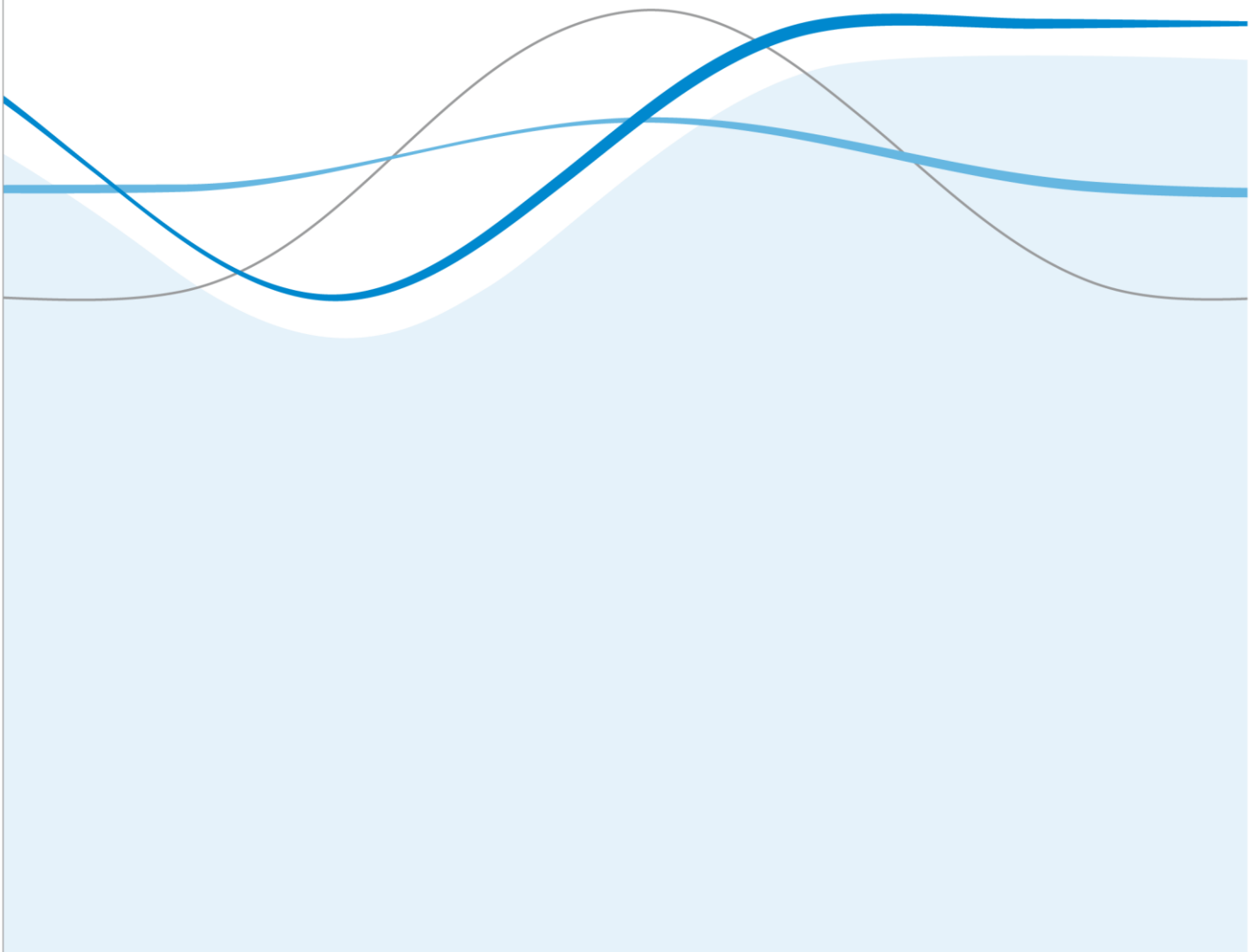


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February 2015

Koonal Shah, Amanda Chapman, Nancy Devlin, Paul Barnsley



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Office of Health Economics

February 2015

Consulting Report

Commissioned by the Pharmaceutical Oncology Initiative

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## **EXECUTIVE SUMMARY**

### **Background and objectives**

- Stated preference studies are increasingly being used to understand the views of members of the general public about the relative importance of different criteria for making health care priority setting decisions. A recent example is the study commissioned by the UK Department of Health and undertaken by its Policy Research Unit in Economic Evaluation of Health and Care Interventions (EEPRU). The EEPRU sought to obtain weights for burden of illness that could be applied to new technologies and displaced activities.
- Such studies typically involve presenting survey respondents with priority setting scenarios involving hypothetical patients and medical conditions. In order to minimise bias, researchers usually present the scenarios in an abstract manner and provide limited descriptive information. This has led to concerns that the answers given by respondents do not reflect those that they might have given had they been better informed about the nature of the hypothetical medical conditions and the patients affected by them. It is therefore legitimate to ask whether the findings of such studies would have been different if the scenarios had been presented in “real-world” rather than abstract terms (i.e. in terms that general public respondents would be more familiar with).
- A further concern associated with public preference studies is that it is unclear whether the respondents would agree with the policy implications of their responses to the abstract choice tasks. The extent to which respondents in social preference studies agree with researchers’ interpretations of their responses has received only limited attention in the health economics literature to date.
- The primary aims of this study are:
  - to examine the impact of presenting hypothetical priority setting scenarios in “real-world” rather than abstract terms;
  - to examine the extent to which the study respondents agree with the policy implications of their responses to stated preference tasks.

### **Methods**

- A stated preference survey was designed to elicit data on people’s preferences regarding health care priority setting. The questions formed the basis for two focus group discussions and a self-completion survey administered over the Internet. The survey comprised a series of priority setting scenarios. In each scenario, respondents were presented with information about pairs of hypothetical patient groups and were asked which group they thought should be treated if the health service had enough funding to treat one of the groups but not both.
- The scenarios covered a range of priority setting challenges. For example, one scenario involved choosing between giving a one-year life extension to patients with three years of life expectancy without treatment and a shorter (six-month) life extension to patients with a shorter life expectancy (six months) without treatment.

- The scenarios presented information about the patients, medical conditions and treatments in an abstract manner. Text descriptions were presented using short bullet points, alongside conceptual diagrams which used shaded blocks to represent the situations of the patients. Quality of life information was presented using percentage weights. Information about age was not presented explicitly, though the scenarios did describe how long the patients would live for if they did not have their medical conditions.
- In the Internet survey, two “real-world” scenarios were included in order to assess the impact of using an alternative presentation of the information. These scenarios corresponded directly to two of the abstract scenarios that respondents had considered earlier in the survey. In the real-world scenarios, the conceptual diagrams were omitted and the text descriptions were more detailed and informative. The text in these scenarios stated the ages of the patients explicitly and included qualitative descriptions of the patients’ quality of life (e.g. describing their levels of pain/discomfort and anxiety/depression). Neither the abstract scenarios nor the real-world scenarios mentioned any specific medical conditions by name.
- After completing the questions relating to the scenarios, respondents were presented with “policy implication questions” designed to test whether they agreed with possible interpretations of their choices. These involved asking the respondents whether they agreed with a series of general policy statements (regarding how the health service should make prioritisation decisions) that appeared, *prima facie*, to correspond to certain responses to the earlier choice tasks. Similar exercises were undertaken both in the focus groups and in the Internet survey.
- For the focus groups, members of the general public were recruited to take part in two separate group discussions. The focus groups were moderated by an expert in qualitative research methods. Participants completed an adapted version of the survey and were encouraged, for each question, to discuss their views with each other before declaring their “final” choice.
- The Internet survey was administered on a broadly representative sample of members of the general public. All of the respondents were members of an online panel. Routing was used to link respondents’ scenario question responses to the corresponding general statements in the policy implication questions.

### **Results – focus groups**

- Two focus group discussions were conducted in Gunnersbury, London in May 2014.
- Participants in the focus groups were often divided in opinion about which patient group should be treated in the hypothetical scenarios. Some participants consistently sought to give priority to the group that they considered to be worse-off, with several citing a desire for a “level playing field”. Others consistently chose to treat the group that stood to gain the most from treatment. A variety of priority setting criteria were mentioned and used by participants to justify their choices.
- Only one participant mentioned the information provided about patients’ life expectancies if they did not have their medical conditions, even though this attribute

was described in the very first text bullet point in each scenario. The participants rarely mentioned the ages of the patients when considering the scenarios, and we did not observe any attempt by participants to infer the ages of the patients from the information about their life expectancies without the medical conditions.

- When faced with the policy implication questions, a number of participants claimed to agree with statements other than the ones that we might have predicted from their responses to the scenario questions. Some participants agreed with the statement “The health service should give priority to treating the patients who are very ill”, despite choosing *not* to treat the severely ill patient group in the corresponding scenario. It seems as though some participants found it difficult to reconcile their ideological views about the purpose of the health service with the types of trade-offs that need to be made when making prioritisation decisions.
- The participants were less likely to agree with the statement “The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition” than we might have predicted from their choices in the corresponding scenario. This can be explained largely by participants’ differing interpretations of the wording used in the policy statements. For example, one participant suggested that the term “soon” was too vague to justify agreeing with the statement, even though they appeared broadly to support the spirit of the policy.

### **Results – Internet survey**

- The Internet survey was completed by 400 respondents in May 2014.
- Just as in the focus groups, the Internet survey respondents were divided in opinion about which patient group should be treated in most of the hypothetical scenarios. Indeed, when the option to “split the funding evenly” was offered to respondents, this was always the most popular choice.
- In the scenarios that involved choosing between one patient group that has a larger *absolute* shortfall and another group that has a larger *proportional* shortfall, a slight majority of respondents (between 56.3% and 59.7%) preferred to treat the group with a larger *absolute* shortfall. This majority increased to 70.3% when the information was presented using real-world rather than abstract terms.
- In one of the scenarios that involved choosing between giving a one-year life extension to patients with three years of life expectancy without treatment and a six-month life extension to patients with six months of life expectancy without treatment, 59.2% of the respondents chose to give priority to the patients with longer life expectancy. The proportion of respondents choosing to treat this group increased to 67.0% when the same scenario was presented in real-world terms, which involved stating explicitly that the patients in both groups were 75 years old.
- When comparing the results for the abstract scenarios with those for the corresponding real-world scenarios, we observe a statistically significant relationship between the framing of the information and the propensity to choose to treat a particular patient group. This indicates that presenting information in alternative formats can have a meaningful impact on the results generated. It is possible that

the shifts in responses were driven by the explicit description of the ages of the patients in the real-world scenarios.

- The majority of respondents agreed with our interpretations of their earlier responses in each of the three policy implication questions. However, only 86 out of the 300 respondents agreed with our interpretations in all three questions. Three respondents *disagreed* with our interpretations in all three questions.
- Most of the respondents used the open-ended text boxes provided to explain their choices when invited to do so. A number of respondents noted that each case is different so it is difficult or inappropriate to make general statements about health service priorities such as those presented in the policy implication questions. Other respondents suggested that the acceptability of the statements depends on the definitions of terms such as “very ill” and “health gains”.
- Several respondents suggested that whether or not the health service should give priority to extending the lives of patients who are expected to die soon depends on the quality of the life extensions and the ages of the patients.
- Some respondents felt that age is not a relevant priority setting criterion, with a number of respondents expressing this view very strongly. Others believed that younger patients should be given priority, either because they felt that the young should be given the opportunity to achieve the same lifetime health as the old, or because the young are relatively productive and more able to contribute to society.
- A number of respondents who disagreed with our interpretations in the policy implication questions expressed the view that all illnesses should be treated the same and that all patients should be given a fair chance of receiving the treatment that they require.

### **Discussion points**

- The results of this study show that people’s stated preferences regarding hypothetical scenarios are influenced by the way in which the information is presented to them. They also show that people do not always agree with the policy implications of their responses to the stated preference tasks.
- Participants in the focus groups were more likely to disagree with our interpretations of their choices than were respondents in the Internet survey. This may reflect differences in the ways in which the policy implication questions were structured between the two modes. It may also reflect the discursive nature of the focus groups, in which participants were encouraged to express their views and disagreements.
- A common theme arising from the analysis of the policy implication questions is that it is unwise to make general statements about people’s priority setting preferences based on their responses to very specific choice tasks. Their answers may be driven by specific attributes and parameters described in the choice tasks.

- The results suggest that if researchers wish to understand whether people have particular preferences regarding the prioritisation of patients according to their age, then the information about age should be expressed explicitly rather than implicitly. Only one of the focus group participants appeared to have recognised the implicit age-related differences between two of the scenarios.
- It is noteworthy that respondents in the Internet survey were more likely to choose to give a longer life extension to non-end of life patients (as opposed to a shorter life extension to end of life patients) when it was made explicit that patients in both groups were 75 years old.
- A number of participants and respondents expressed views that treating the severely ill is the primary purpose of the NHS. However, we would not necessarily have interpreted this attitude from their responses to the choice tasks. It is possible that the importance that people place on giving priority to the severely ill has been understated in existing research because of the abstract nature of the choice tasks typically used by researchers.
- Although the purpose of the study was not to elicit preference data that can be used directly to generate a set of equity weights, some of results are relevant to the debate around the potential introduction of a value-based system for assessing health technologies in the UK.
- A key message that can be drawn from the results of this study is that these kinds of stated preference studies are subject to important framing effects. Researchers often seek to interpret observed responses to stated preference tasks and to use the results to draw conclusions about the types of policies that the study respondents would support. However, whether the respondents actually consider these policies to be acceptable or not will depend on whether they have interpreted the concepts underpinning the choice tasks in the same way as the researchers have. Caution is therefore required when using the results of social preference studies to drive public sector decisions, as the results can be sensitive to the methods used.



## **1. BACKGROUND**

In 2010, the UK Government set out plans for a new value-based approach to the pricing of branded medicines. The proposed scheme sought to give higher priority to “the treatments that society values most” (Department of Health, 2010, p.13). In order to ensure that the proposed scheme reflected society’s preferences, the Department of Health commissioned its Policy Research Unit in Economic Evaluation of Health and Care Interventions (EEPRU; led by researchers at the University of Sheffield) to conduct an empirical study of public preferences to obtain weights for burden of illness that could be applied to new technologies and displaced activities (Rowen et al., 2014). The study took the form of a large-scale discrete choice experiment administered using an Internet self-completion survey, with no opportunities for respondents to discuss their views with each other or with interviewers.

When designing the survey, the EEPRU team sought to minimise bias by presenting scenarios in a neutral, abstract manner; and by avoiding the use of labels and descriptive information (e.g. referring to patients’ quality of life using percentages). This has led to concerns that the answers given by respondents do not reflect those that they might have given had they been better informed about the nature of the hypothetical medical conditions and the patients affected by them. It has been shown in previous work that people’s responses in stated preference studies are highly influenced by framing effects (Shah and Devlin, 2012). It is therefore legitimate to ask whether the findings of such studies would have been different if the scenarios had been presented in “real-world” rather than abstract terms (i.e. in terms that general public respondents would be more familiar with).

A further concern associated with public preference studies is that it is unclear whether the survey respondents would agree with the policy implications of their responses to the abstract choice tasks. Rowen et al. (2014) inferred from their discrete choice experiment data that there was robust and consistent support for an end of life premium (i.e. that respondents expressed an overall preference for giving priority to life-extending treatments for patients with short life expectancy). Yet the responses to follow-up attitudinal questions in the same survey indicated that most of the respondents believed that the NHS should give priority to treating patients who will get the largest amount of benefit from treatment rather than to extending the life of patients expected to die soon. The extent to which respondents in social preference studies agree with researchers’ interpretations of their responses to hypothetical stated preference tasks has received only limited attention in the health economics literature to date.

## **1.1 Objectives**

The primary aims of this study are:

- to examine the impact of presenting hypothetical priority setting scenarios in “real-world” rather than abstract terms;
- to examine the extent to which the study respondents agree with the policy implications of their responses to stated preference tasks.

A secondary aim is to add to the existing empirical literature on public preferences regarding the prioritisation of health care resources according to factors such as burden of illness.

## 2. METHODS

A stated preference survey was designed to elicit data on people's preferences regarding health care priority setting. The questions formed the basis for two focus group discussions and a self-completion survey administered over the Internet. Section 2.1 describes the overall survey design. Sections 2.2 and 2.3 set out the methods used for the focus groups and Internet survey, respectively.

### 2.1 Survey design

The survey design was loosely based on the aforementioned EEPRU study (Rowen et al., 2014). The survey comprised nine priority setting "scenarios". In each scenario, respondents were presented with information about pairs of hypothetical patient groups (patient group A and patient group B) and were asked which group they thought should be treated if the health service had enough funding to treat one of the groups but not both.<sup>1</sup>

In our survey, the following information was provided to respondents (using a combination of basic text descriptions and diagrams in scenarios 1 to 7; and detailed text descriptions without diagrams in scenarios 8 and 9):

- how long the patients would live for from today **if they did not have their medical condition;**
- what general level of health<sup>2</sup> the patients would live in **if they did not have their medical condition;**
- how long the patients would live for from today **if they are not treated today;**
- what general level of health the patients would live in **if they are not treated today;**
- how long the patients would live for from today **if they are treated today;**
- what general level of health the patients would live in **if they are treated today.**

The survey began with instructions which introduced the diagrams as a way of showing how different medical conditions and treatments affect people's health and life expectancy. Different levels of health were shown using a health scale, where 0% represented "dead"; 100% represented "full health"; and a health level of less than 100% represented someone who has health problems. It was explained that patients consider being in 50% health for two years to be equally desirable as being in 100% health for one year.

The instructions asked the respondents to assume that the health service has only enough funds to treat one of the two patient groups, and that there are no alternative treatments available. To prevent respondents from making choices based on hope that a cure for the conditions may be found in the future, they were told that "the nature of the medical conditions is such that further treatment will not be possible if the patients are not treated today – this is the only opportunity for treatment."

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<sup>1</sup> An alternative approach would have been to ask respondents to choose between two individual patients. This was the approach used in the study by Shah et al. (2015), amongst others. In this study we sought to follow the design of Rowen et al. (2014) as closely as possible.

<sup>2</sup> The terms "health" and "quality of life" are used interchangeably in this paper.

It was emphasised that there were no right or wrong answers to the questions. In accordance with advice given by the EEPUR study lead author (Rowen, personal communication, 11 April 2014), the instructions also emphasised that respondents should indicate how they “would prefer the limited health service funding to be spent” rather than which patient group they “would prefer to be in the position of”.

In each scenario, the first question (the “forced choice question”) asked to respondents was worded as follows:

*Suppose that **there is only enough funding to treat one of the two patient groups**. Patients in the other group will live for the rest of their life **without treatment**. Which patient group do you think should be treated?*

- Patient group A
- Patient group B

Respondents were then asked a second question (the “non-forced choice question”):

*Now suppose a third option is also available – you could choose to split the funding evenly between the two patient groups. Which of the following options best describes your view?*

- All of the funding should be spent on treating patient group A
- The funding should be split evenly between patient group A and patient group B
- All of the funding should be spent on treating patient group B

The non-forced choice question was included in order to elicit information about the strength of respondents’ stated choices. We would expect a respondent with a very strong preference for giving priority to patient group A in a given scenario to choose the “All of the funding should be spent on treating patient group A” option in the non-forced choice question. On the other hand, a respondent with only a weak preference for giving priority to patient group A and who felt that there was also a reasonably strong case for giving priority to patient group B would be more likely to choose the split funding option in the non-forced choice question.

The use of indifference options is generally discouraged as they are often used by respondents as a default choice, thus providing a way to avoid taking time to make difficult decisions and leading to the unnecessary censoring of data (Bridges et al., 2011). Hence, the majority of our analyses focus on the responses to the forced choice questions. In accordance with the feedback of the client, the patients, conditions and treatments were described in generic terms (e.g. “medical condition”) since the use of labels (e.g. “cancer”) may induce emotional and biased responses.

Table 1 summarises the information underpinning each of the nine scenarios. Respondents did not see any of the information relating to QALYs (quality-adjusted life years), burden of illness, absolute QALY shortfall or proportional QALY shortfall – these terms were not used at any point in the survey. In scenarios 1 to 7 the gains from treatment were not presented to respondents, though these could be calculated fairly easily. In scenarios 8 and 9, this information was presented more explicitly.

**Table 1. Summary of scenarios used in the survey**

Scenario	Group	Without condition			Without treatment			Burden of illness (shortfall)		Gains from treatment			With treatment		
		LE (yrs)	QOL	QALY	LE (yrs)	QOL	QALY	Abs.	Prop.	LE (yrs)	QOL	QALY	LE (yrs)	QOL	QALY
1	A	40	1	40	20	1	20	20	0.5	10	0	10	30	1	30
	B	40	1	40	20	1	20	20	0.5	5	0	5	25	1	25
2	A	40	1	40	20	1	20	20	0.5	10	0	10	30	1	30
	B	20	1	20	5	1	5	15	0.75	10	0	10	15	1	15
3	A	40	1	40	20	0.5	10	30	0.75	0	0.25	5	20	0.75	15
	B	20	1	20	5	0.5	2.5	17.5	0.875	10	0	5	15	0.5	7.5
4	A	40	1	40	20	1	20	20	0.5	5	0	5	25	1	25
	B	40	1	40	30	1	30	10	0.25	6	0	6	36	1	36
5	A	40	1	40	40	0.75	30	10	0.25	0.5	0	0.375	40.5	0.75	30.375
	B	40	1	40	20	1	20	20	0.5	1	0	1	21	1	21
6	A	5	1	5	0.5	1	0.5	4.5	0.9	0.5	0	0.5	1	1	1
	B	5	1	5	3	1	3	2	0.4	1	0	1	4	1	4
7	A	40	1	40	40	0.5	20	20	0.5	0	0.2	8	40	0.7	28
	B	40	1	40	40	0.75	30	10	0.25	0	0.25	10	40	1	40
8	A	40	1	40	20	0.5	10	30	0.75	0	0.25	5	20	0.75	15
	B	20	1	20	5	0.5	2.5	17.5	0.875	10	0	5	15	0.5	7.5
9	A	5	1	5	0.5	1	0.5	4.5	0.9	0.5	0	0.5	1	1	1
	B	5	1	5	3	1	3	2	0.4	1	0	1	4	1	4

Note: LE = life expectancy; QOL = quality of life; QALY = quality-adjusted life year; Abs. = absolute QALY shortfall; Prop. = proportional QALY shortfall

QALYs without condition = LE without condition \* QOL without condition

QALYs without treatment = LE without treatment \* QOL without treatment

QALYs with treatment = LE with treatment \* QOL with treatment

QALY gains from treatment = QALYs with treatment - QALYs without treatment

Absolute QALY shortfall = QALYs without condition - QALYs without treatment

Proportional QALY shortfall = (QALYs without condition - QALYs without treatment) / QALYs without condition

Figure 1. Scenario 1

**Scenario 1**

**Patient group A**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **20** years from today with **100%** health.
- With treatment, they will live for **30** years from today with **100%** health.

**Patient group B**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **20** years from today with **100%** health.
- With treatment, they will live for **25** years from today with **100%** health.

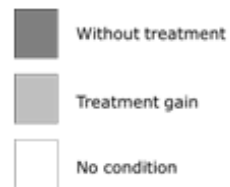
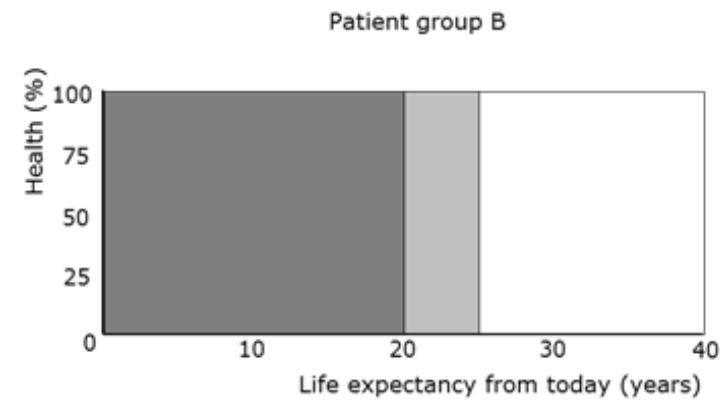
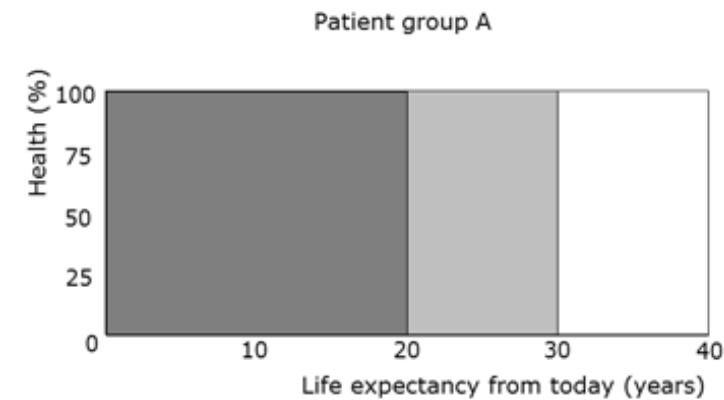


Figure 2. Scenario 2

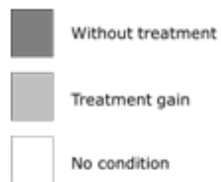
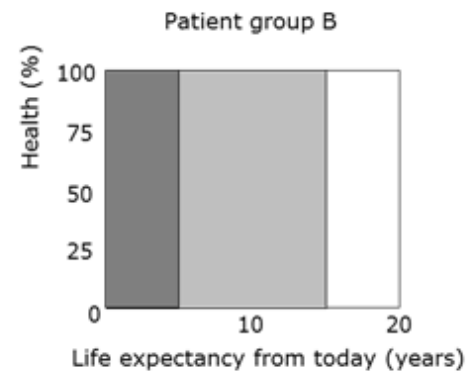
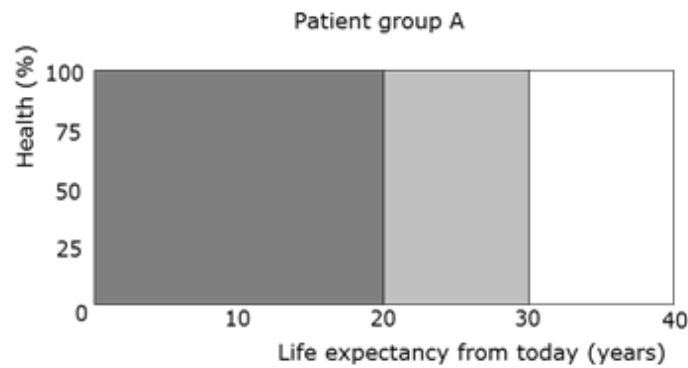
**Scenario 2**

**Patient group A**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **20** years from today with **100%** health.
- With treatment, they will live for **30** years from today with **100%** health.

**Patient group B**

- If they did not have their medical condition, they would live for **20** years from today with **100%** health.
- Without treatment, they will live for **5** years from today with **100%** health.
- With treatment, they will live for **15** years from today with **100%** health.

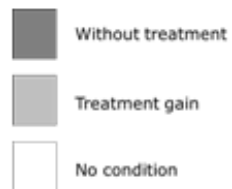
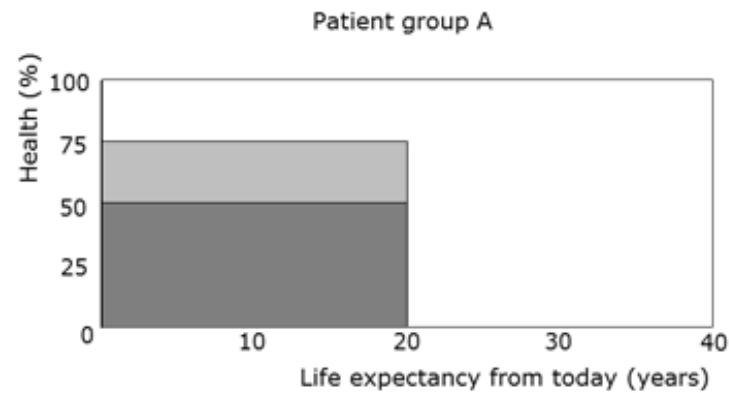


### Figure 3. Scenario 3

#### Scenario 3

##### Patient group A

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **20** years from today with **50%** health.
- With treatment, they will live for **20** years from today with **75%** health.



##### Patient group B

- If they did not have their medical condition, they would live for **20** years from today with **100%** health.
- Without treatment, they will live for **5** years from today with **50%** health.
- With treatment, they will live for **15** years from today with **50%** health.

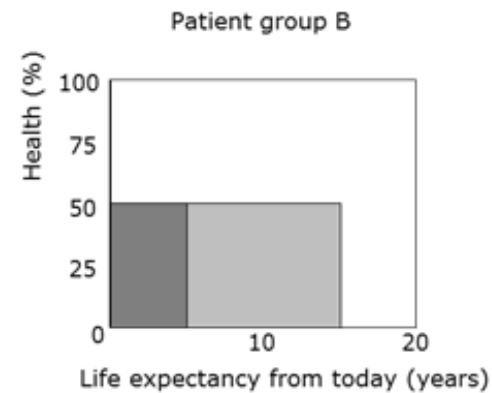


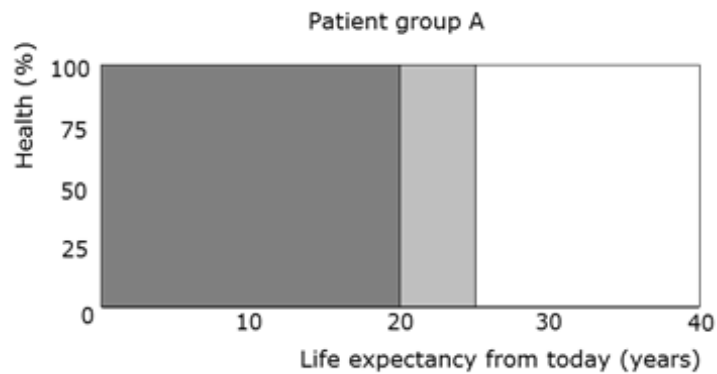


Figure 4. Scenario 4

**Scenario 4**

**Patient group A**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **20** years from today with **100%** health.
- With treatment, they will live for **25** years from today with **100%** health.



**Patient group B**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **30** years from today with **100%** health.
- With treatment, they will live for **36** years from today with **100%** health.

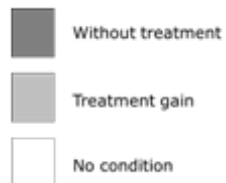
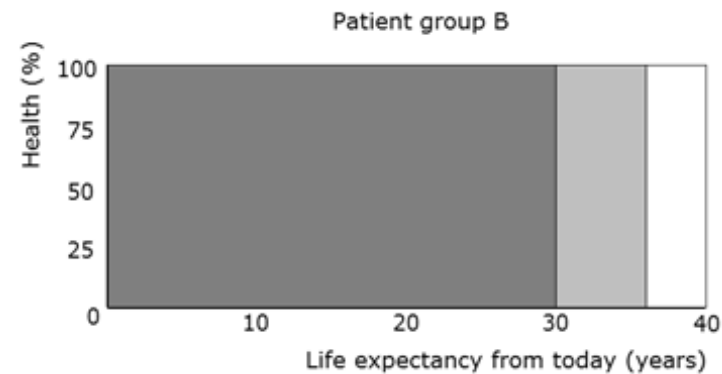


Figure 5. Scenario 5

Scenario 5

Patient group A

- If they did not have their medical condition, they would live for **40 years** from today with **100%** health.
- Without treatment, they will live for **6 months** from today with **100%** health.
- With treatment, they will live for **1 year** from today with **100%** health.

Patient group B

- If they did not have their medical condition, they would live for **40 years** from today with **100%** health.
- Without treatment, they will live for **3 years** from today with **100%** health.
- With treatment, they will live for **4 years** from today with **100%** health.

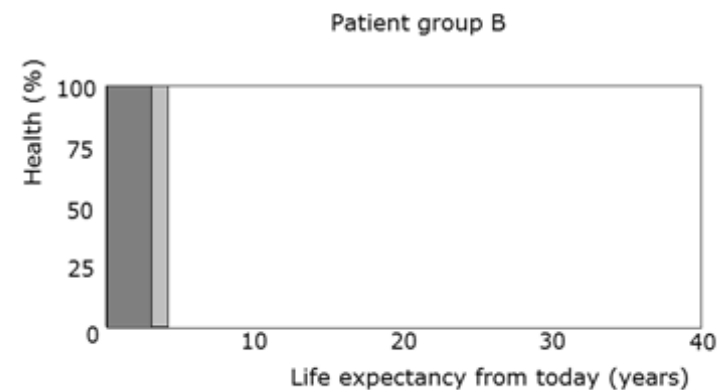
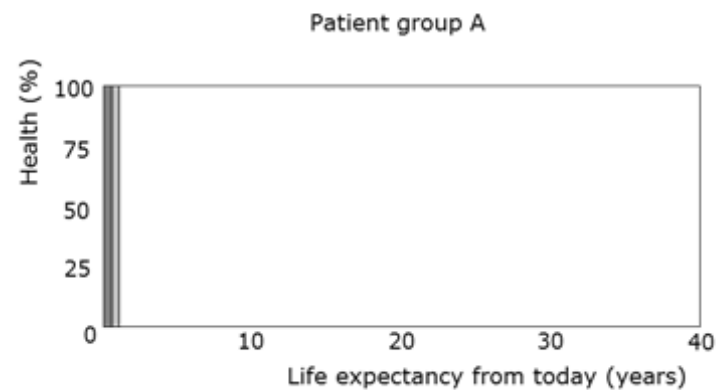


Figure 6. Scenario 6

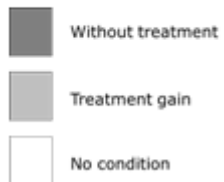
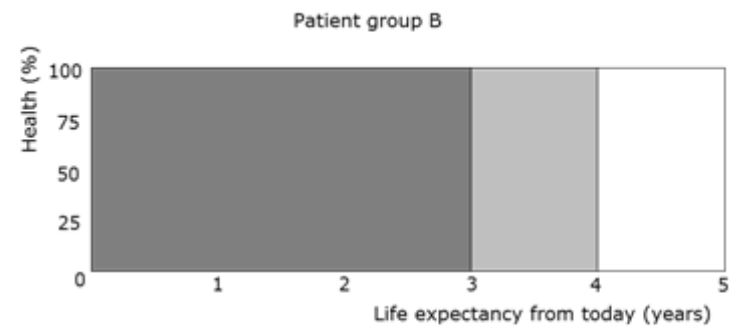
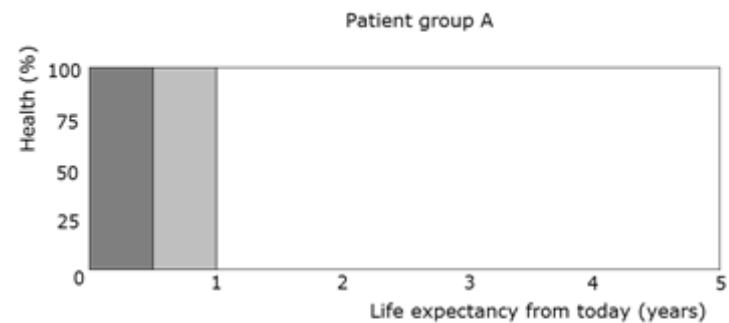
**Scenario 6**

**Patient group A**

- If they did not have their medical condition, they would live for **5 years** from today with **100%** health.
- Without treatment, they will live for **6 months** from today with **100%** health.
- With treatment, they will live for **1 year** from today with **100%** health.

**Patient group B**

- If they did not have their medical condition, they would live for **5 years** from today with **100%** health.
- Without treatment, they will live for **3 years** from today with **100%** health.
- With treatment, they will live for **4 years** from today with **100%** health.



**Figure 7. Scenario 7**

**Scenario 7**

**Patient group A**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **40** years from today with **50%** health.
- With treatment, they will live for **40** years from today with **70%** health.

**Patient group B**

- If they did not have their medical condition, they would live for **40** years from today with **100%** health.
- Without treatment, they will live for **40** years from today with **75%** health.
- With treatment, they will live for **40** years from today with **100%** health.

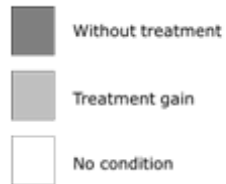
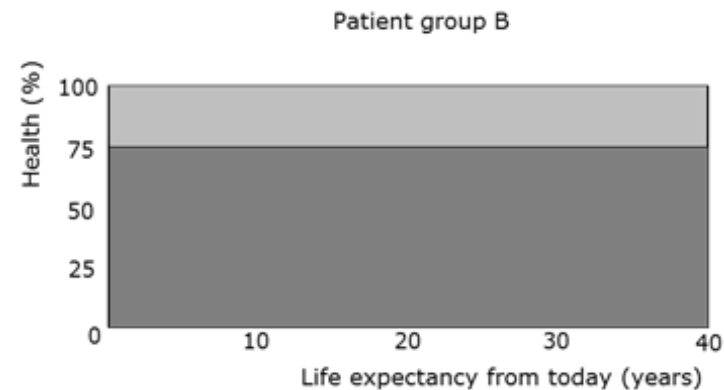
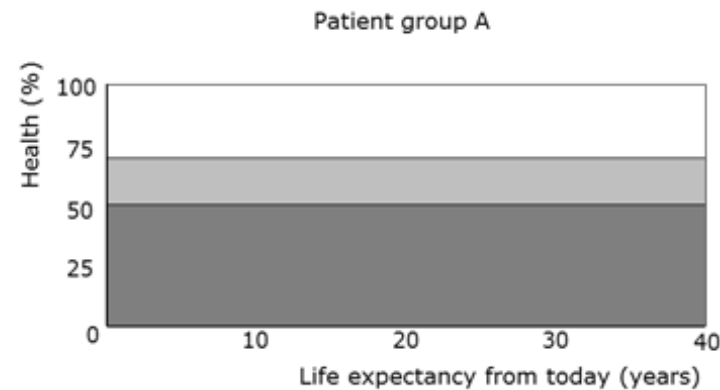


Figure 8. Scenario 8

**Scenario 8**

<b>Patient group A</b>	<b>Patient group B</b>
<p>Patients in group A are <b>40 years old</b>. If they did not have their medical condition, they would live for another <b>40 years</b> from today, to the age of 80 years, with no problems with their general health.</p> <p>Their medical condition affects how long they live for. Without treatment, they will only live for <b>20 years</b> from today, which is 20 years less than if they did not have the condition.</p> <p>Their medical condition also affects their general level of health. Patients with this condition have <b>moderate pain/discomfort</b>, are <b>extremely anxious/depressed</b>, and have <b>slight problems doing their usual activities</b>. Based on what people generally think of these health problems, we shall refer to the patients as being in <b>50%</b> health.</p> <p>Treatment would not affect how long the patients live for, but it would <b>improve some the symptoms</b> associated with their condition. Following treatment, the patients would be <b>slightly anxious/depressed</b> and would <b>no longer have any pain/discomfort</b>. They would still have <b>slight problems doing their usual activities</b>. Based on what people generally think of these health problems, we shall refer to their improved condition as representing <b>75%</b> health.</p> <p>So, with treatment, the patients would live for <b>20 years</b> from today with <b>75%</b> health.</p>	<p>Patients in group B are <b>60 years old</b>. If they did not have their medical condition, they would live for another <b>20 years</b> from today, to the age of 80 years, with no problems with their general health.</p> <p>Their medical condition affects how long they live for. Without treatment, they will only live for <b>5 years</b> from today, which is 15 years less than if they did not have the condition.</p> <p>Their medical condition also affects their general level of health. Patients with this condition have <b>moderate pain/discomfort</b>, are <b>extremely anxious/depressed</b>, and have <b>slight problems doing their usual activities</b>. Based on what people generally think of these health problems, we shall refer to the patients as being in <b>50%</b> health.</p> <p>Treatment would not affect the symptoms associated with their condition, but would <b>extend their life by 10 years</b>.</p> <p>So, with treatment, the patients would live for <b>15 years</b> from today with <b>50%</b> health.</p>

## Figure 9. Scenario 9

### Scenario 9

<b>Patient group A</b>	<b>Patient group B</b>
<p>Patients in group A are <b>75 years old</b>. If they did not have their medical condition, they would live for <b>5 years</b> from today, to the age of 80 years, with no problems with their general health.</p> <p>Their medical condition affects how long they live for. Without treatment, they will only live for <b>6 months</b> from today, which is 4 years and 6 months less than if they did not have the condition. The condition does not affect their general level of health, so we shall refer to them as being in <b>100%</b> health.</p> <p>Treatment would <b>extend their life</b> by <b>6 months</b>.</p> <p>So, with treatment, the patients would live for <b>1 year</b> from today with <b>100%</b> health.</p>	<p>Patients in group B are <b>75 years old</b>. If they did not have their medical condition, they would live for <b>5 years</b> from today, to the age of 80 years, with no problems with their general health.</p> <p>Their medical condition affects how long they live for. Without treatment, they will only live for <b>3 years</b> from today, which is 2 years less than if they did not have the condition. The condition does not affect their general level of health, so we shall refer to them as being in <b>100%</b> health.</p> <p>Treatment would <b>extend their life</b> by <b>1 year</b>.</p> <p>So, with treatment, the patients would live for <b>4 years</b> from today with <b>100%</b> health.</p>

## **2.2 Detailed scenario descriptions**

In scenario 1, both patient groups would have the same life expectancy and quality of life without their conditions. The fact that they would have the same life expectancy without the conditions as each other implies that there is no difference in age between the two groups. Both groups also have the same level of burden of illness, as their life expectancy and quality of life without treatment is the same. The only difference between the groups is that patient group A gains more from treatment than patient group B (10-year life extension vs. five-year life extension; equivalent to 10 QALYs vs. 5 QALYs). A respondent who prefers larger QALY gains to smaller QALY gains should therefore choose to treat patient group A.

Scenario 1 was included primarily as a rationality check (we would expect most respondent to prefer larger QALY gains to smaller QALY gains) and as a simple warm-up task.

In scenario 2, both patient groups gain the same amount of health from treatment (10-year life extensions; equivalent to 10 QALYs). Patients in group A would live for 40 years from today if they did not have their condition, whereas patients in group B would only live for 20 years if they did not have without their condition. This implies, all else being equal, that patients in group B are 20 years older than patients in group A. As a result, whether patients in group A or group B are considered to have the greater burden of illness depends on whether the burden is measured using absolute or proportional QALY shortfall. See Towse and Barnsley (2013) for an overview of these concepts. Patient group A has a larger absolute QALY shortfall than patient group B (A: 20 QALY shortfall; B: 15 QALY shortfall). Patient group B has a larger proportional QALY shortfall than patient group A (A: 0.50; B: 0.75). A respondent who cares about giving higher priority to patients with higher levels of absolute QALY shortfall should choose to treat patient group A. A respondent who cares about giving higher priority to patients with higher levels of proportional QALY shortfall should choose to treat patient group B.

Scenario 2 was included primarily as a “lead-up” task before presenting respondents with the more complex scenario 3.

In scenario 3, both patient groups gain the same amount of health from treatment (10 QALYs), though group A’s gain is in the form of a quality of life improvement and group B’s gain is in the form of a life extension. As in scenario 2, patients in group A would live for 20 years longer than patients in group B without their respective conditions. As a result, whether patients in group A or group B are considered to have the greater burden of illness depends on whether this is measured using absolute or proportional QALY shortfall. Patient group A has a larger absolute QALY shortfall than patient group B (A: 30 QALY shortfall; B: 17.5 QALY shortfall). Patient group B has a larger proportional QALY shortfall than patient group A (A: 0.75; B: 0.875). In principle, a respondent who chooses to treat patient group A (B) in scenario 2 should also choose to treat patient group A (B) in scenario 3, though in practice they may switch if they have preferences for life extensions over quality of life improvements (or vice versa).

This is a complex (and potentially confusing) scenario with many attributes differing across the patient groups. It therefore lends itself well as a candidate for being presented using a “real-world” rather than an abstract description – see scenario 8.

In scenario 4, both patient groups would have the same life expectancy and quality of life without their conditions. Patient group A has a greater (survival-related) burden of illness than patient group B (absolute: 20 QALY shortfall vs. 10 QALY shortfall; proportional: 0.5 vs. 0.25) but gains less from treatment than patient group B (5 QALYs vs. 6 QALYs). A respondent for whom the QALY-maximising objective dominates should choose to treat patient group B. A respondent for whom concern about giving higher priority to higher burden conditions dominates should choose to treat patient group A.

In scenario 5, both patient groups would have the same life expectancy and quality of life without their conditions. Patient group A has a greater (survival-related) burden of illness than patient group B (absolute: 39.5 QALY shortfall vs. 37 QALY shortfall; proportional: 0.988 vs. 0.925) but gains less from treatment than patient group B (0.5 QALY vs. 1 QALY).

According to the criteria used by the National Institute for Health and Care Excellence (NICE) when appraising life-extending end of life treatments, patient group A would be considered an end of life patient (life expectancy is six months, which is less than the two-year cut-off) whereas patient group B would not (life expectancy is three years, which is greater than the two-year cut-off) (NICE, 2009). A respondent for whom the QALY-maximising objective dominates should choose to treat patient group B. A respondent for whom concern about giving higher priority to end of life patients dominates should choose to treat patient group A.

In scenario 6, patient group A has a greater (survival-related) burden of illness than patient group B (absolute: 4.5 QALY shortfall vs. 2 QALY shortfall; proportional: 0.9 vs. 0.4) but gains less from treatment than patient group B (0.5 QALY vs. 1 QALY). Patient group A would be considered an end of life patient under the existing NICE (2009) criteria (life expectancy is six months, which is less than the two-year cut-off) whereas patient group B would not (life expectancy is three years, which is greater than the two-year cut-off). A respondent for whom the QALY-maximising objective dominates should choose to treat patient group B. A respondent for whom concern about giving higher priority to end of life patients dominates should choose to treat patient group A.

The difference between scenario 5 and scenario 6 is that in scenario 5 both patient groups would live for 40 years from today if they did not have their medical conditions; whereas in scenario 6 both patient groups would only live for five years from today if they did not have their medical conditions. This implies that the patients in scenario 6 are considerably older than the patients in scenario 5. Otherwise, the general principles are the same. Comparing scenarios 5 and 6 therefore allows us to examine whether respondents' preferences for giving priority to end of life patients are influenced by the ages of the patients.

In scenario 7, both patient groups would have the same life expectancy and quality of life without their conditions. Patient group A has a greater (quality-related) burden of illness than patient group B (absolute: 20 QALY shortfall vs. 10 QALY shortfall; proportional: 0.5 vs. 0.25) but gains less from treatment than patient group B (8 QALYs vs. 10 QALYs). A respondent for whom the QALY-maximising objective dominates should choose to treat patient group B. A respondent for whom concern about giving higher priority to higher burden conditions dominates should choose to treat patient group A. Scenario 7 is therefore similar to scenario 4, except that the focus is on quality-related



burden and quality of life improvement from treatment rather than on survival-related burden and life extension from treatment.

Scenarios 1 to 7 were shown to respondents using “abstract” presentations of the information. The text descriptions were presented using short bullet points. Quality of life information was presented using percentage weights. The diagrams, which were adapted from the conceptualisation of burden of illness underpinning the proposed value-based assessment scheme (Miners et al., 2013), used shaded blocks to represent the situations of the patients with and without their medical conditions, and with and without treatment. The abstract presentation of information in these scenarios is broadly consistent with that used in other priority setting preference studies such as Rowen et al. (2014).

Scenarios 8 and 9 were included in order to assess the impact of using an alternative presentation of the information. Scenario 8 corresponds directly to scenario 3. There is no difference between the scenarios in terms of the patients’ life expectancy and quality of life without their conditions, without treatment or with treatment. However, in scenario 8 the conceptual diagrams are omitted, and the text descriptions are more detailed and informative. In scenario 3, respondents are advised that patients in groups A and B would live for 40 years and 20 years (respectively) if they did not their conditions. There is no explicit information about the ages of the patients, though a respondent who assumes that healthy people can normally expect to live for 80 years (which is very close to the United Nations Department of Economic and Social Affairs (2012) estimate of the UK life expectancy at birth) can infer that healthy patients with 40 (20) years of life expectancy are probably around 40 (60) years old. In scenario 8, the ages of the patients are presented explicitly.

Another difference between scenarios 3 and 8 is the way in which the quality of life attributes are presented. In scenario 3, quality of life information was presented using percentage weights (“50% health” and “75% health”). In scenario 8, additional qualitative information was provided by way of descriptions of EQ-5D-5L health states that correspond to these percentage weights. According to the results of the recent EQ-5D-5L value set for England study (Devlin et al., 2014), the health states 11235<sup>3</sup> and 11212<sup>4</sup> were given means values of 0.5 and 0.75, respectively, by a representative sample of members of the general public.

Scenario 9 corresponds directly to scenario 6. Again, explicit information about the ages of the patients is included in the “real-world” presentation in scenario 9 but not in the “abstract” presentation in scenario 6. The patients are described as being 75 years old in scenario 9. This information may influence the choices of respondents who have particular views about the prioritisation of life-extending treatments for patients who are already close to their natural life expectancy. Indeed, previous research has shown that people’s priority setting preferences are likely to be influenced by the ages of the patients (Tsuchiya, 1999). However, we hypothesise that at least some respondents would not infer the likely ages of the patients from information about their life

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<sup>3</sup> Slight problems performing usual activities; moderate pain/discomfort; extreme anxiety/depression; no problems with mobility or self-care

<sup>4</sup> Slight problems performing usual activities; slight anxiety/depression; no problems with mobility, self-care or pain/discomfort

expectancies if they did not have their medical conditions, in which case their choices in scenario 6 would not be driven by concerns about the ages of the patients.

## 2.3 Policy implication questions

After completing the questions relating to the scenarios, the respondents were presented with a series of questions designed to test whether they agreed with possible interpretations of their choices (the “policy implication questions”).

Table 2 shows the statements included in the policy implication questions. The statements in policy implication question 1 were designed to correspond to scenario 7. Recall that in scenario 7, patient group A has a greater (quality-related) burden of illness than patient group B, but gains less from treatment than patient group B. A common way of interpreting respondents’ choices in scenario 7 is as follows: respondents choosing to treat patient group A are more concerned about treating those who are severely ill than in achieving larger health gains from treatment; and respondents choosing to treat patient group B are more concerned about achieving larger health gains from treatment than in treating those who are severely ill. Such an interpretation implies that respondents choosing to treat patient group A (B) in scenario 7 would be more likely to agree with statement 1 (2) than with statement 2 (1) in policy implication question 1.

Similarly, the statements in policy implication question 2 were designed to correspond to scenario 5. Recall that in scenario 5, patient group A is closer to their end of life than patient group B, but gains less from treatment than patient group B. A common way of interpreting respondents’ choices in scenario 5 is as follows: respondents choosing to treat patient group A are more concerned about treating those who are expected to die soon as a result of their medical condition than in achieving larger health gains from treatment; and respondents choosing to treat patient group B are more concerned about achieving larger health gains from treatment than in treating those who are expected to die soon as a result of their medical condition. Such an interpretation implies that respondents choosing to treat patient group A (B) in scenario 5 would be more likely to agree with statement 1 (2) than with statement 2 (1) in policy implication question 2.

The statements in policy implication question 3 were designed to correspond to scenarios 5 and 6. Recall that the difference between scenario 5 and scenario 6 is that in scenario 5 both patient groups would live for 40 years from today if they did not have their medical conditions; whereas in scenario 6 both patient groups would only live for five years from today if they did not have their medical conditions. This implies that the patients in scenario 6 are considerably older than the patients in scenario 5. If respondents choose to treat one patient group in scenario 5 and switch to choosing to treat the other patient group in scenario 6, one interpretation is that this switch will have been driven by preferences relating to the ages of the patients.

In the Internet survey (see section 2.5 for details), routing was used to link respondents’ choices to the appropriate policy statements (the way in which the policy implication questions were used in the focus groups was slightly different – see section 2.4.3). In policy implication question 1, respondents who chose to treat patient group A in (the forced choice question in) scenario 7 were presented with both statements and advised that “Our interpretation of an answer you gave to a previous question is that **you agree**

more with statement 1 than with statement 2.” Similarly, it was suggested to respondents who chose to treat patient group B in scenario 7 that they agreed more with statement 2 than with statement 1. Respondents were asked whether they agreed with our interpretation. They were able to choose from one of three responses: “I agree with this interpretation”; “I do not agree with this interpretation”; and “It depends”. See Figure 10 for an example screenshot.

**Table 2. Statements included in the policy implication questions**

Policy implication question	Statement number	Corresponds to	Statement
1	1	Choosing A in scenario 7	The health service should give priority to treating patients who are very ill.
	2	Choosing B in scenario 7	The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.
2	1	Choosing A in scenario 5	The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition.
	2	Choosing B in scenario 5	The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.
3	1	Same choices in scenarios 5 and 6	Decisions about which patients the health service should give priority to <b>should not</b> depend on how old the patients are.
	2	Different choices in scenarios 5 and 6	Decisions about which patients the health service should give priority to <b>should</b> depend on how old the patients are.

If the respondent claimed that they did not agree with our interpretation, they were asked whether it was fair to say instead that they agreed more with the other of the two statements. Again, three response options were offered: “Yes”, “No” and “It depends”. See Figure 11 for an example screenshot.

Similar routing procedures were used to present our interpretations of respondents’ choices in policy implications questions 2 and 3. In all cases, the respondents were given the opportunity to express why they did or did not agree with our interpretations using an open-ended text box.

The wording of the policy statements was based loosely on the wording of the statements presented in the attitudinal questions used by Rowen et al. (2014). The statements were designed to capture respondents’ general views on priorities for the health service without the complexities and intricacies of the choice tasks.

**Figure 10. Example screenshot from Internet survey: policy implication question (1)**


Please read the following statements:

1. The health service should give priority to treating patients who are very ill.
2. The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.

Our interpretation of an answer you gave to a previous question is that you agree more with statement 1 than with statement 2.

Is this correct?

- Yes, I agree with this interpretation
- No, I do not agree with this interpretation
- It depends

  
69% complete


Skip to... ▼

**Figure 11. Example screenshot from Internet survey: policy implication question (2)**

Since you do not agree with our interpretation that you agree more with statement 1, would it be fair to say that you agree more with statement 2?

1. The health service should give priority to treating patients who are very ill.
2. The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.

- Yes
- No
- It depends

  
70% complete

Skip to... ▼

## **2.4 Focus Groups**

### **2.4.1 Motivation**

Focus groups are a form of group interview that explicitly use communication and interaction between participants in order to generate data (Kitzinger, 1995). In contrast to self-completion questionnaires, focus groups give participants an opportunity to discuss the issues in depth and to develop their views during periods of deliberation (Cookson and Dolan, 1999). It has been argued that group discussion can help people to explore and clarify their views in ways that would be less easily accessible in non-group settings (Kitzinger, 1995). It has previously been shown that the public's views about priorities in health care are systematically different when they have been given opportunities for discussion and deliberation (Dolan et al., 1999).

As agreed with the client, we decided to run two focus group sessions in addition to the Internet survey (section 2.5). It was felt that the qualitative data generated by the focus groups would complement the quantitative data generated by the Internet survey. Specific aims of the focus group were:

- to explore the motivations and reasoning behind participants' choices;
- to improve our understanding of how participants approach the stated preference tasks (e.g. what aspects of the scenarios they focus on, the extent to which they understand the information being presented);
- to validate (or challenge) the results of the Internet survey using an alternative mode of administration;
- to help us to interpret the results of the Internet survey.

### **2.4.2 Sample recruitment**

Adult members of the general public from London were recruited to take part in group discussions. The aim was to recruit two groups of eight to 10 people who would each meet for 90 minutes. Potential participants were asked to indicate their age group, gender and previous experience of participating in focus group discussions, as well as the occupation of the chief wage earner in their household (an indicator of their social grade). In accordance with the advice of the agency responsible for managing the fieldwork (Accent), participants were allocated to their group based on their perceived social grade group. This decision was made with group dynamics in mind – market research agencies often seek to recruit groups in which differences between participants do not become an overpowering distraction (Latimer Appleby, 2014). Kitzinger (1995) notes that homogeneity within a group is often sought by researchers in order to capitalise on participants' shared experiences. Thus, all participants assumed to belong to social grades A, B and C1 were allocated to the "high SG" group, and all participants assumed to belong to social grades C2, D and E were allocated to the "low SG" group.

Each participant was offered an incentive of £40 (to be paid at the end of the meeting) for attending.

### **2.4.3 Design and conduct of the sessions**

The focus groups were moderated by an expert in qualitative research methods from Accent (the “lead moderator”) with assistance from a member of the study team (Koonal Shah).

The topic was introduced by the lead moderator. This was followed by a warm-up group discussion about setting priorities in health care. The participants were then given an adapted version of the survey (in paper form), one question at time. For each question, they were asked first to read the information carefully and to consider their views without conferring with each other, and then to discuss their responses with each other before declaring their “final” choice. Each participant’s choice was recorded by the lead moderator. Throughout the sessions, the lead moderator emphasised to the participants that disagreements were acceptable and that there were no right or wrong answers. She also actively encouraged contributions from the less vocal participants.

The scenarios included in the adapted version of the survey for the focus groups were:<sup>5</sup>

- Scenario 1 (presented to the focus group participants as scenario 1)
- Scenario 4 (presented as scenario 2)
- Scenario 5 (presented as scenario 3)
- Scenario 6 (presented as scenario 4)
- Scenario 7 (presented as scenario 5)

For each of the scenarios, the participants were asked to present arguments for treating patient group A and patient group B, and then to indicate which patient group they thought should be treated if the health service has enough funding to treat one but not both of the groups. No indifference or split funding option was offered.

After making their preferred choice in scenario 5, the participants were presented with the two statements from policy implication question 2 and were asked to indicate which of the statements they agreed with more. If the moderators felt that a given participant’s choice of statements was potentially at odds with their choice in scenario 5, further probing questions were asked. Similar exercises were undertaken after scenario 6 (participants were presented with the statements from policy implication question 3) and scenario 7 (participants were presented with the statements from policy implication question 1).

It was decided not to include scenarios 8 and 9 in the adapted survey for the focus groups. This is because the purpose of including these scenarios in the main survey was to test whether respondents would make different choices when faced with pairs of scenarios comprising largely identical information but presented in different ways. In the focus groups, a concern was that if any of the participants recognised that two of the scenarios were largely identical to each other, they would likely inform the other participants about their finding. This could compromise the findings of the research. Since the rationale for including scenarios 3 and 4 in the main survey was primarily to

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<sup>5</sup> To minimise confusion, we use the same labels for each of the scenarios and policy implication questions throughout this report. Hence, scenario 5 in the Internet survey is the same as scenario 5 in the focus group, even though it was actually presented to the focus group participants as scenario 3.

accompany or build up to scenario 8, these scenarios were also excluded from the adapted survey for the focus groups.

Both of the sessions were audio recorded. The audio recordings were transcribed by Accent and analysed by the study team (see section 3.1). It was agreed at the beginning of each session that none of the choices or comments made by participants would be attributed to them in any reports or presentations resulting from the study.

## **2.5 Internet survey**

### **2.5.1 Motivation**

Internet surveys offer a quick and cost-effective means of collecting a large amount of choice data, and can be custom-designed to present and elicit information in a clear, user-friendly manner (Shah et al., 2015). Interviewer-led (or moderator-led) survey administration is often preferred because the interviewer can explain the instructions more fully if required (Bridges et al., 2011) and respondents may be more attentive whilst under supervision. However, the use of interviewers can lead to forms of interviewer bias, which is not the case with Internet surveys.

Internet surveys are increasingly being used as a means of eliciting public preferences regarding health care priority setting (e.g. Abel Olsen, 2013; Linley and Hughes, 2013; Rowen et al., 2014). The use of an Internet survey in this study enables direct comparisons to be made with such studies, in particular the Department of Health-commissioned EPRU study (Rowen et al., 2014).

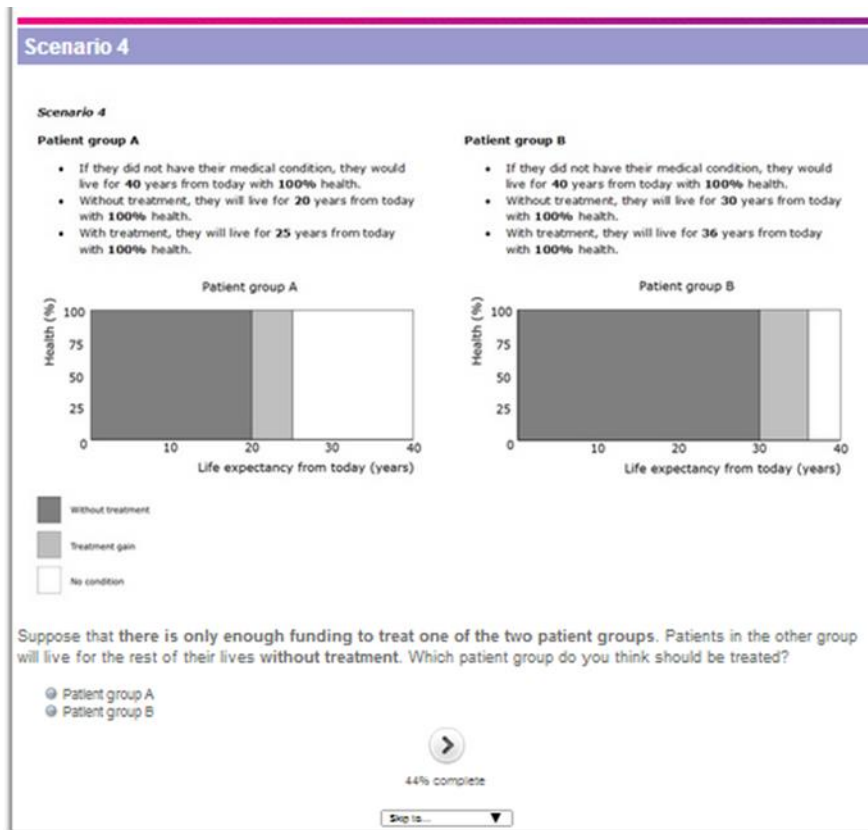
### **2.5.2 Sample recruitment**

The survey was administered on a sample of adult members of the UK general public, all of whom were members of a panel managed by Aurora MR, a market research agency. We sought a sample that was broadly representative of the general population in terms of age and gender. Screen-in questions, combined with a “minimum quota” approach, were used to ensure that the sample comprised individuals with the appropriate characteristics. Respondents were compensated for taking part by way of “reward points” which can be redeemed for gift vouchers.

### **2.5.3 Design and administration of the survey**

The questions were included in a self-completion Internet survey. Information about the scenarios was presented using a combination of text descriptions and diagrams (see Figure 12 for an example screenshot). All responses were recorded via the Internet survey. In order to control for potential left-to-right bias (Spalek and Hammad, 2005), half of the respondents were randomly allocated to a version of the survey in which the labels for patient group A and patient group B were reversed (in other words, for these respondents the group described as patient group A in section 2.1 was instead presented as patient group B and appeared on the right hand side of the screen rather than the left hand side). All respondents completed the same questions, in the same order.

Figure 12. Example screenshot from the Internet survey: scenario





### 3. RESULTS

Data collection took place in May 2014. The results of the focus groups and the Internet survey are presented in sections 3.1 and 3.2, respectively. For the focus groups, we have sought to draw out recurring themes in the data and present quotations from participants that are pertinent to these themes.

#### 3.1 Focus groups

The focus groups took place in Gunnersbury, London in May 2014. Table 3 summarises the background characteristics of the participants and shows that females and older people are overrepresented in the high SG group.

**Table 3. Background characteristics of the sample**

		Group 1 (low SG)		Group 2 (high SG)	
		n	%	n	%
<b>Age (years)</b>	<b>18 to 39</b>	3	37.5%	2	20.0%
	<b>40 to 59</b>	2	25.0%	4	40.0%
	<b>60+</b>	3	37.5%	4	40.0%
<b>Gender</b>	<b>Female</b>	4	50.0%	7	70.0%
	<b>Male</b>	4	50.0%	3	30.0%
<b>Social grade</b>	<b>High (ABC1)</b>	0	0.0%	10	100.0%
	<b>Low (C2DE)</b>	8	100.0%	0	0.0%
<b>Total</b>		<b>8</b>		<b>10</b>	

A small number of comments made in the focus groups indicated that participants had misread the information or were struggling to understand what was required of them. However, the participants aided each other's understanding through discussion (something that is not possible in self-completion modes of administration). It was the view of the lead moderator that, by the end of the sessions, only one of the 18 participants had struggled to such an extent that their responses should be deemed to be unreliable. Nevertheless, it is clearly beneficial to collect data using more than one mode of administration.

##### 3.1.1 Warm-up discussion

Each participant was provided a showcard displaying the following statement:

*No country can afford all the health care interventions that might benefit patients. Clinical need will always outstrip available resources so priorities have to be agreed. How this prioritisation process takes place varies from country to country but the need to prioritise in some way is clear. There just isn't (and never will be) enough money to provide every possible service.*

This statement, which was also read aloud by the lead moderator, was taken directly from the NICE Citizens' Council "Departing from the threshold" meeting report (NICE, 2008, p.26), though the source was not revealed to the participants.

The participants were then asked the following questions: "With this in mind, if you were responsible for setting priorities in health care, how would you go about it? Very generally, who or what would you prioritise?"

Further probing questions were asked in order to encourage the discussion and debate:

- "How do you think the NHS currently sets priorities?"
- "What do you think I mean when I talk about allocating resources *fairly*?"
- "What makes one patient more deserving of treatment than another?"

### **Low SG group**

#### **Who or what would you prioritise?**

*"The young."*

*"those who are ... at risk or are vulnerable"*

*"people in wheelchairs and people who can't manoeuvre a lot"*

#### **How do you think the NHS currently sets priorities?**

*"I [would have] thought that priority would be given to those whom care would benefit most ... if somebody was going to live for six months with the treatment or somebody was going to live for 10 years, we would probably prioritise the person who is going to live for 10 years rather than the person who is only going to live for six months."*

*"Money is obviously a big thing ... they have to prioritise in terms of cost of drugs and cost of treatment and stuff like that"*

#### **What do you think I mean when I talk about allocating resources *fairly*?**

*"For everyone."*

*"We have got to also look at budgets. If people earn £60,000 or £80,000 a year they can pay a little [for their] care, but it's unfair to ask people who are earning very little or are unemployed to pay [for their care]."*

*"I think that anybody who has paid in, anybody who is a resident of this country, who is entitled to it, deserved it, should get it."*

#### **What makes one patient more deserving of treatment than another?**

*"[if] they are making a choice to damage themselves and cause their problems and their bad health, then what's the point of keeping bailing them out?"*

*"you are playing God if you are choosing who is more deserving"*

## **High SG group**

### **Who or what would you prioritise?**

*"more emphasis on prevention"*

*"making sure the people who use it are actually entitled to it"*

### **How do you think the NHS currently sets priorities?**

### **What do you think I mean when I talk about allocating resources *fairly*?**

### **What makes one patient more deserving of treatment than another?**

*"If there's somebody who needs a liver transplant due to some degenerative illness that wasn't self-induced through alcohol, then perhaps they [should be] ahead in the queue. Morally it would be better if that was the case."*

*"everybody wants to sit here and say that nobody's more deserving, and everyone should have equal access [...] but the reality is if you have somebody who has a five-year expectancy of life versus someone who has a 55-year [expectancy] [...] where do you place the [...] resource? There's got to be a cost-benefit at some point"*

*"it's a terrible thing to have to decide"*

## **Summary of responses to the warm-up discussion questions**

The comments made by participants covered a variety of prioritisation criteria, including age, severity of illness, size of treatment gain, budget impact, efficiency and responsibility for one's illness. Most participants accepted the need to make difficult prioritisation decisions.

### **3.1.2 Scenario 1**

#### **Low SG group responses to scenario 1**

Six participants preferred to treat patient group A (larger gain group).

*"logic would say A"*

*"Why not? It's the extra life expectancy"*

*"why would anybody opt to give somebody five years less life?"*

The other two participants expressed a preference for patient group B (smaller gain group), although this could be interpreted as a rejection of the view that one group is more deserving than another.

*"The only thing I would say is that they are equally deserving, whether it's five years less, it's still life regardless [...] yes obviously it"*

*makes sense that logically you'd go for group A but on the other hand it doesn't mean that group B is any less deserving. Those five years are still a lifeline for some people."*

*"I feel that life is life regardless. I don't feel that just because someone is going to live a bit less that they are less deserving of treatment."*

### **High SG group responses to scenario 1**

Nine participants preferred to treat patient group A.

*"[The treatment for group A] is more effective than the treatment for group B."*

*"there's no clear reason why you'd go for B. I can't see a clear reason."*

*"This really is a no-brainer. Of course, they've each got the same quality of life and so go for the longer life."*

One participant was less certain that it was fair to decide based on the size of the life extension offered by treatment.

*"I'm still not sure. I don't think it's right just to given [the treatment to] them just because they will live longer. I don't think that's fair [...] I can't decide."*

### **Summary of responses to scenario 1**

Most of the participants preferred to treat patient group A (the larger gain group). Many of these participants felt that this was an easy decision with an obvious answer. A small number of participants preferred to treat patient group B. Their comments suggest that this choice was driven by the fact that patients for whom the treatment gains are smaller are no less deserving than those for whom the treatment gains are larger.

## **3.1.3 Scenario 4**

### **Low SG group responses to scenario 4**

Six participants preferred to treat patient group A (worse-off, smaller-gain group). They expressed the view that it was fair to give patient group A the opportunity to live for as long as patient group B would live for without treatment.

*"Patient group B, they get six years extra but they've already had the extra 10 years so in effect they are getting 16 years, whereas I think patient group A – if we are talking compassionately, which is what we were doing with the last lot, they would be more deserving [...] they will be coming close to patient group B's 30 years"*

*"level playing field"*

*"Patient group A are now given the opportunity to at least get close to that"*

The other two participants preferred to treat patient group B (better-off, larger-gain group).

*"Just purely on that extra life expectancy."*

*"with treatment they are living for 36 years from today with 100% health and that's got to be good."*

#### **High SG group responses to scenario 4**

Seven participants preferred to treat patient group A. One of those participants had initially expressed a preference for treating patient group B, but changed their mind after hearing the views of others.

*"For two reasons. One is that the effect of the treatment is sooner, or the realisation of the benefit of treatment is sooner. And the second is that the proportional increase in life expectancy is larger for group A than it is for group B. So you're getting a bigger benefit, in proportional terms."*

*"B have already got 30 years, which is way above what A would have. So I'd like to give A at least another five years."*

*"the 25 year people [...] they'll be catching up with the people who've already had 30"*

*"It was purely the return on the investment, because the 36 is 20% whereas the 25 [offers a] greater return"*

*"I was thinking in terms of fairness rather than investment"*

The other three participants preferred to treat patient group B.

*"it's simply a gut reaction, what I would want [for myself]."*

*"purely on the basis that group B get six years and group A only five. But some reason really good points have been made so now I'll have to go to really not sure."*

The issue of age was raised. It was clear that the participants had not all assumed that patients in the two patient groups were the same age as each other.

*"But the starting point is not your birth [...] it may be somebody who is 60, it might be somebody who is 20."*

*"But the groups are exactly the same."*

*"[...] there's another thing missing. The person in group A could be 20 years old. The person in B could be 50."*

*"So I'm assuming that each one is say 20 years old. This person's going to only live to 40 years old, plus an extra five, whereas this person is going to live to 50 plus an extra six."*

#### **Summary of responses to scenario 4**

In both focus groups, the majority of participants preferred to treat patient group A (worse-off, smaller-gain group). In the low SG group, participants making this choice described reasons relating to fairness and seeking a "level playing field". In the high SG group, participants additionally mentioned that the *proportional* improvement for patient group A is in fact larger than that for patient group B.

### **3.1.4 Scenario 5**

#### **Low SG group responses to scenario 5**

Five participants preferred to treat patient group A (end of life, smaller-gain group).

*"the first one [gets] to live 50% longer, and the second one only gets to live a quarter longer."*

*"you can do a hell on a lot of living with six months."*

*"I think if they are going to have three years anyway they have got enough time in that to do what they want to do, sort things out. And not being harsh but they've got more chance than somebody [with six months] [...] what chance have they got to sort things out"*

*"it's about giving them time to get their affairs in order"*

*"Group B without treatment [...] they've got more time, much more time than Group A"*

The other three participants preferred to treat patient group B (non-end of life, larger-gain group).

*"Again it's because of the extra life expectancy. Live longer and be more useful"*

#### **High SG group responses to scenario 5**

Four participants preferred to treat patient group A. One of those participants had initially expressed a preference for treating patient group B, but changed their mind after hearing the views of others.

*"6 months is a bit, it would take that long to get over the shock, I think. You've got a year, it doesn't sound quite so bad [...] 6 months to a year, [...] they've got a chance to recover enough [from] the shock, and finish off what they were trying to do with their life"*

*"you've got 100% return because you double their life expectancy whereas [for patient group B] it's only a third ... the 100% health issue as well, because people are still able to have quality of life for a year."*

*"there's a bigger difference for [patient group A], they've got six months more. [Patient group B has] got a year more but they've had three years already."*

The other six participants preferred to treat patient group B.

*"I went against my instincts [...] being quite callous. The difference between six months and a year, it starts to feel emotionally negligible. I understand that's doubling the time, but six months, 12 months – it's not a big deal – rather than three years to four years [which] feels more beneficial, more of an emotional benefit."*

*"the extra benefit is one extra year rather than one extra half year, so to me there's better overall benefit. And again I'm looking at this in a completely cold, logical way, which I hate"*

*"I can hear people saying you'll get another six months but people die in accidents without saying goodbye"*

### **Summary of responses to scenario 5**

Opinion was split in both focus groups, though the low SG participants were more inclined to treat patient group A (end of life, smaller-gain group) overall. The arguments suggested by participants were similar to those used in the previous scenario. Some of the participants who preferred to treat patient group B referred to the "negligible" nature of small life extensions.

## **3.1.5 Scenario 6**

### **Low SG group responses to scenario 6**

Six participants preferred to treat patient group A (end of life, smaller-gain group). These were the five participants who also preferred to treat patient group A in scenario 5, plus a participant who admitted that they had not fully understood what was being asked of them in scenario 5.

*"This is similar to what we had before yes, so I'd go for patient group A again."*

*"The same reason actually. It's better to give someone six months than give them a death sentence."*

The other two respondents preferred to treat patient group B (non-end of life, larger-gain group). Their reasons were similar to those used in scenario 5.

*"because of the extra life expectancy, that's all. It's logic, you know, head ruling heart"*

One participant referred to the information about the patients' life expectancy without the condition, touching on the concept of proportional shortfall.

*"what I find interesting is that [...] if they didn't have the medical condition, both people will be living [for] five years. I think three out of those five years without treatment is still a very good deal, so I would be more likely to go for patient group A to give them that little bit of an extension."*

### **High SG group responses to scenario 6**

Four participants preferred to treat patient group A. These were the four participants who also preferred to treat patient group A in scenario 5.

*"Exactly the same."*

*"No, the graph scale's different actually."*

*"They're trying to catch us out!"*

*"It's a 100% gain [...] as opposed to 33%."*

*"the other people have got three years at least to wind things up."*

The other six participants preferred to treat patient group B.

*"If it was me, another six months would be hugely important."*

*"Yeah if somebody told me I'd only got six months to live and they [could give] me another six months, I'd be over the moon."*

### **Summary of responses to scenario 6**

The responses and reasons given by participants for scenario 6 were almost identical to those given for scenario 5. The age of the patients was not mentioned by any of the participants. Only one participant mentioned the information provided about patients' life expectancies if they did not have their medical conditions. Most of the participants seemed to consider scenarios 5 and 6 to be identical to each other.

## **3.1.6 Scenario 7**

### **Low SG group responses to scenario 7**

Four participants preferred to treat patient group A (worse-off, smaller-gain group). Two of those participants had initially expressed a preference for treating patient group B, but changed their minds after hearing the views of others.

*"I was just thinking in terms of getting to a level playing field"*



*"So with treatment patient group B gets to live [in] 100% [quality of life], but that still leaves patient group A [with] 50% quality of life. That's awful."*

The other four participants preferred to treat patient group B (better-off, larger-gain group).

*"70% – I understand that sound pretty good [to others] but it doesn't to me, I'd rather have the 100%."*

*"just go for the percentage"*

### **High SG group responses to scenario 7**

Eight participants preferred to treat patient group A. One of those participants had initially expressed a preference for treating patient group B, but changed their mind after hearing the views of others.

*"It's on the basis that even with treatment they don't reach the level that people [in group B] without the treatment are already at."*

*"they're doing much worse in terms of their health than group B, so I think they'd get a better benefit"*

*"if you can get yourself three quarters fit then you'll probably be taking less money out of the system, and putting more into the system, because you're functioning better ... I'd rather get everyone up to a reasonable level than have one lot really alright and one lot not alright."*

The other two participants preferred to treat patient group B (better-off, larger-gain group).

*"The [group with] 70% would still need all sorts of treatments, or caring at home"*

*"I'm loathe to be Darwinian about it but someone who's 100% fitter is more productive in every sense ... it's better to have as many people [as possible] at 100% health"*

### **Summary of responses to scenario 7**

Most of the participants in the high SG group preferred to treat patient group A (worse-off, smaller-gain group), whereas opinion was more evenly split in the low SG group. The arguments given by participants related primarily to fairness, helping the worse-off and seeking a level playing field (justifications for treating patient group A); and the benefits to society of having people in full health (justification for treating patient group B).

### 3.1.7 Policy implication question 1 (relates to scenario 7)

1. The health service should give priority to treating patients who are very ill.
2. The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.

#### Low SG group responses to policy implication question 1

Seven participants agreed more with statement 1.

*"To me that's what the health service is mainly all about. That's what they should be doing."*

*"the whole point of having the health service is to deal with and to be able to treat people who are very ill"*

*"I think that if they are really, really ill, they should be treated first because they could then go on to lead a productive life."*

One participant agreed more with statement 2.

*"how much can you help someone, should it be at the expense of somebody who will have more"*

Table 4 provides a cross-tabulation of participants' responses to scenario 7 and policy implication question 1. The value in each cell refers to the number of participants making that combination of choices.

**Table 4. Cross-tabulation – scenario 7 vs. policy implication question 1 (low SG)**

		Response to policy implication question 1	
		Statement 1	Statement 2
Response in scenario 7	Patient group A	3	1
	Patient group B	4	0

**"Inconsistent" = A2 or B1**

Four participants expressed the view that the health service should give priority to treating the very ill (rather than to treatments offering larger health gains), despite choosing to treat the better-off, larger-gain patient group in scenario 7.

*"that's the point of the health service [...] to treat people who can't do anything for themselves."*

*"if somebody is very ill you have got to treat"*

The sole participant who expressed the view that the health service should give priority to treatments offering larger health gains chose *not* to treat the better-off, larger-gain patient group in scenario 7, but was unable to articulate the reasons for this apparent inconsistency.

### High SG group responses to policy implication question 1

Six participants agreed more with statement 1.

*"Well, with the caveat that I actually agree with both. [Statement] 1 I agreed with almost immediately because I think if somebody is very ill I probably would feel that I would want them to get priority over people who are less ill."*

*"I would say that's what I think the NHS should be for, treating people who are very ill."*

*"if you're very ill you really do need them."*

The other four participants agreed more with statement 2, though some of these participants expressed the view that the patients that stood to achieve larger gains from treatment would often be the more seriously ill.

*"those who are treated would be the people who are the most ill and would get the most benefit from the treatment"*

*"the illness of those who are most ill would fit into the people who get the largest health gains."*

*"I was going for 2 but I have to assume that people who are very ill are within 2 as well."*

Several participants made the point that it was difficult to choose because of the vague nature of the statements.

*"This is impossible [...] because are you talking about babies that are very ill or middle aged people who are very ill?"*

*"It says ill, not terminally ill."*

*"If we had actual cases it would be so much easier."*

**Table 5. Cross-tabulation – scenario 7 vs. policy implication question 1 (high SG)**

		Response to policy implication question 1	
		Statement 1	Statement 2
Response in scenario 7	Patient group A	5	3
	Patient group B	1	1

**"Inconsistent" = A2 or B1**

Nearly half of the participants gave seemingly "inconsistent" pairs of responses. One participant expressed the view that the health service should give priority to treating the very ill (rather than to treatments offering larger health gains), despite choosing to treat the better-off, larger-gain patient group in scenario 7. Three participants expressed the

view that the health service should give priority to treatments offering larger health gains, despite choosing to treat the worse-off, smaller-gain patient group in scenario 7.

### **Summary of responses to policy implication question 1**

A number of participants agreed more with the statement other than the one that we might have predicted from their choice in scenario 7, though the patterns of responses differed across the two focus groups. Some strongly agreed with statement 1 (health service should give priority to treating the very ill), despite choosing to treat the better-off, larger-gain patient group in scenario 7. This may be driven by differing interpretations of the wording used – for example, some participants may not consider “very ill” to correspond to patients described as being in “50% health”. It also seemed as though some participants found it difficult to reconcile their ideological views about the health service with the types of trade-offs that need to be made when making prioritisation decisions.

### **3.1.8 Policy implication question 2 (relates to scenario 5)**

1. The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition.
2. The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains.

#### **Low SG group responses to policy implication question 2**

Five participants agreed more with statement 1.

*“I found it really easy because I was in that situation [...] I was told I would live two months with the condition that I had, a heart condition. They gave me a pacemaker and defibrillator and seven years later I am still here. So [...] sometimes I think they should take that chance.”*

*“I think the quality of life is important [...] it might make them live longer but what’s the quality of life? Are they tied up on drips, are they tied up on life support machines?”*

The other three participants agreed more with statement 2.

Table 6 provides a cross-tabulation of participants’ responses to scenario 5 and policy implication question 2. The value in each cell refers to the number of participants making that combination of choices.

**Table 6. Cross-tabulation – scenario 5 vs. policy implication question 2 (low SG)**

		Response to policy implication question 2	
		Statement 1	Statement 2
Response in scenario 5	Patient group A	2	3
	Patient group B	1	2

**“Inconsistent” = A2 or B1**

Some of the participants who chose to treat patient group A in scenario 5 whilst agreeing more with statement 2 explained that this was because of the importance they placed on quality of life. One interpreted “health gains” as potentially covering quality of life. Similarly, the other claimed that their preference for patient group A in scenario 5 was driven by the fact that those patients would have full quality of life.

*“in scenario [5] [...] they have all got the same level of quality of life, right? This is a general statement though, so that’s why I switched – I guess because I thought that in general I would put quality of life over length of life”*

*“in scenario [5] we have been given set parameters that they are going to be having 100% quality of life, whether shortened or extended. But in the follow-up exercise it doesn’t state the same thing for [statement] number 1. I think it doesn’t state that they are going to have the same quality of life and without that guarantee, that changes things for me.”*

The one participant who chose to treat patient group B in scenario 3 whilst agreeing more with statement 1 admitted that they had not fully understood what was being asked of them.

### **High SG group responses to policy implication question 2**

All 10 participants agreed more with statement 2.

*“as a return on cost-benefit, everything logical says I have to go for 2.”*

*“2 is probably more sensible, again all things being absolutely equal.”*

*“with 2, if you’ve got larger health gains and you’ve got a fitter population [...] they will be able to work. This is going back to money, which I don’t normally do, but they will be able to work, pay more taxes – you’ll have more money for the health service.”*

**Table 7. Cross-tabulation – scenario 5 vs. policy implication question 2 (high SG)**

		Response to policy implication question 2	
		Statement 1	Statement 2
Response in scenario 5	Patient group A	0	4
	Patient group B	0	6

**“Inconsistent” = A2 or B1**

The participants who chose to treat patient group A in scenario 5 whilst agreeing more with statement 2 explained that they didn’t necessarily agree that statement 1 (2) corresponded with prioritising patient group A (B) because of the way in which the statements were worded.

*"So dying soon, what does soon mean? One person could think soon means three months. Somebody else might think that soon means five years."*

*"to me this looks like my eye treatment or something like that, a large health gain. I didn't associate that with people dying so much, but keeping fit and healthy, and working and earning money, and paying into the health service. That's how I saw it, so I didn't really associate 2 with B particularly."*

Some of the participants again referred to the difference between absolute and relative/proportional improvements.

*"[It depends on] how you define a large health benefit, in proportional terms"*

*"although one year is longer than six months, the six months is relatively more in that group."*

### **Summary of responses to policy implication question 2**

Participants in both focus groups were more likely to agree with statement 2 (health service should give priority to treatments offering larger health gains) than we might have predicted from the choices in scenario 5. This can be explained largely by participants' differing interpretations of the wording used in the policy statements. For example, one participant suggested that the term "soon" was too vague to justify choosing statement 2, even though they appeared broadly to support the spirit of the policy. A number of participants had not considered life extensions to fall within the concept of "health gains", in which case they would not have interpreted patient group B to have larger health gains from treatment than patient group A in scenario 5. Some of the participants emphasised that when thinking about larger health gains, they assumed that the health gains were larger in relative rather than absolute terms.

### **3.1.9 Policy implication question 3 (relates to scenarios 5 and 6)**

1. Decisions about which patients the health service should give priority to should not depend on how old the patients are.
2. Decisions about which patients the health service should give priority to should depend on how old the patients are.

#### **Low SG group responses to policy implication question 3**

Four participants agreed more with statement 1.

*"you shouldn't discount people if they are older necessarily ... quality of your life would be the most important thing."*

*"people's age shouldn't really come into it"*

*"Because number 2 is really ageist, and that's totally wrong"*

*"especially as I am one of the elderly."*

The other four participants agreed more with statement 2.

*"I don't see the point in prolonging very, very old life. It totally depends on the quality of that person's life [...] but I have got strong views on people being [kept] alive once they are past their natural shelf life."*

*"I just think you should give priority to younger people but I suppose it depends how long you feel the older person is going to live for."*

*"Someone young can give more to society than someone who is older."*

One participant noted that they had children rather than adults in mind when considering the scenarios and statements.

*"you have mentioned about this ageism. I didn't see it that way at all because as far as I am concerned patient group A could be five year olds and patient group B could be 10 year olds. [...] I would want the priority to be given to maybe the five year olds just to have the opportunity that a 10 year old has, to actually get to that point. But I didn't see it as someone older – maybe like a pensioner's age – to not be given treatment because they have already lived. I didn't see it that way."*

Table 8 provides a cross-tabulation of participants' responses to scenarios 5 and 6 and policy implication question 3. The value in each cell refers to the number of participants making that combination of choices.

**Table 8. Cross-tabulation – scenarios 5 and 6 vs. policy implication question 3 (low SG)**

		Response to policy implication question 3	
		Statement 1	Statement 2
Responses in scenarios 5 and 6	AA/BB	3	4
	AB/BA	1	0

**"Inconsistent" = AB1 or BA1**

The participants who agreed that prioritisation decisions should depend on age did not, on the whole, interpret any differences between scenarios 5 and 6 in terms of the ages of the patients.

### **High SG group responses to policy implication question 3**

Seven participants agreed more with statement 1.

*"someone who's 50 could still get 20 years' worth of productive and happy life"*

"I don't think it should depend on how old you are. You'd start stopping so many people [...] why should my age make any difference to what treatment I get, and thank goodness it hasn't."

"if they start discriminating on age they then might pick up on other things. They might start discriminating against people in other ways [...] So I don't want any discrimination of any kind, whether it's ageism or any kind of discrimination [...] to me it's a bit of a slippery slope."

"if they are older, as we've said before, somebody said before, if they've been paying their taxes, maybe they haven't even used the NHS previous, and I think they deserve [to be treated]."

"you should be fair to a person, no matter what age they are."

The other three participants agreed more with statement 2.

"I think give life to those who potentially have more ahead of them."

"whilst in an ideal world I'd go for 1, the reality is there is a finite amount of resource. [...] we've got the same prognosis and life expectancy [...] and there's only one pot of money and there's only one pill on the table. You have to give it to the 19 year old, in my opinion."

**Table 9. Cross-tabulation – scenarios 5 and 6 vs. policy implication question 3 (high SG)**

		Response to policy implication question 3	
		Statement 1	Statement 2
Responses in scenarios 5 and 6	AA/BB	7	3
	AB/BA	0	0

"Inconsistent" = AB1 or BA1

Just as in the low SG group, the participants who agreed that prioritisation decisions should depend on age did not, on the whole, interpret any differences between scenarios 5 and 6 in terms of the ages of the patients.

### Summary of responses to policy implication question 3

Some participants expressed strong views about prioritising according to age, yet age was not mentioned at all in any of the discussions relating to scenarios 5 and 6. This suggests that if researchers are interested in eliciting people's age-related preferences, the information about age needs to be expressed explicitly rather than implicitly.



## 3.2 Internet survey

### 3.2.1 Sample

The Internet survey was carried out in May 2014. Respondents who completed the survey in less than five minutes were excluded due to concerns about data quality, leaving a sample of 400 respondents. The median time taken to complete the survey was 13 minutes and 26 seconds. Table 10 summarises the background characteristics of the respondents. The sample is broadly representative of the general population, though older, retired individuals are overrepresented.

**Table 10. Background characteristics of the sample**

Characteristic	Category	n	%	General population <sup>6</sup>
<b>Age (years)</b>	<b>18 to 24</b>	31	10.3%	11.9%
	<b>25 to 44</b>	92	30.7%	34.8%
	<b>45 to 59</b>	76	25.3%	24.7%
	<b>60+</b>	101	33.7%	28.6%
<b>Gender</b>	<b>Female</b>	168	56.0%	50.8%
	<b>Male</b>	132	44.0%	49.2%
<b>Employment status</b>	<b>Employed</b>	147	49.0%	59.4%
	<b>Student</b>	19	6.4%	8.8%
	<b>Retired</b>	75	25.0%	13.1%
	<b>Other</b>	59	19.6%	18.7%
<b>Social grade</b>	<b>ABC1</b>	179	59.7%	53.0%
	<b>C2DE</b>	121	40.3%	47.0%
<b>Self-rated health using EQ-5D-5L</b>	<b>11111</b>	84	28.0%	
	<b>Any other state</b>	216	72.0%	
<b>Experience of terminal illness in close friend or family member</b>	<b>Yes</b>	183	61.1%	
	<b>No</b>	113	37.7%	
	<b>Not answered</b>	4	1.3%	
<b>Total</b>		<b>300</b>	<b>100.0%</b>	

### 3.2.2 Response data – aggregate

Eleven respondents (3.7%) chose to treat the same patient group in the non-forced choice question for all nine scenarios. Ten of these 11 respondents always chose to treat patient group A. There was no statistically significant difference between the two study versions (i.e. between those for whom the labels for patient group A and patient group B were reversed and those for whom the labels were not reversed) in terms of the propensity to choose to treat one patient group or the other ( $p > 0.05$ ).

Table 11 reports the aggregate response data for the forced choice questions for each of the nine scenarios. The majority choice is highlighted in yellow in cases where the result is statistically significantly greater than 50% at the 5% level. In scenario 4 (choice between giving a smaller life extension to the group with higher survival-related burden and a larger life extension to the group with lower survival-related burden) and scenario 7 (choice between giving a smaller quality of life improvement to the group with higher quality-related burden and a larger quality of life improvement to the group with lower quality-related burden), there was no clear majority choice.

<sup>6</sup> General population data based on results for England and Wales from the 2011 Census (ONS, 2011) and the National Readership Survey (2012-2013), where available.

**Table 11. Aggregate response data for all scenarios – forced choice questions**

Scenario	Prefer to treat A		Prefer to treat B		Group preference implied by the most popular choice
	count	%	count	%	
1	241	80.3	59	19.7	QALY maximisation
2	169	56.3	131	43.7	Absolute QALY shortfall
3	179	59.7	121	40.3	Absolute QALY shortfall
4	147	49.0	153	51.0	
5	113	37.7	187	62.3	QALY maximisation
6	130	43.3	170	56.7	QALY maximisation
7	158	52.7	142	47.3	
8	211	70.3	89	29.7	Absolute QALY shortfall
9	99	33.0	201	67.0	QALY maximisation

Note: majority choice is highlighted in yellow in cases where the result is statistically significantly greater than 50% at the 5% level

Table 12 reports the aggregate response data for the non-forced choice questions for each of the nine scenarios. In all scenarios, the “split the funding evenly” option was the most commonly chosen response. The proportion of respondents choosing to “split the funding evenly” ranged from 52.3% (scenario 6) to 83.0% (scenario 1).

**Table 12. Aggregate response data for all scenarios – non-forced choice questions**

Scenario	All funding to A		Split funding evenly		All funding to B	
	count	%	count	%	count	%
1	41	13.7	249	83.0	10	3.3
2	44	14.7	191	63.7	65	21.7
3	61	20.3	188	62.7	51	17.0
4	46	15.3	216	72.0	38	12.7
5	46	15.3	166	55.3	88	29.3
6	63	21.0	157	52.3	80	26.7
7	56	18.7	191	63.7	53	17.7
8	69	23.0	210	70.0	21	7.0
9	33	11.0	200	66.7	67	22.3

When comparing responses to a given scenario with and without the “split the funding evenly” option, we observe low levels of inconsistency, where inconsistency is defined as choosing A and then B, or B and then A. The average level of inconsistency observed across the scenarios was 2.0%. This gives us confidence that the non-forced choice response data do not contradict the forced choice response data. The tendency to choose the split funding option suggests that many respondents found it difficult to choose between the two patient groups and that their choice in the forced choice questions had not been driven by a strong preference. Alternatively, this tendency may reflect reluctance by respondents to give *all* of the funding to one patient group, even if they considered that group to be more deserving of treatment than the other group, on balance.

The non-forced question choice data can be used to interpret some of the forced choice question results. For example, we observe that a sizeable minority of respondents chose to treat patient group B in the forced choice question in scenario 1. This involves choosing a five-year life extension over a 10-year life extension. Some of the focus group participants had also made the same choice. However, when offered the

opportunity to split the funding evenly between the two groups, almost all of the respondents who chose to treat patient group B in the forced choice question then opted to split the funding evenly in the parallel non-forced choice question. This seems consistent with our finding from the focus groups that participants who expressed a preference for treating patient group B did not necessarily believe that this group was more deserving of treatment, but rather that those patients should be given an equal opportunity to be treated.

Below we briefly summarise the key results for scenarios 1 to 9.

### **Scenario 1**

The vast majority of respondents (241 respondents; 80.3%) chose to treat the patient group that would gain a greater number of QALYs from treatment. Of the 59 respondents who chose to treat the smaller-gain patient group, 52 (88.1%) chose to split the funding evenly between the two patient groups when that option was made available.

### **Scenario 2**

A slight majority of respondents (169 respondents; 56.3%) chose to treat the patient group with larger *absolute* QALY shortfall, as opposed to the patient group with larger *proportional* QALY shortfall. Forty-four of those respondents (26.0%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

### **Scenario 3**

The majority of respondents (179 respondents; 59.7%) chose to give a quality of life improvement to the patient group with larger *absolute* QALY shortfall, as opposed to giving a life extension to the patient group with larger *proportional* QALY shortfall. Fifty-seven of those respondents (31.8%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

### **Scenario 4**

The respondents were roughly evenly split between giving a larger life extension to the patient group with lesser survival-related burden (147 respondents; 49.0%) and giving a smaller life extension to the patient group with greater survival-related burden (153 respondents; 51.0%).

### **Scenario 5**

The majority of respondents (187 respondents; 62.3%) chose to give a larger life extension to the patient group with longer life expectancy, as opposed to giving a smaller life extension to the patient group with shorter life expectancy. Eighty-four of those respondents (44.9%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

### Scenario 6

The majority of respondents (170 respondents; 56.7%) chose to give a larger life extension to the patient group with longer life expectancy, as opposed to giving a smaller life extension to the patient group with shorter life expectancy. Seventy-seven of those respondents (45.3%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

Comparing respondents’ choices in scenarios 5 and 6, 255 respondents (85.0%) made the same choice in both scenarios.

### Scenario 7

The respondents were roughly evenly split between giving a larger quality of life improvement to the patient group with lesser quality-related burden (158 respondents; 52.7%) and giving a smaller quality of life improvement to the patient group with greater quality-related burden (142 respondents; 47.3%).

### Scenario 8

The majority of respondents (211 respondents; 70.3%) chose to give a quality of life improvement to the patient group with larger *absolute* QALY shortfall, as opposed to giving a life extension to the patient group with larger *proportional* QALY shortfall. Sixty-five of those respondents (30.8%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

### Scenario 9

The majority of respondents (201 respondents; 67.0%) chose to give a larger life extension to the patient group with longer life expectancy, as opposed to giving a smaller life extension to the patient group with shorter life expectancy. Sixty-six of those respondents (32.8%) continued to choose to treat this patient group when the “split the funding evenly” option was available.

## 3.2.3 Response data – cross-tabulations

In this section we analyse cross-tabulations of the response data. We begin by comparing the results for scenarios 8 and 9 (which used real-world presentations of the information) with those for scenarios 3 and 6 (the corresponding scenarios that used abstract presentations of the information), respectively. We then compare the responses to the three policy implication questions with the results of the corresponding choice tasks.

### 3.2.3.1 Abstract versus real-world scenarios

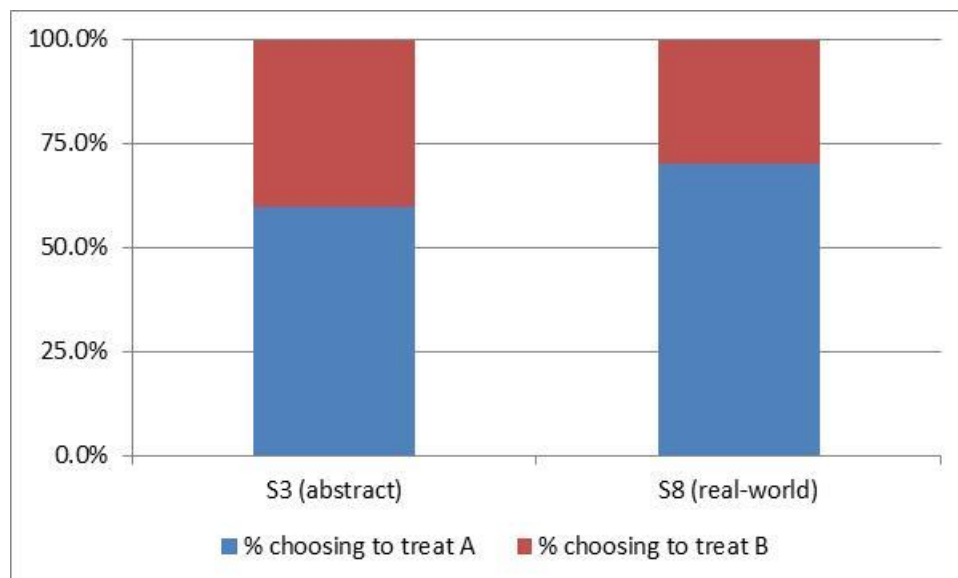
#### Scenario 3 versus scenario 8

**Table 13. Cross-tabulation – scenario 3 versus scenario 8**

	Scenario 8 (real-world)		
	A	B	Total

<b>Scenario 3 (abstract)</b>	<b>A</b>	145 (48.3%)	34 (11.3%)	179 (59.7%)
	<b>B</b>	66 (22.0%)	55 (18.3%)	121 (40.3%)
	<b>Total</b>	211 (70.3%)	89 (29.7%)	300 (100.0%)

**Figure 13. Scenario 3 versus scenario 8**



Comparing respondents' choices in scenarios 3 and 8, 200 respondents (66.7%) made the same choice in both scenarios. There was a slight overall shift towards giving a quality of life improvement to the patient group with larger *absolute* QALY shortfall when quality of life with and without treatment was described in words and the ages of the patients were made explicit – 31.3% of the respondents who chose to give a life extension to the patient group with larger *proportional* QALY shortfall in scenario 3 switched to choosing to treat the other patient group in scenario 8. This meant an increase in the majority preferring to allocate funding on the basis of absolute QALY shortfall from 59.7% (scenario 3) to 70.3% (scenario 8).

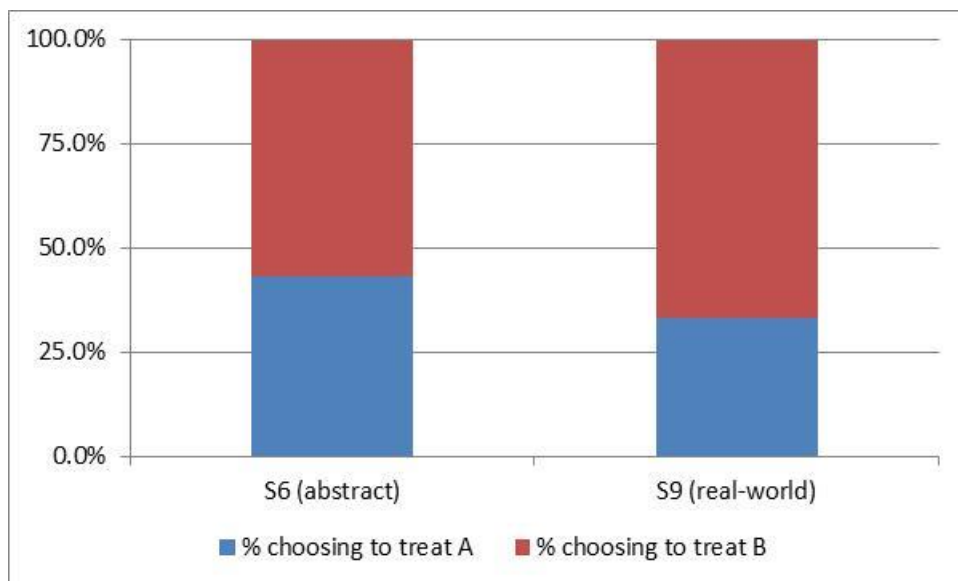
There is a statistically significant association between the framing of the information and the propensity to choose to treat a particular patient group ( $p < 0.001$ ). This indicates that presenting information in alternative formats can have a meaningful impact on the results generated.

### Scenario 6 versus scenario 9

**Table 14. Cross-tabulation – scenario 6 versus scenario 9**

		<b>Scenario 9 (real-world)</b>		
		<b>A</b>	<b>B</b>	<b>Total</b>
<b>Scenario 6 (abstract)</b>	<b>A</b>	77 (25.7%)	53 (17.7%)	130 (43.3%)
	<b>B</b>	22 (7.3%)	148 (49.3%)	170 (56.7%)
	<b>Total</b>	99 (33.0%)	201 (67.0%)	300 (100.0%)

**Figure 14. Scenario 6 versus scenario 9**



Comparing respondents’ choices in scenarios 6 and 9, 225 respondents (75.0%) made the same choice in both scenarios.

There was an overall shift towards giving a larger life extension to the patient group with longer life expectancy when it was made explicit that the patients were older adults (75 years old) – 40.8% of the respondents who chose to give a smaller life extension to the patient group with shorter life expectancy in scenario 6 switched to choosing to treat the other patient group in scenario 9. This meant an increase in the majority preferring to allocate funding on the basis of QALY maximisation from 56.7% in scenario 6 to 67.0% in scenario 9.

There is a statistically significant association between the framing of the information and the propensity to choose to treat a particular patient group ( $p < 0.001$ ). This indicates that presenting information in alternative formats can have a meaningful impact on the results generated. More specifically, it suggests that the results may be affected by whether information about the ages of patients is presenting implicitly (as in scenario 6) or explicitly (as in scenario 9).

**Relationship between abstract scenario choices and real-world scenario choices**

Approximately half of the respondents (50.3%) made the same choices in real-world scenarios 8 and 9 as the choices they made in the corresponding abstract scenarios 3 and 6 (Table 15). A small minority of respondents (8.7%) made choices in the two real-world scenarios that both differed from their choices in the corresponding abstract scenarios.

**Table 15. Cross-tabulation – scenarios 3 and 8 versus scenarios 6 and 9**

		Scenario 6 and scenario 9		
		Same choice	Different choice	Total
Scenario 3 and scenario 8	Same choice	151 (50.3%)	49 (16.3%)	200 (66.7%)
	Different choice	74 (24.7%)	26 (8.7%)	100 (33.3%)
	Total	225 (75.0%)	75 (25.0%)	300 (100.0%)

We did not find any clear differences in background characteristics between the respondents whose choices in the abstract and real-world scenarios were the same and those whose were not.

### 3.2.3.2 Policy implication questions versus corresponding scenarios

#### *Policy implication question 1*

In policy implication question 1, it was suggested that respondents agreed more with the statement “The health service should give priority to treating patients who are very ill” if they chose to treat patient group A in scenario 7; and with the statement “The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains” if they chose to treat patient group B in scenario 7.

**Table 16. Cross-tabulation – scenario 7 versus policy implication question 1**

Response to our interpretation	Choice in scenario 7		
	A	B	Total
Yes, I agree with this interpretation	93 (58.9%)	96 (67.6%)	189 (63.0%)
No, I do not agree with this interpretation	8 (5.1%)	10 (7.0%)	18 (6.0%)
It depends	57 (36.1%)	36 (25.4%)	93 (31.0%)
Total	158 (100.0%)	142 (100.0%)	300 (100.0%)

The results are shown in Table 16. The majority of respondents (63.0%) agreed with the policy statement implied by their choice in scenario 7. A small minority of respondents (6.0%) stated that they did not agree with our interpretation. Respondents who chose to treat patient group A in scenario 7 were less likely to agree with our interpretation than those who chose to treat patient group B, with over one-third stating that “It depends”. We found that participants in the focus groups were more likely to disagree with the policy implications of their choices in this scenario when faced with a similar exercise.

When pressed further, half of the 18 respondents who stated that they did not agree with our interpretation said that they agreed more with the other statement, as shown in Table 17.

**Table 17. Policy implication question 1 – respondents who did not agree with our interpretation**

Response	Count	%
Yes (agree with other statement)	9	50.0%
No (do not agree with other statement either)	4	22.2%
It depends	5	27.8%
<b>Total</b>	<b>18</b>	<b>100.0%</b>

#### *Policy implication question 2*

In policy implication question 2, it was suggested that respondents agreed more with the statement “The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition” if they chose to treat patient group A in scenario 5; and with the statement “The health service should give priority to



treatments offering larger health gains over treatments offering smaller health gains” if they chose to treat patient group B in scenario 5.

**Table 18. Cross-tabulation – scenario 5 versus policy implication question 2**

Response to our interpretation	Choice in scenario 5		
	A	B	Total
Yes, I agree with this interpretation	65 (57.5%)	129 (69.0%)	194 (64.7%)
No, I do not agree with this interpretation	9 (8.0%)	15 (8.0%)	24 (8.0%)
It depends	39 (34.0%)	43 (23.0%)	82 (27.3%)
Total	113 (100.0%)	187 (100.0%)	300 (100.0%)

The results are shown in Table 18. The majority of respondents (64.7%) agreed with the policy statement implied by their choice in scenario 7. A small minority of respondents (8.0%) stated that they did not agree with our interpretation. Respondents who chose to treat patient group A in scenario 5 were less likely to agree with our interpretation than those who chose to treat patient group B, with over one-third stating that “It depends” (similar to the results for policy implication question 1 – see above). This could be reflect some of the points made by participants in the focus groups that their agreement with statement 1 depends on what exactly is meant by “soon” or on information about the quality of life associated with the life extensions.

When pressed further, just over half of the 24 respondents who stated that they did not agree with our interpretation said that they agreed more with the other statement, as shown in Table 19.

**Table 19. Policy implication question 2 – respondents who did not agree with our interpretation**

Response to our interpretation	Count	%
Yes (agree with other statement)	13	54.2%
No (do not agree with other statement either)	7	29.2%
It depends	4	16.7%
<b>Total</b>	<b>24</b>	<b>100.0%</b>

### **Policy implication question 3**

In policy implication question 3, it was suggested that respondents agreed more with the statement “Decisions about which patients the health service should give priority to **should not** depend on how old the patients are” if they chose to treat same patient group in scenarios 5 and 6; and with the statement “Decisions about which patients the health service should give priority to **should** depend on how old the patients are” if they chose to treat different patient groups in scenario 5 and 6.

**Table 20. Cross-tabulation – scenarios 5 and 6 versus policy implication question 3**

Response to our interpretation	Choice in scenarios 5 and 6		
	AA/BB	AB/BA	Total
Yes, I agree with this interpretation	137 (53.7%)	29 (64.4%)	166 (55.3%)
No, I do not agree with this interpretation	54 (21.2%)	8 (17.8%)	62 (20.7%)
It depends	64 (25.1%)	8 (17.8%)	72 (24.0%)
Total	255 (100.0%)	45 (100.0%)	300 (100.0%)



The results are shown in Table 20. A slight majority of respondents (55.3%) agreed with the policy implied by their choice in scenarios 5 and 6. A larger proportion of respondents stated that they did not agree with our interpretation than was the case for the other policy implication questions (20.7%, compared to 6.0% and 8.0% in policy implications questions 1 and 2, respectively). This is unsurprising, since the interpretation that respondents do not consider age to be a relevant priority setting criterion just because their answers did not vary across scenarios 5 and 6 requires some quite strong assumptions to be made, such as the assumption that the respondents recognised that the patients' ages differed across the scenarios (the findings from the focus group suggest that this is unlikely to have been the case). Furthermore, it may be the case that a given respondent's preferences regarding life-extending end of life treatments (the focus of scenarios 5 and 6) do not depend on whether the patients are younger adults (as is implied in scenario 5) or older adults (as in implied in scenario 6), but the ages of the patients may matter in other circumstances (e.g. when being asked to choose between quality of life improvements and life extensions, or between the treatment of adults and the treatment of children).

However, it is notable that 17.8% of the respondents who made *different* choices in scenarios 5 and 6 disagreed with the statement that prioritisation decisions *should not* depend on the ages of the patients. This suggests that respondents may have interpreted the information about how long the patients would live for if they did not have their respective medical conditions (this is the only attribute that differed between scenarios 5 and 6) differently from how we might expect them to have.

When pressed further, 36 of the 62 respondents (58.1%) who stated that they did not agree with our interpretation said that they agreed more with the other statement, as shown in Table 21.

**Table 21. Policy implication question 2 – respondents who did not agree with our interpretation**

<b>Response to our interpretation</b>	<b>Count</b>	<b>%</b>
Yes (agree with other statement)	36	58.1%
No (do not agree with other statement either)	13	21.0%
It depends	13	21.0%
<b>Total</b>	62	100.0%

### ***Relationship between scenario choices and policy implication question responses***

The majority of respondents agreed with our interpretation in each of the three policy implication questions (63.0% in policy implication question 1; 64.7% in policy implication question 2; 55.3% in policy implication question 3). However, only 86 respondents (28.7%) agreed with our interpretations in all three questions. Three respondents (1.0%) *disagreed* with our interpretations in all three questions.

Respondents who agreed with our interpretations in all three questions were more likely to be male and older (60 years and over) than those who did not. The median time taken by these respondents to complete the survey (13 minutes and 30 seconds) was very similar to the corresponding statistic for the overall sample (13 minutes and 26

seconds), which suggests that they were not putting any less effort and consideration into their responses.

Somewhat unexpectedly, respondents who expressed a preference for splitting the funding evenly between the patient groups in the non-forced choice questions in scenarios 5 and 7 were less likely than average to choose the “It depends” option in the corresponding policy implication questions.

### **3.2.4 Respondent subgroup analysis**

In accordance with feedback received from the client, we divided the Internet survey sample into subgroups in order to examine whether respondents with certain characteristics were more likely than others to give particular responses to the survey questions. These subgroups were defined in terms of age group (respondents aged between 18 and 34 years; respondents aged between 35 and 59 years; respondents aged 60 years and older) and social grade (respondents in higher grades A, B or C1; respondents in lower grades C2, D or E).

Regarding age group, we do not observe a statistically significant association between the age group of respondents and their propensity to choose to treat one patient group or the other in scenarios 1 to 7. We also do not observe a statistically significant association between the age group of respondents and their propensity to make the same choices in real-world scenarios 8 and 9 as the choices they made in the corresponding abstract scenarios 3 and 6. In the policy implication questions, older respondents were more likely than younger respondents to disagree with our interpretations of their earlier choices. The association between the age group of respondents and their responses is statistically significant at the 5% level for policy implication questions 1 and 3.

Regarding social grade, we do not observe a statistically significant association between the social grade of respondents and their propensity to choose to treat one patient group or the other in scenarios 1 to 7 (with the exception of scenario 5, in which respondents in higher social grades were more likely to choose to treat patient group A – the end of life, smaller gain group – than were respondents in lower social grades). We also do not observe a statistically significant association between the social grade of respondents and their responses to the policy implication questions. Compared to respondents in lower social grades, respondents in higher social grades were statistically significantly more likely to make the same choice in real-world scenario 8 as the choice they made in the corresponding abstract scenario 3. This was not the case when comparing respondents’ choices in real-world scenario 9 and the corresponding abstract scenario 6.

Table 22 shows the relationship between the age of respondents and their inferred views about whether health service prioritisation decisions should depend on how old the patients are. Similarly, Table 23 shows the relationship between the social grade of respondents and their inferred views about whether health service prioritisation decisions should depend on how old the patients are.

In both tables, we inferred respondents’ views as follows:

- Inferred view 1 comprises respondents who *agreed* with the statement “Decisions about which patients the health service should give priority to *should not* depend on how old the patients are” or *disagreed* with the statement “Decisions about which patients the health service should give priority to *should* depend on how old the patients are” when completing policy implication question 3.
- Inferred view 2 comprises respondents who *disagreed* with the statement “Decisions about which patients the health service should give priority to *should not* depend on how old the patients are” or *agreed* with the statement “Decisions about which patients the health service should give priority to *should* depend on how old the patients are” when completing policy implication question 3.
- Inferred view 3 comprises respondents who selected the “It depends” option when completing policy implication question 3.

**Table 22. Relationship between age of respondents and their inferred views about whether prioritisation decisions should depend on age**

Inferred view	Age (years)		
	18 to 34	35 to 59	60+
1. Prioritisation decisions <b>should not</b> depend on how old the patients are	38 (54.3%)	53 (41.1%)	54 (53.5%)
2. Prioritisation decisions <b>should</b> depend on how old the patients are	17 (24.3%)	40 (31.0%)	26 (25.7%)
3. It depends	15 (21.4%)	36 (27.9%)	21 (20.8%)
<b>Total</b>	<b>70 (100.0%)</b>	<b>129 (100.0%)</b>	<b>101 (100.0%)</b>

**Table 23. Relationship between social grade of respondents and their inferred views about whether prioritisation decisions should depend on age**

Inferred view	Social grade	
	ABC1	C2DE
1. Prioritisation decisions <b>should not</b> depend on how old the patients are	91 (50.8%)	54 (44.6%)
2. Prioritisation decisions <b>should</b> depend on how old the patients are	48 (26.8%)	35 (28.9%)
3. It depends	40 (22.3%)	32 (26.4%)
<b>Total</b>	<b>179 (100.0%)</b>	<b>121 (100.0%)</b>

We do not observe a statistically significant association between either the age or the social grade of respondents and their inferred views about whether health service prioritisation decisions should depend on how old the patients are. For all respondent subgroups, the most popular view was that health service prioritisation decisions *should not* depend on how old the patients are.

### **3.2.5 Qualitative data**

Most of the respondents provided comments to explain their choices using the open-ended text boxes when invited to do so.

In policy implication question 1, many of the respondents who did not agree with our interpretation of their choice in scenario 7 (or who chose the “It depends” option) suggested that whether the severely ill or those who stand to gain most from treatment should be prioritised depends on the specifics of each individual situation. Several respondents noted that each case is different so it was difficult or inappropriate to make general statements about health service priorities such as those presented in policy implication question 1. Other respondents suggested that the acceptability of the statements depends on the definitions of “very ill” and “health gains” (e.g. whether the gains involve life extensions or quality of life improvements).

In policy implication question 2, several respondents suggested that whether or not the health service should give priority to extending the lives of patients who are expected to die soon depends on the quality of the life extensions and the ages of the patients.

The comments regarding policy implication question 3 indicate a split in opinion amongst the respondents. Some respondents feel that age is not a relevant priority setting criterion, with a number of respondents expressing this view very strongly. Others believe that younger patients should be given priority, either because they feel that the young should be given the opportunity to achieve to same lifetime health as the old, or because the young are relatively productive and more able to contribute to society.

A number of respondents who disagreed with our interpretations in the policy implication questions expressed the view that all illnesses should be treated the same and that all patients should be given a fair chance of receiving the treatment that they require.

### **3.2.6 Comparison with the EEPRU study**

The EEPRU study (Rowen et al., 2014), which used a discrete choice experiment to elicit social preferences originally intended to form the basis for the scheme for the value-based assessment of branded medicines in the UK, reported evidence of:

- an overall preference for treating patients with larger QALY gains;
- positive, significant and robust coefficients for burden of illness (i.e. an overall preference for treating patients with higher levels of burden of illness);
- robust and consistent support for end of life (though the authors note that end of life overlaps conceptually with burden of illness and that the two should not be used together).

The responses to the follow-up attitudinal questions in the same study indicate that most respondents believed that the health service should give priority to treating patients who will get the largest amount of benefit from treatment, rather than to those who are very ill or who are close to their end of life.

Table 24 compares the responses to the attitudinal questions in the EEPRU study (taken from Rowen et al., 2014, pp.37-38) with proportions of respondents in our study who

agreed with the corresponding statements in the policy implication questions. It should be noted that the statements do not match exactly across the two studies.

**Table 24. Comparison of responses to the policy implication questions with responses to the attitudinal questions in the EEPRU study**

<b>EEPRU study attitudinal questions</b>		<b>Policy implication questions in this study</b>	
<b>Statement</b>	<b>% choosing statement</b>	<b>Statement</b>	<b>% indicating that they agreed more with this statement*</b>
The NHS should give priority to treating patients who are very ill	40.7%	The health service should give priority to treating patients who are very ill	49.0%
The NHS should give the same priority to treating all patients who are ill, regardless of how ill they are	59.3%	The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains	51.0%
The NHS should give priority to extending the life of patients expected to die soon	12.0%	The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition	34.8%
The NHS should give priority to treating patients who will get the largest amount of benefit from treatment	88.0%	The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains	65.2%

\* excludes respondents who chose the "It depends" option

The modal response across the various attitudinal questions used in the EEPRU study was that the same priority should be given to treating all patients (regardless of how ill they are or when they will die). The authors suggest that this may reflect a preference for equal access to health care when a patient is in need, rather than a rejection of the need to prioritise according of burden of illness or end of life. This finding from the EEPRU study is consistent with the responses to the non-forced choice questions in our study, which show that many respondents wished to split the funding evenly between the patient groups in all of the scenarios.

## 4. DISCUSSION

This study used focus group discussions and an Internet survey to elicit the preferences of the UK general public regarding a range of health care priority setting scenarios. We have found that people's stated preferences regarding the hypothetical scenarios are influenced by the way in which information regarding the scenarios is presented to them. We have also found that they do not always agree with the policy implications of their responses to the stated preference tasks (though it should be noted that the majority of respondents *did* agree with our interpretations).

People hold different, legitimate and articulable views about how health care should be prioritised – for the most part, participants in the focus groups were able to explain their views, and were consistent in their responses. Similarly, respondents in the Internet survey largely gave consistent responses and sensible reasons for their choices when prompted to do so.

Results from the Internet survey indicate that there is a statistically significant association between the choices that respondents make when faced with hypothetical priority setting exercises and the way in which information is framed and presented to them in those exercises. When the ages of the patients were stated explicitly, and the descriptions of the patients' conditions and treatments were presented in greater detail (and without the use of abstract diagrams), a sizeable minority of respondents switched from preferring to treat one patient group to preferring to treat the other.

We found that respondents do not always agree with the policy statements that we might expect them to agree with, given their responses to the hypothetical choice tasks. Participants in the focus groups were more likely to disagree with our interpretations of their choices than were respondents in the Internet survey. This might reflect the fact that in the Internet survey we presented respondents with our interpretations and asked whether they agreed with them, which may have led to acquiescence bias or "yea saying" (Ternent and Tsuchiya, 2013). By comparison, the discursive nature of the focus groups may have made it easier for participants to express their views and disagreements. Efforts were made to ensure that the focus group participants did not simply give the responses that they thought the moderator expected them to give.

A common theme arising from the analysis of the policy implication questions is that it is unwise to make general statements about people's priority setting preferences based on their responses to very specific choice tasks. For example, a respondent may prefer to give a six-month life extension to patients with one year of life expectancy rather than a one-year life extension to patients with three years of life expectancy. This does not necessarily mean that they are in favour of a general policy of giving higher priority to life-extending end of life treatments. Their preference may be specific to the size of the gain specified in the choice task (they may not feel the same about a four-month life extension) and may depend on the quality in which the additional life is lived.

Participants in the focus groups said that they found it difficult to know how to interpret the policy statements because of the vagueness of the wording. For example, one participant suggested that the specific meaning of "soon" was important. Other participants seemed to differ in their interpretations of what was meant by "very ill". Similar comments were made by respondents in the Internet survey, some of whom

noted that the value that they placed on “extending the life” of end of life patients depended on the size and quality of the extension.

It became apparent during the focus group discussions that some participants interpreted the term “larger” (as in “larger health gains”) as meaning larger in absolute terms, whereas others interpreted it as meaning larger in relative terms. Thus, some participants considered a six-month life extension for patients with one year of life expectancy to represent a larger gain than a one-year life extension for patients with three years of life expectancy.

The results suggest that if researchers wish to understand whether people have particular preferences regarding the prioritisation of patients according to their age, it is necessary to present age-related information explicitly. Only one of the focus group participants appeared to have recognised the implicit age-related differences between two of the scenarios.

A key message that can be drawn from the results of this study is that these kinds of stated preference studies are subject to important framing effects. Researchers often seek to interpret observed responses to stated preference tasks and to use the results to draw conclusions about the types of policies that the study respondents would support. However, whether the respondents actually consider these policies to be acceptable or not will depend on whether they have interpreted the concepts underpinning the choice tasks in the same way as the researchers have. Caution is therefore required when using the results of social preference studies to drive public sector decisions, as the results can be sensitive to the methods used.

## **4.1 Implications for value-based assessment**

At the time of analysis (July to August 2014), the proposals for value-based assessment (NICE, 2014a) involved applying weights to QALYs based both on absolute and proportional QALY shortfall, and suggested that the existing premium for life-extending end of life treatments (NICE, 2009) would be subsumed by the new system. Following a period of consultation, NICE recommended to its Board in September 2014 that no changes to the technology appraisal methodology should be made in the short term and that the supplementary policy for the appraisal of life-extending end of life treatments should be retained in its current form (NICE, 2014b). Nevertheless, it is still informative to understand the implications of the results of this study for value-based assessment, as a similar system including elements of value that go beyond health effects could be adopted by policy makers in the UK or elsewhere in the future.

### **4.1.1 Absolute QALY shortfall and prioritisation according to age**

The proposals for value-based assessment (NICE, 2014a) involved applying weights to QALYs based both on absolute and proportional QALY shortfall. The former was to be used as an indirect measure of “societal shortfall” (the effect of an illness on a person’s ability to interact with and contribute to society); the latter as a measure of burden of illness.

Absolute QALY shortfall may be sensitive to age since younger individuals have a greater number of QALYs to lose than older individuals. A policy that gives higher priority to



those with greater absolute QALY shortfall may therefore benefit younger patients at the expense of older patients.

In scenarios 2 and 3 in our study, both of which involved choosing between one patient group that has a greater absolute QALY shortfall and another group that has a greater proportional QALY shortfall, a slight (but statistically significant) majority of respondents preferred to treat the group with a greater absolute QALY shortfall (56.3% in scenario 2; 59.7% in scenario 3). This majority increased to 70.3% in scenario 8, in which the scenario 3 information was presented in less abstract terms and the ages of the patients were stated explicitly.

In spite of this result, the most common view amongst both the focus group participants and the Internet survey respondents was that decisions about which patients the health service should give priority to *should not* depend on how old the patients are. A number of participants and respondents expressed strongly that it was inappropriate for age to be a factor in making health care prioritisation decisions.

#### **4.1.2 Replacing the end of life premium with a burden of illness weighting**

The proposals for value-based assessment (NICE, 2014a) suggested that that the existing premium for life-extending end of life treatments (NICE, 2009) would be replaced by a premium for patients with high levels of proportional QALY shortfall. The end of life premium benefits those who meet its criteria (patients with less than two years of life expectancy without treatment and who stand to gain at least three months of life expectancy from treatment). Abandoning the end of life premium would therefore disadvantage these patients. A policy that gives higher priority to those with greater proportional QALY shortfall will favour patients who are severely ill but would not have met the end of life criteria, such as patients with three years of life expectancy without treatment or whose quality of life is very poor.

In our Internet survey, we found that a slight (but statistically significant) majority of respondents preferred to give a larger life extension to patients with three years of life expectancy (and therefore *would not* meet the current end of life criteria) than to give a smaller life extension to patients with one year of life expectancy (and therefore *would* meet the current end of life criteria). This majority *increased* when the scenarios were described in less abstract terms and the ages of the patients were stated explicitly. The focus group participants were evenly divided between the two options.

When asked explicitly, more of the Internet survey respondents and focus group participants agreed with the statement “The health service should give priority to treatments offering larger health gains over treatments offering smaller health gains” than with the statement “The health service should give priority to extending the life of patients who are expected to die soon as a result of a medical condition”. Our study therefore suggests that members of the public are not, on the whole, in favour of a premium for life-extending end of life treatments.

The focus group participants were somewhat divided in opinion about whether to give a larger quality of life improvement to patients with higher levels of quality-related burden or to give a smaller quality of life improvement to patients with lower levels of quality-



related burden. When asked explicitly, however, most of the participants indicated that they felt that health service should give priority to treating patients who are very ill, with several participants stating that this is the primary purpose of the health service. A number of participants emphasised that quality of life is at least as important as life expectancy.

The current end of life policy accommodates life extensions and concerns about short life expectancy, but not quality of life improvements and concerns about poor quality of life. A policy of giving priority to patients with high levels of (absolute or proportional) QALY shortfall would accommodate all of these aspects. Our study suggests that members of the public are, on the whole, in favour of giving priority to those with high levels of QALY shortfall.

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