cross-tabulation – S2 versus S3

S3 S2	Prefer A	No preference	Prefer B	Total
Prefer A	0	0	0	0
No preference	1	2	1	4
Prefer B	5	1	11	17
Total	6	3	12	21

Of the respondents who preferred to treat patient B in S2, approximately two thirds preferred to treat patient B in S3; the majority of the remaining respondents switched to preferring to treat patient A. One respondent chose to treat patient B in S3 but had no preference in S2. His reasoning was that patient A could be viewed as the better off of the two patients in S3 (and indeed in S1) due to having nine extra years to prepare for death, but it seems unfair to take this into account in S2 as patient A may not have made good use of this time.

Five respondents went further, choosing to treat patient A in S3. Some of these respondents did so due to a concern for the young (described above in the discussion of S1 versus S3), whilst the others did so due to a belief that the life extension should be given to the patient who has more time to participate in society (described above in the discussion of S1 versus S2).

Table 8: Cross-tabulation – S4 versus S5

S5 S4	Prefer A	No preference	Prefer B	Total
Prefer A	6	1	5	12
No preference	0	1	2	3
Prefer B	0	0	6	6
Total	6	2	13	21

Just over half of the respondents preferred to treat patient A in S4, which indicates that they prefer to give priority to quality of life-improving rather than life-extending treatments for patients with one year of remaining life expectancy. Half of those respondents then either switched to preferring to treat patient B or having no preference in S5. The likely explanation for these combinations of choices is that whilst a preference for quality of life-improving treatments continues to exist in S5, this preference is outweighed by the preference to prioritise the treatment of those with short remaining life expectancy. In general, the comments made by respondents support this explanation.

Table 9: Cross-tabulation – S3 versus S5

S5 S3	Prefer A	No preference	Prefer B	Total
Prefer A	4	0	2	6
No preference	0	1	2	3
Prefer B	2	1	9	12
Total	6	2	13	21

Of the 12 respondents who appeared to show a preference for prioritising end of life treatments by choosing to treat patient B in S3, most also chose to treat patient B in S5. Three respondents switched to preferring to treat patient A or having no preference in S5 – all three claimed that the preference for quality of life-improving treatments outweighed (or in one case, cancelled out) the preference for prioritising end of life treatments in this scenario.

5.2. Responses to probing questions

1. How did you find the survey?

Almost all of the respondents said that they found the survey interesting. Some mentioned that the scenarios were unpleasant to think about, but none suggested that they regretted taking part. This supports the interviewer's observation that all respondents were highly engaged throughout the interviews.

2. To what extent do you feel you understood the questions being asked?

Almost all of the respondents said that they felt that they understood the questions well (although in a few cases this was not always consistent with the interviewer's observation that they were hesitant or confused at some points during the interview). Where misunderstanding did occur, respondents typically blamed their inattentiveness rather than the way in which the information had been presented.

3. What did you think about the graphical illustrations of the scenarios?

Most respondents said that the diagrams were helpful. A few respondents were particularly approving, claiming that they relied on them heavily. On the other hand, some respondents said that they did not use them at all. A few respondents indicated that they were confused by the distinction between health without treatment and health gains from treatment in the diagrams.

4. How difficult did you find it to decide on your answers?

Some respondents said that they found it very difficult to decide without more information (in particular, on whether both patients were children or adults); others said that they found it easier to make decisions without such complicating factors.

The general consensus was that scenarios S4 and S5 were more difficult to answer than the previous three scenarios. This was due in part to respondents not having clear or considered reasons for preferring either quality of life improvement or life extension, and in part to the lack of clarity about what exactly is meant by '50% health'.

5. In some of the tasks, you preferred to treat neither patient A nor patient B. Can you tell me a bit more about why you were unwilling or unable to choose between them?

Only six respondents expressed 'no preference' in any of the scenarios. One respondent declined to choose between patient A and patient B in any of the scenarios. She felt that both patients were equally entitled to treatment, and that differences between the patients are not relevant in terms of their claims to health care. Other reasons given for expressing no preference included: not having enough information to justify choosing between the two patients; belief that the patients are equally worthy of treatment; and lack of clarity about what is meant by '50% health' (one respondent claimed that if 50% health still allows you to 'enjoy what's left', then she would prefer to treat patient B in S4, but if 50% health would prevent you from enjoying your remaining life expectancy, then she would prefer to treat patient A).

6. When deciding which patient to treat, what sorts of things did you take into account?

Aside from the factors discussed in probing questions 7-10 (see below), a number of other considerations were mentioned in response to this question. Several respondents said their thinking had been guided by personal experiences of seeing friends and family in serious ill health. Several respondents spoke to trying to put themselves 'in the shoes' of the hypothetical patients – that is, trying to imagine what they would want for themselves if they were in the position of patient A or patient B.

A number of respondents referred to the idea of treatment giving patient B a greater 'proportional' or 'percentage' gain in life extension. In S1, for example, these respondents claimed that their

preference for treating patient B would hold as long as patient B was gaining proportionately more time than patient A (i.e. more than 2.6 weeks). Some respondents referred to an objective of achieving fairness and/or equality, suggesting that the treatment should be given to whichever patient is deemed to be the 'worse off'.

Regarding scenarios S4 and S5, some respondents justified their preference for treating patient A by explaining that whereas they could reasonably assume that 'everyone wants better quality of life', it could not be assumed that 'everyone wants to live longer'.

Other considerations mentioned included: 'suffering', 'how much one treasures life', the personal and family circumstances of the patients, how able patients are to adapt to the idea that they are dying, and any other health problems that the patients might be facing.

7. When deciding which patient to treat, did you think about how old the patients would be when they die?

Most respondents said that they thought about age but did not take it into account when making their choices. As described above, those respondents that did explicitly take age into account tended to be more concerned about age at treatment than in age at death. Some respondents felt strongly that age should not be used as a priority setting criterion.

8. When deciding which patient to treat, did you think about whether the patients would have sufficient time to 'prepare for death'?

Almost all of the respondents said that they took this factor into account. Of those that did not, one respondent questioned whether having ten years to live before a specified time of death is a good or a bad thing (due to disutility from knowing that you are going to die). Another respondent said that he was "not from a culture that does great death preparation" and therefore questioned the value of having extra 'time to prepare'.

9. When deciding which patient to treat did you think about the fact that some of the benefits of treatment wouldn't take place until far away into the future?

Almost all of the respondents answered no to this question, claiming that the only way in which timing matters is in terms of how much time the patients have in good health before reaching their end of life. A few respondents said that when considering longer timeframes it would be reasonable to hope for the possibility of medical breakthroughs or further treatment (although the interviewer emphasised that it should be assumed that further treatment would not be possible if the respondents brought this up whilst considering the scenarios).

10. Thinking about scenarios 4 and 5, when deciding which patient to treat, did you think about the possibility that being in only 50% health would involve being a burden on others or on society?

A slight majority of respondents said that they did not think about this possibility. Some respondents said that they were aware of but specifically ignored this issue as they were not asked to consider it. A few respondents rejected the idea that people in poor health can be described as a burden. Of those that considered this possibility, only one respondent suggested that it had been a deciding factor in his choices. Considerations mentioned by respondents included: the need for caregivers;

the inability to work (and associated loss of income and production); and the cost of adjusting one's home to accommodate a disabled person.

11. Might your answers have been different if you had been asked to choose which of two groups of patients to allocate health care funding to, as opposed to which of two patients to treat?

Most respondents said that considering groups would make no difference – the principles behind their decision making would remain the same. Some suggested that it would be easier to make decisions when considering groups, as this would make the scenario more impersonal and therefore less 'heart-wrenching'. Others suggested that there would be a case for dividing resources amongst groups (with an even or uneven split), something that was not possible in the single treatment, two patient scenario.

12. "Society has a special responsibility towards those who have a short time left to live." What are your thoughts about this statement?

Most respondents agreed with this statement, although several were unclear about the definitions of the words 'society' and 'special'. A few respondents strongly disagreed with the statement, claiming that those with a short time left to live are no more important or worthy of treatment than anyone else. Several respondents claimed that caring for those at the end of life is not exclusively a health care system responsibility, arguing that society should focus on palliative care and objectives relating to ensuring sociability, comfort and dignity, rather than on life-extending health care technologies.

6   Discussion

This study has piloted an approach to eliciting public preferences regarding life-extending, end of life treatments. The purpose of the study was not to elicit preferences that can readily be used for decision making, but to inform the design and methods of larger scale, random sample studies. The study was completed without any major problems, and offers support for the use of face-to-face interviews for this type of survey. The results provide some indication of public support for a policy which prioritises the treatment of patients with short remaining life expectancy and whose disease onset has been sudden. However, all findings should be interpreted with caution, given the small sample size and exploratory nature of the study. Furthermore, even if robust evidence of public support for giving special weighting to end of life treatments is found, there are a number of challenges involved in incorporating such equity weights into cost effectiveness analysis (Wailoo, Tsuchiya and McCabe, 2009). The study highlighted a number of issues that warrant further investigation, some of which are examined below.

6.1.   Unexpected rationales for choices

The comments made by respondents as they completed the survey indicate that a number of rationales exist for making priority setting choices that had not been picked up by our conjectured explanations in Table 2. For example, we had not anticipated that any respondents would prefer to treat patient A in S1. Yet three respondents did, arguing that it would be more valuable to give a life extension to someone who has more time to participate in society and who has a better opportunity to get their life in order. The fact that these respondents did not consider six months to be a worthwhile life extension for individuals with only one year left to live indicates that they would also consider the three month minimum standard applied in the supplementary criteria to be insufficient.

It was hypothesised that if respondents switched from choosing to treat patient B in S1 to having no preference in S2, then the S1 choice will have been driven by time and/or age preferences. In fact, the two respondents who made this switch gave a different explanation, appearing to treat the additional time that patient A has as a 'sunk benefit'. Their argument was that if a benefit is yet to be enjoyed then it should be taken into account, but it has already passed then it should not. We had not anticipated that respondents would apply this 'sunk benefit' concept in their decision making.

Finally, we had anticipated that those respondents who used age information to decide which patient to treat would tend to choose to treat the patient who would be younger at their time of death. This would be consistent with a 'fair innings' type argument (Williams, 1997) since the patient who would die younger in absence of treatment will have enjoyed a smaller amount of lifetime health, *ceteris paribus*. In fact, some respondents sought to give priority to the patient who was younger *at the time of treatment*.

These examples show that people support a variety of principles of justice and rationing that may not be immediately obvious to researchers. It is therefore important to capture not only respondents' choices but also the reasons for those choices in order to understand fully the nature of their preferences.

6.2.   Having no preference

Very few respondents said they had no preference between treating patient A and patient B. This (lack of) preference accounted for only 13% of all choices made. It may be the case that respondents' observed reluctance to express indifference was driven by the survey design. Beneath the written description and diagram for each scenario in the paper questionnaire, the prompt "Would you prefer to treat patient A or patient B?" was included. Although the interviewer made efforts to emphasise that a 'no preference' choice was acceptable, both at the beginning of the interview and whenever respondents displayed uncertainty, the fact that this option was not included in the written instructions may have resulted in a framing effect. In future studies, we would recommend that any 'no preference' option should be included explicitly and given the same weight as competing options in any written and oral instructions. It is important to include a 'no preference' option, as this represents a defensible position for respondents who believe that end of life treatments should be given neither higher nor lower priority than any other treatments.

6.3.   Interpreting '50% health'

Some respondents appeared to find the concept of '50% health' confusing. The reason that a percentage weight was used rather than a qualitative label was to minimise ambiguity about the severity of the imperfect health state in relation to perfect health. In practice, however, the way in which '50% health' was interpreted also differed from respondent to respondent. When describing their reasons for choosing to treat patient A in S4, some respondents appeared to be valuing one year in full health more highly than two years in 50% health, and it was not always clear whether this was based on a social preference or on a belief that the former is more desirable than the latter for the patients themselves. A possible solution for this would to emphasise the fact that 50% health should be interpreted as half as desirable as perfect health – for example, by adding the sentence: "Patients have told us that being in this health state for two years is equally desirable as being in full health for one year; we will therefore call this 50% health".

7   Conclusion

In this paper we have described an exploratory study which examined whether there is support for giving higher priority to life-extending end of life treatments. The study was conducted successfully, which indicates that a similar approach can be used for a large scale study using a sample that is representative of the general population.

8   Acknowledgements

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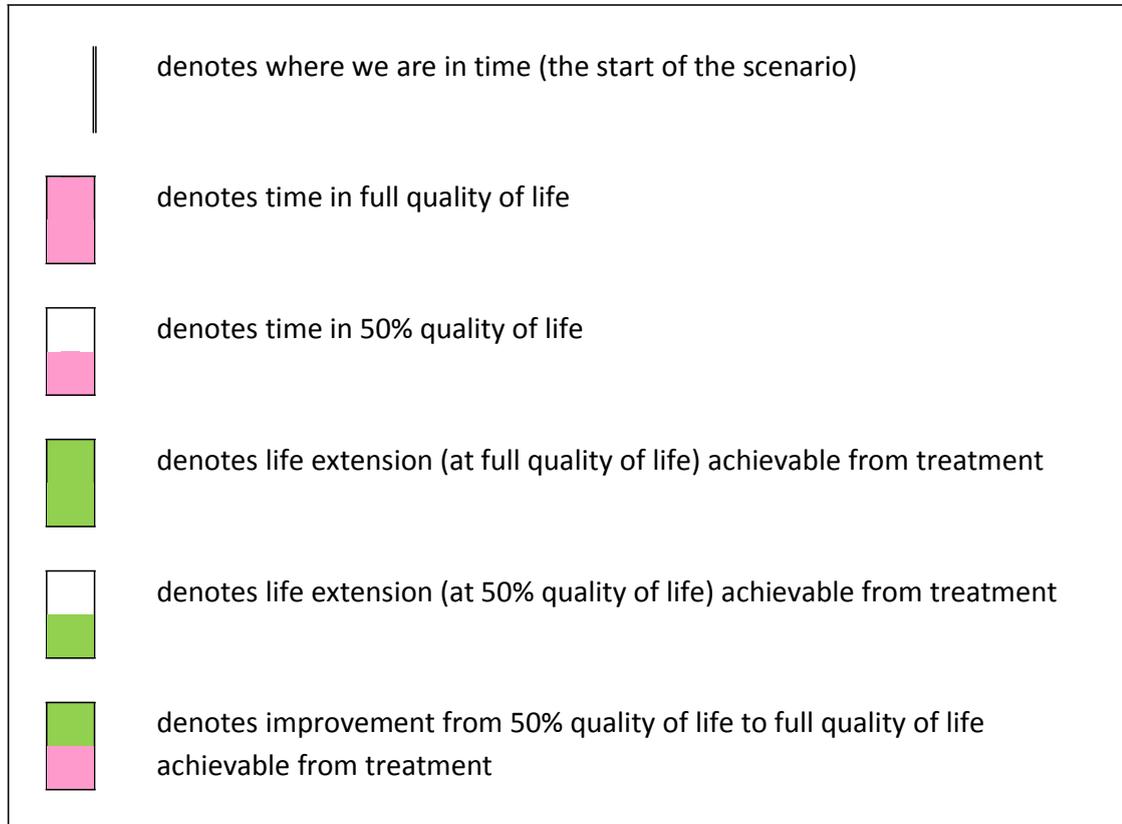
(cover page, followed by scenarios S1-S5)

Health care priority setting preference project

ID: _____

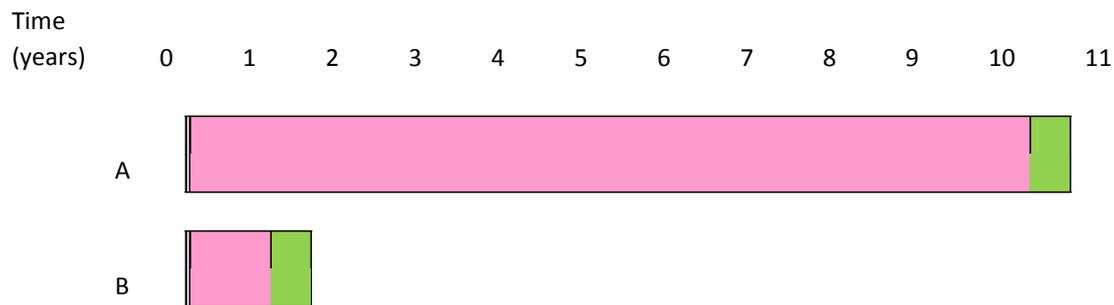Date: _____/ __ __ / __ __

Time: _____: __ __

There are five scenarios in this questionnaire. Please read the description for each scenario carefully. Please let the interviewer know if you have any questions at any stage of the interview. Remember, there are no right or wrong answers – we are simply seeking your views.

Key to diagrams:

denotes where we are in time (the start of the scenario)

denotes time in full quality of life

denotes time in 50% quality of life

denotes life extension (at full quality of life) achievable from treatment

denotes life extension (at 50% quality of life) achievable from treatment

denotes improvement from 50% quality of life to full quality of life achievable from treatment

Scenario 1

Time
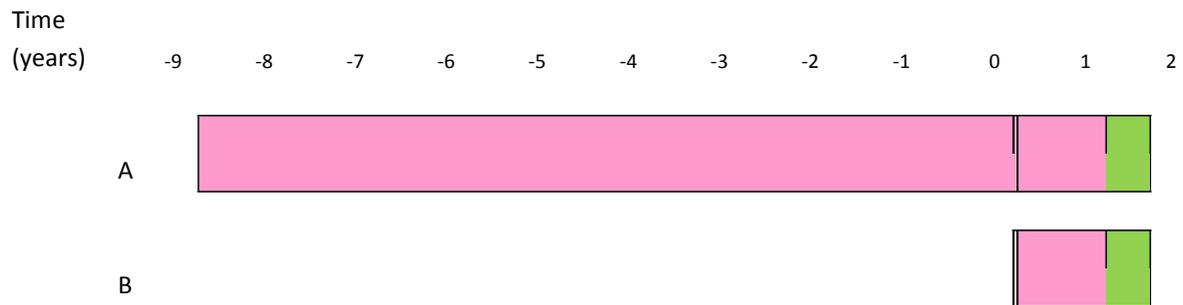(years)　0　1　2　3　4　5　6　7　8　9　10　11

A

B

Consider two patients, patient A and patient B, who are the same age as each other. Suppose that both patient A and patient B have just been diagnosed with illnesses. The illnesses are asymptomatic – that is, they have no effect on the patient's quality of life.

Patient A will live for 10 years, from today, before dying. Patient B will live for 1 year, from today, before dying.

There is a treatment, which, if taken today, would extend the life of either patient A or patient B by 6 months. Treatment would not affect either patient's quality of life. However, the health service has only enough funds to treat one of the two patients, and there are no alternative treatments available (furthermore, the nature of the illnesses is such that further treatment will not be possible if either patient is not treated today).

Would you prefer to treat patient A or patient B?

Scenario 2

Time
(years)

Consider two patients, patient A and patient B, who are the same age as each other. Patient B has just been diagnosed with an illness; patient A has an illness which he/she was diagnosed with 9 years ago. Both illnesses are asymptomatic – that is, they have no effect on the patient's quality of life.

Patient A was told 9 years ago that he/she will live for 10 years before dying. This means that from today, he/she will live for 1 year before dying.

Patient B has been told that he/she will live for 1 year, from today, before dying.

There is a treatment, which, if taken today, would extend the life of either patient A or patient B by 6 months. Treatment would not affect either patient's quality of life. However, the health service has only enough funds to treat one of the two patients, and there are no alternative treatments available (furthermore, the nature of the illnesses is such that further treatment will not be possible if either patient is not treated today).

Would you prefer to treat patient A or patient B?

Scenario 3
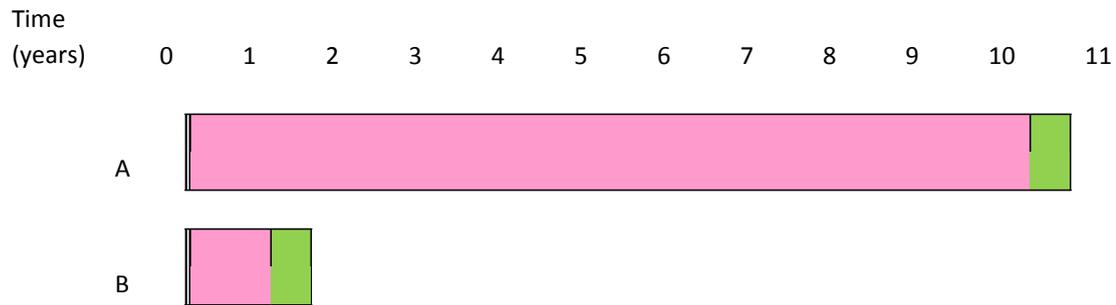
Time
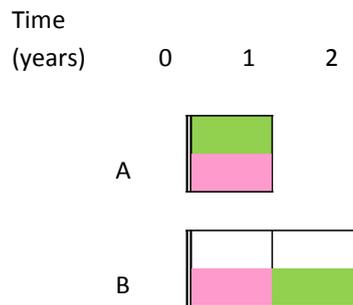(years)   0   1   2   3   4   5   6   7   8   9   10   11

Consider two patients, patient A and patient B. Suppose that both patient A and patient B have just been diagnosed with illnesses. The illnesses are asymptomatic – that is, they have no effect on the patient's quality of life.

Patient A will live for 10 years, from today, before dying. Patient B will live for 1 year, from today, before dying. Patient B is 9 years older than patient A, so both patients will die at the same age without treatment.

There is a treatment, which, if taken today, would extend the life of either patient A or patient B by 6 months. Treatment would not affect either patient's quality of life. However, the health service has only enough funds to treat one of the two patients, and there are no alternative treatments available (furthermore, the nature of the illnesses is such that further treatment will not be possible if either patient is not treated today).

Would you prefer to treat patient A or patient B?

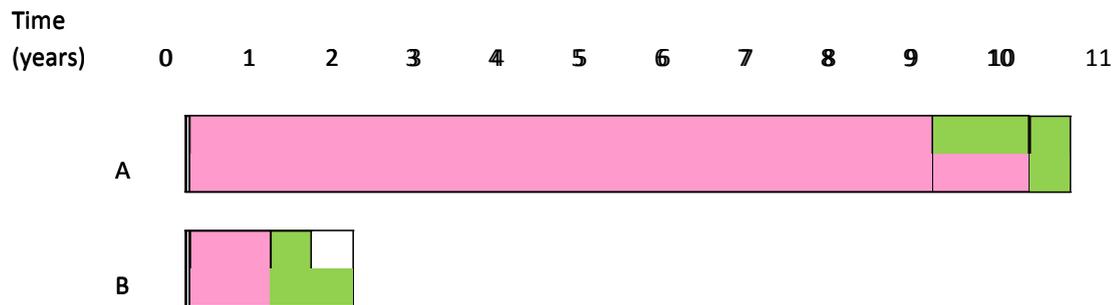# Scenario 4

Time
(years)   0   1   2

Consider two patients, patient A and patient B, who are the same age as each other. Suppose that both patient A and patient B have just been diagnosed with illnesses.

Patient A will live for 1 year, from today, before dying. Patient B will also live for 1 year, from today, before dying. The illnesses have a negative impact on quality of life – both patients will experience their final year of life at 50% of full health.

There is a treatment, which, if taken today, would restore patient A to full health. It would not affect patient A's life expectancy. Another treatment would, if taken today, extend the life of patient B by 1 year. It would not affect patient B's quality of life, so patient B's remaining life would be lived at 50% health. The health service has only enough funds to treat one of the two patients, and there are no alternative treatments available (furthermore, the nature of the illnesses is such that further treatment will not be possible if either patient is not treated today).

Would you prefer to treat patient A or patient B?

Scenario 5

Time
(years) 0   1   2   3   4   5   6   7   8   9   10   11

Consider two patients, patient A and patient B. Suppose that both patient A and patient B have just been diagnosed with illnesses.

Patient A will live for 10 years, from today, before dying. Patient B will live for 1 year, from today, before dying. The illnesses have a negative impact on quality of life – both patients will experience their final year of life at 50% of full health. Patient B is 9 years older than patient A, so both patients will die at the same age without treatment.

There is a treatment, which, if taken today, would restore patient A to full health in her final year of life. It would not affect patient A's life expectancy. The same treatment would, if taken today, extend the life of patient B by 1 year. It would not affect patient B's quality of life, so patient B's remaining life would be lived at 50% health.

The health service has only enough funds to treat one of the two patients, and there are no alternative treatments available (furthermore, the nature of the illnesses is such that further treatment will not be possible if either patient is not treated today).

Would you prefer to treat patient A or patient B?

Scenario 5