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Understanding Social Preferences Regarding the Prioritisation of Treatments Addressing Unmet Need and Severity

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Acknowledgements

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Abstract

<u>Background</u>: The UK Government is proposing to include "burden of illness" in its proposed scheme for the value-based pricing (VBP) of branded medicines. The VBP consultation document suggests that medicines that tackle diseases associated with high levels of burden of illness will be rewarded more highly than those that do not. It includes a definition of burden of illness that incorporates consideration of severity (in terms of either length or quality of life) and unmet need (the degree to which treatments exist). However, there is a dearth of empirical evidence on societal preferences regarding this particular definition of unmet need.

<u>Objective</u>: The aim of this exploratory study is to design and pilot an approach to eliciting public preferences regarding the prioritisation of health care resources according to unmet need and severity.

<u>Methodology</u>: In face-to-face interviews, respondents answered 11 questions. Some of these involved the consideration of hypothetical priority setting scenarios; others involved consideration of pairs of statement about NHS priorities and required choosing the statement with which they most agreed. The various questions were designed to examine the extent to which respondents were willing to make trade-offs between health gains, treating the severely ill, and addressing areas of unmet need.

<u>Results</u>: Sixty members of the general public in southeast England were interviewed in May 2012. We find that maximising health gain is considered by most respondents to be more important than the competing objectives of giving priority to the severely ill and giving priority to treating conditions for which no alternative treatments exist. According to the interviewers, most of the respondents showed a good understanding of the survey tasks.

<u>Discussion and Conclusions</u>: Some of our findings run counter to those of empirical studies elsewhere in the literature that examine social preferences regarding unmet need and severity. However, framing effects clearly are at play, since the level of support for an implied policy of giving priority according to unmet need varies greatly from question to question. A key finding is that people's responses to stated preference questions appear to be influenced heavily by the ways in which the questions are framed.

Background

The UK Government is proposing to include "burden of illness" in its proposed scheme for the value-based pricing (VBP) of branded medicines. The consultation document on VBP, published by the Department of Health (DH), describes the objectives of the scheme as follows as follows [emphasis added]:

- improve outcomes for patients through better access to effective medicines;

- Stimulate innovation and the development of high value treatments;

- improve the process for assessing new medicines, ensuring transparent, predictable and timely decision-making;

- *include a wide assessment, alongside clinical effectiveness, of the range of factors through which medicines deliver benefits for patients and society;*

- ensure value for money and best use of NHS resources (DH, 2010, page 11).

The italicised text indicates that "value" is derived not only from the health gains from treatment, but also from other factors that may be of benefit to society. Under the proposed new system, the Government would use these factors to develop a range of (explicitly) adjusted price thresholds reflecting the maximum that society is prepared to pay for new medicines. The consultation document sets out the proposed price threshold structure as follows [emphasis added]:

- there would be a basic threshold, reflecting the benefits displaced elsewhere in the NHS when funds are allocated to new medicines;

- *there would be higher thresholds for medicines that tackle diseases where there is greater 'burden of illness': the more the medicine is focused on diseases with unmet need or which are particularly severe, the higher the threshold*;

- there would be higher thresholds for medicines that can demonstrate a greater therapeutic innovation and improvements compared with other products;

- there would be higher thresholds for medicines that can demonstrate wider societal benefits (DH, 2012, page 13).

The inclusion of burden of illness in the proposed VBP scheme constitutes a key departure from the current approach to assessing and pricing medicines, which typically do not include such considerations. Burden of illness is defined only in vague terms in the consultation document, e.g.: "The most important factors contributing to the measurement of 'Burden of Illness' would be the severity of the condition and the level of unmet need" (DH, 2012, page 14).

Although there is a growing body of research on the use of severity and unmet need in health care priority setting, a lack of clarity remains about how these components should be defined, what evidence is needed to generate measures that can be applied in VBP, and how they should be combined to form a single burden of illness metric (if at all).

The VBP consultation document suggests that severity may be defined as health (in terms of quality adjusted life years (QALYs)) without treatment:

> Severity could reflect the health status without the new treatment, and also if the condition leads to premature death or serious morbidity. It could be assessed in terms of the existing QALY unit of health benefit – which could be used to quantify the outstanding health loss (DH, 2012, page 14).

The QALY combines two aspects of health: length of life and health-related quality of life. The definition suggested in the VBP consultation implies that severity can be interpreted as very poor health (of an individual) in the absence of treatment, in terms of either of these aspects of health. In a review of literature on the use of severity as a health care priority setting criterion, Shah reports findings from a range of empirical public preference studies that suggest that "people are, on the whole, willing to sacrifice aggregate health in order to give priority to the severely ill" (Shah, 2009, page 77).

Regarding unmet need, the VBP consultation document suggests the following definition:

> Unmet need could reflect the degree to which there are existing treatments. A condition for which there is no effective treatment, and where there is, therefore,

significant unmet need, could be characterised by a high QALY loss, and deemed to exhibit a high 'Burden of Illness'. Conversely, conditions that were already well served with effective treatments would be scored at a lower level of this measure – even if the untreated condition was itself severe and life-threatening (DH, 2012, page 14).

This definition of unmet need is consistent with the definition used in the European Commission Regulation on the conditional marketing authorisation for medicinal products for human use (EU Commission, 2006). This states:

. . . "unmet medical needs" means a condition for which there exists no satisfactory method of diagnosis, prevention or treatment authorised in the Community or, even if such a method exists, in relation to which the medicinal product concerned will be of major therapeutic advantage to those affected (page 8).

It is worth noting that some definitions of unmet need are concerned with whether the services are being received rather than whether they exist. (See, e.g. Carr and Wolfe, 1976.) However, our interpretation of the Government's proposals is that this definition is not relevant to VBP. Rather, the Government is seeking to incentivise the development of treatments where none exist currently. If a treatment for a particular condition already exists, then the need is considered to be "met". If not, then it is "unmet".

Whilst there is a growing body of evidence on the extent to which the public support the use of severity in health care priority setting (Shah, 2009), we are aware of only a small number of published empirical studies that examine people's preferences regarding unmet need. In a public preference study designed to elicit the relative importance of four different generic social value judgements, Green and Gerard included an attribute which described "whether a patient group has any other effective treatment options available (other than the option being appraised) or whether the current standard treatment is best supportive care" (Green and Gerard, 2008, page 957). Two levels were assigned to this attribute: (1) no other effective treatment options available and (2) other effective treatment options available. In a study of the stated preferences of 37 members of appraisal committees of the National Institute for Health and Clinical Excellence, Tappenden et al (2007) included an

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attribute that described "whether alternative effective therapies are available to manage to condition or not" (page 687). Two levels were assigned to this attribute: (1) no other effective therapies are available and (2) other therapies are available.

Both studies reported coefficients on the unmet need variables such that the likelihood of choosing to fund a hypothetical health technology increases if there are no other effective treatment options available. However, the results from the predicted probability analysis conducted by Green and Gerard (2008) suggests that the extent of unmet need is rarely a determining factor – if other key factors are present (e.g. good value for money, large health improvement, severe condition), then the technology is likely to be chosen even if other effective treatment options are available. Likewise, if those factors are absent, the fact lack of other effective treatment options does not improve greatly the likelihood of the technology being chosen. Tappenden et al (2007) do not provide specific interpretation of the result for the unmet need attribute other than to note that it is one of several factors which, if present, make it more likely that technologies with unfavourable cost-effectiveness profiles nevertheless would be considered viable for adoption.

More recently, Linley and Hughes (2012) conducted a large-scale study of societal preferences for a variety of prioritisation criteria, including those proposed under the VBP system. Their survey asked respondents how they would prefer NHS money to be spent when faced with a choice between a treatment for a disease for which no other medicines are available and a treatment for a disease for which several other medicines are available. The results suggest, all else being equal, that this particular definition of unmet need was supported by respondents as a valid prioritisation criterion. Indeed, the observed preference for giving priority to the treatment that addresses unmet need remained present even when this treatment offered a smaller health gain than the treatment that did not address unmet need.

Given the Government's proposals to reward medicines that tackle diseases associated with high levels of burden of illness, our understanding of the extent to which society places value on such treatments need to be improved further. One way of obtaining information on societal value is to elicit the stated preferences of members of the general public. This approach is consistent with the NHS's policy objective of ensuring public involvement in

health care priority-setting activities (DH, 1997 and 2001). To this end, the DH has asked its Policy Research Unit in Economic Evaluation of Health and Care Interventions (EEPRU) to conduct a large-scale empirical study to obtain weights for burden of illness, therapeutic improvement and end of life that can be applied to new technologies and displaced activities (project in progress).

Our understanding is that the EEPRU study defines burden of illness as the distance from "normal" health. In effect, burden of illness is being treated as a combined measure of severity of the current situation (i.e. the severity associated with the disease, plus the impact of any existing standard therapy) in terms of both length and quality of life. In that study, the presence or absence of an existing therapy appears to be taken into account only inasmuch as it is a contributing factor to the overall level of burden. An alternative interpretation of the VBP definition of unmet need—the existence of alternative treatments *per se*—does not appear explicitly in the EEPRU study. This paper describes a small-scale study of social preferences regarding severity and this latter definition of unmet need.

Objectives

The aim of this exploratory study is to design and pilot an approach to eliciting public preferences regarding the prioritisation of health care resources according to severity and unmet need. The study focuses on the definition of unmet need presented in the previous section – the existence of alternative treatments *per se* (alternative definitions, such as the extent to which existing treatments are effective in terms of producing health improvements or reducing disease burden, are plausible but not considered in this paper).

The study seeks to add to the existing literature on public preferences (Schwappach, 2002; Dolan et al, 2005) by extending the range of candidate VBP attributes that have been subjected to testing for public preferences.

The survey was designed to explore the following research questions:

1. Do people wish to give higher priority to the severely ill than to the moderately ill?

2. Do people wish to give higher priority to treatments that address unmet need than to treatments that do not address unmet need?

3. Do people distinguish between different definitions of unmet need?

4. Are people willing to sacrifice health gain in order to give priority to the severely ill?

5. Are people willing to sacrifice health gain in order to give priority to treatments that address unmet need?

6. Are people willing to sacrifice the opportunity to give priority to the severely ill in order to give priority to treatments that address unmet need?

7. To what extent are people's stated priority setting preferences driven by the method used to elicit these preferences?

Methodology

Survey instrument

The survey comprised 11 questions. Questions 1 to 7 involved hypothetical priority setting scenarios. In each scenario, information was presented about two patient groups with conditions that affected   life expectancy (patients with condition A; patients with condition B). Both patient groups could benefit from new life-extending treatments that were available, but respondents were advised that health care funds were limited and that a choice needed to be made about which of the two treatment options should be provided. Each question required respondents to indicate which of five statements best described their view:

1. I strongly prefer the treatment of patients with condition A

2. I slightly prefer the treatment of patients with condition A

3. I have no preference between the two treatments

4. I slightly prefer the treatment of patients with condition B

5. I strongly prefer the treatment of patients with condition B

The decision to ask respondents to indicate the strength of their preference for one option or the other, rather than to simply ask them which option they preferred, was driven by a concern based on previous research that respondents may express an aversion to "sitting on the fence" when presented with these sorts of choice tasks—referring to factors such as severity as a "tie-breaker "when they feel that there is little to choose between the options (Shah, Tsuchiya and Wailoo, 2011). The decision to describe the conditions and treatment in generic terms (e.g. "condition A") was concern that the use of labels (e.g. "cancer") would induce biased responses based on respondents' personal experiences and interpretations. It also was informed by research that suggests that the level of respondent engagement is not sensitive to the provision of supporting clinical information (Roberts et al, 2009).

Questions 8 and 9 sought to elicit respondents' views about health care priority setting more directly, by asking them which of two statements about the NHS they agreed with most. Question 8 asked whether they thought that the NHS should give priority to treating

patients "for whom there are no other treatments available" or those "who will get the largest health gain from treatment". Question 9 asked whether they thought that the NHS should give priority to treating patients "who are severely ill" or those "who will get the largest health gain from treatment". The inclusion of these questions allows us to examine the extent to which people's stated attitudes are consistent with the attitudes that are implied by their choices in the corresponding trade-off questions.

Question 10 presented again the scenario information from an earlier question (Question 4) in which the only difference between the two conditions was that until now no treatment has been available for condition A, whereas some treatments already exist for condition B. However, rather than being asked to choose which treatment option should be provided, respondents were asked how they would split an unspecified health care budget between the two options (comparable to budget-pie or allocation-of-points techniques that have been used occasionally in the health care context (Ryan et al, 2001)). Eleven response options were provided, ranging from allocating 100% of the budget to one of the treatments to allocating 50% of the budget to each. Comparing respondents' answers to Questions 4 and 10 allows us to explore whether respondents' choices are influenced by the way in which the questions are framed (specifically, the number of response options for indicating strength of preference that are included).

Finally, Question 11 asked respondents to provide any comments they had about the scenario that they had considered in Question 10 (and Question 4). This question was included to elicit qualitative information about respondents' preferences that may help to explain their responses to the earlier choice tasks.

Table 1 summarises the information provided to respondents in Questions 1-7. The survey is reproduced in full in the Appendix.

Table 1: Summary of scenarios depicted in Questions 1-7

	Patients with condition A			Patients with condition B			What was being tested?
	Life expectancy	Life extension	Other treatments?	Life expectancy	Life extension	Other treatments?	
Q1	5 yrs	2 yrs	Yes	5 yrs	1 yr	Yes	Health gain
Q2	5 yrs	1 yr	Yes	1 yr	1 yr	Yes	Severity

	Patients with condition A			Patients with condition B			What was being tested?
	Life expectancy	Life extension	Other treatments?	Life expectancy	Life extension	Other treatments?	
Q3	5 yrs	2 yrs	Yes	1 yr	1 yr	Yes	Health gain vs. severity
Q4	5 yrs	1 yr	No	5 yrs	1 yr	Yes	Unmet need
Q5	5 yrs	1 yr	No	5 yrs	1 yr	Yes (but difficult to take)	Unmet need (alternative)
Q6	5 yrs	1 yr	No	1 yr	1 yr	Yes	Unmet need vs. severity
Q7	5 yrs	1 yr	No	5 yrs	2 yrs	Yes	Unmet need vs. health gain

In Question 1, both patients with condition A and patients with condition B have five years to live with the treatments currently available. The new treatment for condition A extends patients' lives by a further two years, whilst the new treatment for condition B extends patients' lives by a further one year. This question tests whether respondents prefer larger gains to smaller gains (with life extension used as a proxy for overall health gains), and was included to act as a straightforward task to "warm up" respondents, and also to act as a test of dominance. (We would not expect respondents to prefer smaller gains to larger gains.)

In Question 2, patients with condition A have five years to live with the treatments currently available, whilst patients with condition B have one year to live with the treatment currently available. The effects of the new treatments are the same for both conditions—an extension of patients' lives by a further one year. The question tests whether respondents prefer treating patients with shorter remaining life expectancy to treating patients with longer remaining life expectancy, and closely corresponds to the scenario depicted in a similar empirical study conducted by Shah et al (2011) that sought to examine whether the public supports giving higher priority to "end of life" patients than to "non-end of life" patients.

Question 3 combines Questions 1 and 2 by asking respondents to choose between giving a larger life extension to the patient group with longer life expectancy (condition A) and a smaller life extension to the patient group with shorter life expectancy (condition B).

Considerations of unmet need are introduced in Question 4, in which both groups of patients have the same amount of time to live both with and without the new treatments. The only difference between the two options is that until now no treatment has been

available for condition A, whereas some treatments already exist for condition B. However, even with the treatments currently available, patients with condition B are no better off in terms of life expectancy than patients with condition A; the question focuses on whether there is special value in providing treatments for those from whom no alternative treatments are available (as Linley and Hughes point out, "the NHS would always provide some level of care, even if that is limited to symptomatic and palliative care";[6] however, for the sake of simplicity we distinguish only between "no treatment available" and "treatments already exist" scenarios in this study).

Question 5 examines an alternative definition of unmet need. Again, both groups of patients have the same amount of time to live, both with and without the new treatments, and until now no treatment has been available for condition A. Although some treatments exist for condition B, they are described as being difficult to take and disruptive to patients' lives. Thus, whilst it is clear that condition A is associated with high levels of unmet need, it also might be argued that condition B is associated with some unmet need in that the treatments that are available have undesirable properties and new treatments are needed that are more suitable for patients.

Question 6 combines Questions 2 and 4 by asking respondents to choose between treating the patient group with longer life expectancy for whom no treatments currently exist (condition A) and the patient group with shorter life expectancy for whom alternative treatments are already available (condition B). Similarly, Question 7 combines Questions 1 and 4 by asking respondents to choose between giving a smaller life extension to the patient group for whom no treatments currently exist (condition A) and a larger life extension to the patient group for whom alternative treatments are available already (condition B).

Respondents were asked to assume that the only differences between the two options were those presented—the patient groups were the same in all other respects, such as their age and gender. They were also asked to assume that the nature of the patients' conditions is such that further treatment will not be possible if they are not treated at the time of the decision, in order to prevent assumptions about the possibility of new treatments being discovered or used in the future. For the sake of simplicity, quality of life was not mentioned at any point in the survey.

An early draft version of the survey was piloted using a small convenience sample of individuals employed by the project sponsor to assess levels of understanding and acceptability.

Administration of survey

The survey was administered using face-to-face interviews, undertaken by a team of four interviewers employed by Accent, an experienced market research agency. The interviewers completed training on the specifics of the methodology and procedures for this study. All interviews were carried out in a one-on-one setting in the homes of respondents.

Background information (age, social grade and gender of the respondent) was collected at the beginning of the interview. Respondents then considered the questions one at a time, progressing to the next question once they had been given time to consider their views and had provided an answer. The interviewers permitted respondents to amend their answers to earlier questions if they changed their minds during the course of the interview.

Information about the scenarios was presented in two ways: (1) the scenario description was read aloud to the respondent by the interviewer, following a script and (2) the scenario description was presented alongside a tabular summary of the key pieces of information in a paper booklet given to the respondent. These booklets also were used to record respondents' answers to the questions, with respondents completing the booklets themselves in order to avoid interviewer bias (or inaccurate paraphrasing in Question 11).

After concluding the interview, the interviewer was asked to answer three "diagnostic" multiple choice questions. These were concerned with assessing: (1) how well the respondent had "understood and carried out the tasks" (2) how much "effort and concentration" the respondent had put into the tasks; and (3) the extent to which there were "disruptions and interruptions" in the interview environment. All data were collated and entered into an Excel database by the market research agency.

Sample

The survey was administered on a sample of adult members of the general public, split evenly between two areas of southeast England (London and Kent). The target sample size of 60 respondents was determined on the basis of available funding and the desire to complete the data collection as quickly as possible. A "minimum quota" approach was used to recruit a sample that was broadly representative of the UK general population in terms of

age, social grade and gender. The sample was recruited using a "door knock" approach, with the interviewer approaching a household member of every fourth home in a randomly allocated postal area and scheduling interview appointments for those individuals who agreed to participate. A small cash payment was offered as an incentive for participation.

The study was given exemption from the need for review by a research ethics committee by the NHS National Research Ethics Service (NRES).

Results

Interviews were completed in May 2012. All 60 respondents completed the interview in full. The sociodemographic characteristics of the sample are presented in Table 2. The sample is broadly representative of the general population in terms of gender and age, but includes a smaller proportion of individuals in the highest social grades than in the general population (ONS, 2001; NRS, 2010). According to the interviewers, the majority of interviews were carried out in distraction-free environments, with respondents who concentrated on and showed a good understanding of the survey tasks. (In three instances of the interviewers reported that they were doubtful that the respondent had understood the tasks).

Table 2: Sample sociodemographic characteristics

Characteristic		% of sample	General population
Gender	Male	40	48
	Female	60	52
Age	18-34	26	29
	35-64	51	50
	65+	21	21
Social grade	A	0	3
	B	8	20
	C1	48	28
	C2	22	21
	DE	22	28

Responses to choice tasks (Question 1-10)

Aggregate response data are reported in Table 3 (Questions 1-7), Table 4 (Questions 8-9) and Figure 1 (Question 10).

Table 3: Aggregate response data for Questions 1-7

	Prefer to treat A		No preference	Prefer to treat B	
	Strongly prefer A	**Slightly prefer A**	**No preference**	**Slightly prefer B**	**Strongly Prefer B**
Q1	35 (58%)	18 (30%)	4 (7%)	1 (2%)	2 (3%)
Health gain		53 (88%)	4 (7%)		3 (5%)
Q2	23 (38%)	9 (15%)	6 (10%)	12 (20%)	10 (17%)
Severity		32 (53%)	6 (10%)		22 (37%)
Q3	20 (33%)	14 (23%)	11 (18%)	12 (20%)	3 (5%)
Health gain vs. severity		34 (57%)	11 (18%)		15 (25%)
Q4	12 (20%)	12 (20%)	12 (20%)	14 (23%)	10 (17%)
Unmet need		24 (40%)	12 (20%)		24 (40%)
Q5	6 (10%)	16 (27%)	9 (15%)	26 (43%)	3 (5%)
Unmet need (alt)		22 (37%)	9 (15%)		29 (48%)
Q6	12 (20%)	13 (22%)	9 (15%)	20 (33%)	6 (10%)
Unmet need vs. severity	25 (42%)		9 (15%)	26 (43%)	
Q7	6 (10%)	9 (15%)	13 (22%)	14 (23%)	18 (20%)
Unmet need vs. health gain	15 (25%)		13 (22%)	32 (53%)	

In Question 1, the vast majority of respondents (88%) chose to treat the patient group for which the treatment gain is largest. In Question 2, responses were divided; a slight majority of respondents (53%) choose to treat the patient group with longer life expectancy without treatment, and a sizeable minority (37%) expressed the opposite preference. In Question 3, the majority of respondents (57%) chose to give a larger life extension to the patient group

with longer life expectancy at the expense of a smaller life extension to the patient group with shorter life expectancy.

In Question 4, responses were split roughly equally amongst all response options, with an equal number of respondents favouring and opposing the treatment of the patient group for which no treatments exist (40% in both cases). The results for Question 5 were similar to that for Question 4 except for a slight increase in tendency to treat patient group B, for which alternative treatments already exist but are difficult to take.

In Question 6, respondents were split roughly equally between choosing to treat the patient group with longer life expectancy for which no treatments exist and the patient group with shorter life expectancy for which treatments already exist. In Question 7, the majority of respondents chose to give a larger life extension to the patient group for which treatments already exist at the expense of a smaller life extension to the patient group for which treatments do not exist. "No preference" was expressed in 15% of all cases overall, with two respondents choosing this option in all seven questions. In no question did more than a quarter of respondents indicate that they had no preference.

Table 4: Aggregate response data for Question 8-9

Q8	
Statement	**Respondents choosing statement**
I think that the NHS should give priority to treating patients for whom there are no other treatments available	26 (43%)
I think that the NHS should give priority to treating patients who will get the largest health gain from treatment	34 (57%)
Q9	
Statement	**Respondents choosing statement**
I think that the NHS should give priority to treating patients who are severely ill	29 (48%)
I think that the NHS should give priority to treating patients who will get the largest health gain from treatment	31 (52%)

Figure 1: Aggregate response data for Question 10
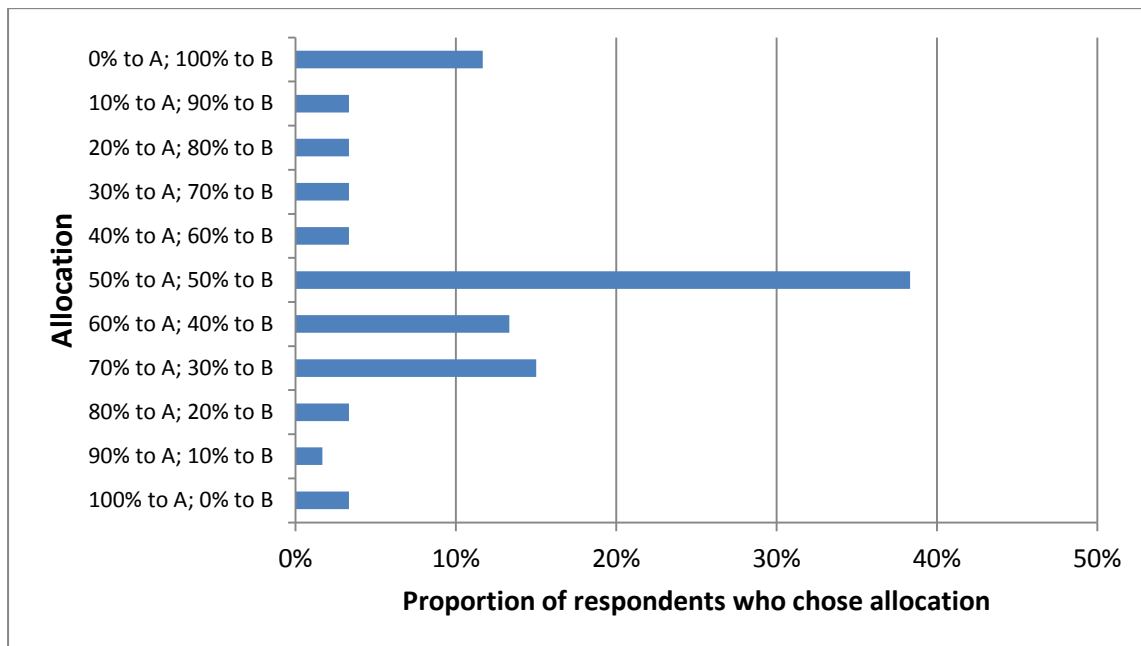
In both Question 8 and Question 9, neither statement was selected by a clear majority of respondents. In Question 10, there was a clear tendency toward an even split of the budget amongst the two treatment options, with 38% respondents choosing this option. Of those who did not choose an even split, a slight majority chose to allocate a larger proportion of the budget to the patient group for which no treatments exist.

The results do not appear to vary greatly depending with the sociodemographic characteristics of the respondents. In Question 7, for example, preferring the larger life extension for the patient group for which treatments already exist was the most common choice amongst respondents in all subgroups defined by gender, age or social grade.

Identification of potentially inconsistent choices

The responses to Question 2, which involved choosing between a patient group with longer life expectancy without treatment (5 years) and another with shorter life expectancy without treatment (1 year), are inconsistent with findings elsewhere in the empirical literature that most people wish to give at least equal priority to those who are severely ill, all else being equal.[3] However, it should be noted that many studies report that whilst the majority of respondents express support for giving priority to the severely ill, a sizeable

number of respondents strongly oppose such a prioritisation approach, and in some cases these respondents are able to articulate clearly the reasons for their position.[11]

Nevertheless, the study design allows us to check whether respondents are behaving consistently (in terms of the choices they make) throughout the survey. For example, we find that 31 of the respondents (52%) preferred (either strongly or slightly) the treatment offering a larger life extension in Question 1, and also preferred (either strongly or slightly) to treat the patient group with longer life expectancy without treatment in Question 2. We would expect these respondents to prefer to treat patient group A in Question 3, since this choice would involve giving a larger life extension to the patient group with longer life expectancy without treatment, thereby combining the respondents' preferred attributes from these previous two questions. Yet 11 of these respondents in fact prefer to treat patient group B. This apparent inconsistency in choices suggests that one response may have been made incorrectly. This possibility is discussed in section 5. Other instances of apparent inconsistency within Questions 1 to 7 did occur, but to a much lesser extent.

Table 5: Cross-tabulation – Question 7 vs. Question 8

		Q8		
		Unmet need > Health gain	Health gain > unmet need	Total
Q7	**Strongly prefer A** (health gain > unmet need)	4	2	6
	Slightly prefer A (health gain > unmet need)	6	3	9
	No preference (health gain = unmet need)	8	5	13
	Slightly prefer B (unmet need > health gain)	6	8	14
	Strongly prefer B (unmet need > health gain)	2	16	18
	Total	26	34	60

Question 8 was designed to address the same issue as Question 7 (whether it is more important to give larger health gains or to give priority to those patients for whom no

treatments exist), but in a different format. Table 5 provides a cross-tabulation of the responses to this pair of questions. The majority of respondents gave a consistent pair of responses. Of the 13 respondents who expressed no preference in Question 7, a slight majority (62%) selected the statement implying a preference for a policy of giving priority according to unmet need in Question 8, in which no opt-out or indifference option was available.

Similarly, Question 10 was designed to address the same scenario as Question 4 (whether priority should be given to those for whom no treatments exist, all else being equal), but in a different format. Table 6 provides a cross-tabulation of the responses to this pair of questions. The darkly shaded cells indicate instances where the respondent's choice in Question 4 is clearly inconsistent with their choice in Question 10 (e.g. preferring to treat the patient group for whom no treatments exist in Question 4 and then allocating the minority of the budget to that group in Question 10). This type of inconsistency occurred on five occasions. The lightly shaded cells indicate instances where the respondent indicated indifference (either by choosing "I have no preference between the two treatments" or by allocating 50% of the budget to each option) in one question but not in the other. The majority of respondents gave a consistent pair of responses. In section 5 we discuss possible reasons why respondents may give different sorts of responses to these two questions.

Table 6: Cross-tabulation – Question 4 vs. Question 10

Q10	Q4					Total
	Strongly prefer A	Slightly prefer A	No preference	Slightly prefer B	Strongly prefer B	
100% A	1				1	2
90% A			1			1
80% A	2					2
70% A	4	3	1	1		9
60% A	1	3	3		1	8
50 : 50	2	6	7	4	4	23
60% B	1			1		2
70% B				2		2
80% B					2	2
90% B				1	1	2

Q10	Q4					
	Strongly prefer A	Slightly prefer A	No preference	Slightly prefer B	Strongly prefer B	Total
100% B	1			5	1	7
Total	12	12	12	14	10	60

Comments left by respondents (Question 11)

Fifty of the respondents (83%) left a comment of some sort in response to Question 11. We (the authors) categorised the comments according to whether or not they were relevant to the question of whether higher priority should be given to treatments that address unmet need, independently of each other. We then collated our categorisations and identified all of the comments that we had both considered to be potentially relevant in terms of references to unmet need (or rejection of the importance of unmet need). We also reached consensus about the inclusion of comments that only one of us had identified as being relevant when working independently. The comments that we judged as being pertinent to unmet need are presented in Table 7, along with the relevant respondents' responses to Q4 and Q10. Other comments, such as general statements about the survey as a whole, are not explored further here.

Table 7: Responses to Questions 4, 7 and 10 for selected respondents

Q4	Q10	Q11 comment
Strongly prefer A	70% to A	I decided on A because that person don't have any other options. I want to give more chance to that person.
No preference	60% to A	Condition A has no treatments available so 60% given because we should be looking for new treatments.
Strongly prefer A	60% to A	Since there was no treatment available previously for condition A, I thought more research is needed for it got 60% funding. Since condition B sufferer's already had some treatment options less research is needed hence the smaller funding.
Slightly prefer A	50:50	Existing treatment shouldn't affect the use and development of new treatment which may prove better in long term
Slightly prefer A	70% to A	There should be a higher focus on finding new treatments for patients and then on looking at treatments to replace old ones.
No preference	90% to A	Increased budget for condition A as there are no other treatments available Budget for further development.
No preference	70% to A	Condition A doesn't have any treatment until the new treatment method so I think spending on the new treatment would make such ill people some chance to live.
Strongly prefer A	100% to A	I think they should treat condition A as condition B has some sort of treatment.
Strongly prefer A	70% to A	To give people an option A. A chance to receive medication - and for those on option B to find ways to make it better.
Slightly	70%	As no other treatments were available for condition A I believe that they should have the

Q4	Q10	Q11 comment
prefer A	to A	new treatment because condition B already had something they could take and could live longer anyway.
Slightly prefer B	100% to B	There is another chance for B with because another treatment already exists. Very limited options for A.
No preference	50:50	Both conditions patients die after 5 yrs. A no treatment 5 yrs. B Treatment 5yrs. As far as I can see the overall scenario for both A+B is the same.
Strongly prefer B	80% to B	Condition B has an alternative to choose from there is still hope for alternative B
Strongly prefer A	70% to A	It's difficult to decide who should receive extra treatment however, I found the condition with no current treatment deserved the larger slice of the budget as it could be detrimental in finding a cure.
Slightly prefer A	60% to A	I mainly chose A because the life gain was longer and because there was no other treatment.
No preference	60% to A	Being a new breakthrough treatment I thought it worth giving slightly more of the budget.
Slightly prefer A	70% to A	Strong preference that if no treatments are available for condition A - then this should be proritised.
Strongly prefer B	100% to B	I do believe treatment should be given to people that will really benefit from. Not wasting money on conditions that untreatable, that's it.

The majority of respondents who left a comment referring to the existence of alternative treatments preferred to treat the patient group for which no treatment exists in Question 4 and to allocate the majority of the budget to the treatment of that group in Question 10. Two respondents who expressed no preference between the two patient groups in Questions 4 and 7 made comments in Question 10 that were consistent with this lack of preference. In some cases, it appears that respondents based their choices on assumptions that were not part of the survey instructions—e.g. assuming that the condition for which no treatments had previously been available is "untreatable" and that patients would not really benefit from any new treatments for that condition.

Discussion and Conclusions

This study has elicited the preferences of a sample of the general public in England regarding priority setting issues in health care. The purpose of the study was not to elicit preferences that can readily be used for decision making, but rather to explore different approaches to examining people's preferences regarding the use of severity and unmet need as priority setting criteria. The interviewers reported that the majority of respondents were able to complete the tasks whilst showing good levels of effort and understanding, although this was not always reflected in the choices made by those respondents.

The responses to Questions 1–7, which involved choosing between treatments for two hypothetical patient groups, indicate that health gain was the main consideration for the majority of respondents. Some respondents expressed preferences for giving priority to those who are severely ill (in terms of remaining life expectancy) or those for whom no other treatments exist, but few were willing to sacrifice health gain in order to pursue these objectives.

Regarding severity, the responses to Question 2 imply that there are more respondents who wish to give priority to the *less* severely ill (patients with five years of life expectancy without treatment) than there are respondents who wish to give priority to the *more* severely ill (patients with one year of life expectancy without treatment). This result is unexpected and runs counter to findings elsewhere in the literature. One possible explanation is that some of these respondents were not concentrating fully, and having responded that they preferred to treat patient group A in Question 1 (which is expected as it implies a preference for larger gains over smaller gains), they simply gave the same response in Question 2. Indeed, 26 respondents made exactly the same choice in both questions. A number of these respondents then preferred to treat patient group B in Question 3, which involved giving a smaller life extension to the patient group with shorter life expectancy without treatment. This suggests that their response to Question 2 may have been erroneous. If it is the case that some of the respondents' choices have been made erroneously (whether due to lack of concentration or for any other reason), this raises concerns about the validity of the survey questions. Refining the wording or structure of the

questions or presenting the information using diagrams in addition to the current text/tables might help to reduce respondent error and improve validity.

Regarding unmet need, we find that no clear picture emerges from the responses to Question 4, which involved a straightforward choice between treating a patient group for which treatments exist and a patient group for which treatments do not exist. Indeed, 40% of respondents chose to treat the former group and another 40% chose to treat the latter group. Relatively few respondents (20%) expressed no preference between the two options. Any evidence of an overall preference for prioritising according to unmet need is diluted further in Question 7, in which only a quarter of respondents expressed a willingness to sacrifice a larger health gain for one patient group in order to treat the other group whose condition was associated with unmet need.

Question 10 used the same scenario as Question 4 but allowed respondents to split a budget amongst the two options rather than to state which option they preferred; nearly 40% of respondents opted for an even split of the budget. Very few respondents opted for an allocation that implied a very strong preference for treating one patient group or the other (e.g. allocating more than 70% of the budget to either treatment option). This suggests the presence of a framing effect whereby respondents are attracted to a 50:50 split in a budget allocation exercise but are averse to selections labelled "I have no preference" in choice tasks in which they have been advised that only one of the two options can be provided. Perhaps the respondents avoid this option because it is unclear what would happen to the limited budget in absence of a clear preference for one option or the other (the instructions advise that "one of the two can be provided from the funds available"). Alternatively, respondents may view a 50:50 split as a legitimate choice if they are finding it very difficult to, or do not wish to, choose between the two options, but do not view the "I have no preference" choice in the same way. It would be useful to ask respondents for the reason(s) behind their choices—by providing a list of possible reasons and asking them to tick all that apply, for example. This would allow us to distinguish between those who are unwilling to choose, those who found it difficult to choose, those who considered that the two treatment options are equally worthy of funding, etc. Alternatively, a further response option could be added to allow respondents to state that

they were not able to make a decision and would prefer that the choice be made by others, an approach that was used in a similar study by Green (2009).

The proposed inclusion of unmet need as a value attribute in VBP implies that some believe that society may consider that there is special value in developing treatments that are indicated for conditions for which no alternative treatments exist. If this is the case, then we would expect respondents to respond to Question 4 by indicating that they would prefer to treat patients with condition A. If the respondents do not agree that there is any special value in addressing (this particular definition of) unmet need, then we might expect them to be indifferent between treatments that address unmet need and similarly effective treatments that do *not* address unmet need. It is less clear, however, why respondents would prefer to treat patients with condition B, as this implies that patients with conditions for which treatments already exist are *more* (as opposed to equally) worthy of treatment than patients with conditions for which no treatments exist. Again there is a possibility that this result is driven by question framing. If respondents strongly reject the notion that priority should be given to treatments addressing unmet need, they may express this feeling by actively voting for the alternative option.

Notwithstanding these possible framing effects, we do not find strong evidence in the choice tasks that people wish to give priority to treatments addressing unmet need over those that do not, especially if doing so would be at the expense of achieving larger health gains. However, the responses to Question 8 indicate the over 40% of respondents agree more with the statement "I think that the NHS should give priority to treating patients for whom there are no other treatments available" than with the statement "I think that the NHS should give priority to treating patients who will get the largest health gain from treatment". This is not necessarily inconsistent with the findings from the earlier questions: some of the respondents who chose the former statement were those who expressed no preference in Question 7, where this option was available. Furthermore, respondents may not necessarily equate "largest health gain" with longer life expectancy (in Questions 1−7, health is presented purely in terms of life expectancy) and therefore may feel that Questions 7 and 8 are addressing slightly different sets of issues. Again, this highlights the

fact that different approaches to eliciting preferences are likely to deliver different sets of results.

In total, 22 respondents made at least one combination of choices that we considered to be "inconsistent". Of these supposedly 'inconsistent' respondents, 60% scored poorly on at least one of the interviewer diagnostic questions (i.e. the interviewers judged that the respondents either had not understood the tasks, or had not put in a great deal of effort, or had been distracted whilst completing the survey). By comparison, only 37% of the entire sample scored less than perfectly on these diagnostic questions. Overall, we found that the interviewers' assessments of how well the respondents understood and concentrated on the survey predicted fairly well how likely they were to give inconsistent answers. It should be noted that excluding from the sample respondents who scored poorly on the diagnostic questions makes very little difference to the results and would not affect our overall conclusions. A 50:50 budget split was the preferred response in Question 10 both for the respondents who understood and concentrated on the tasks and for the respondents who did not.

Overall, the findings of this study suggest that maximising health gain is considered by most people to be more important than alternative objectives such as giving priority to those who have shorter remaining life expectancy without treatment and giving priority to treatments addressing areas of unmet need. Regarding unmet need specifically, whilst many people seem to favour the principle of giving priority to treating patients for whom there are no other treatments available (as per the responses to Question 8), most do not wish to do so at the expense of patients for whom there *are* other treatments available but who otherwise are equally ill and could benefit equally from further treatment. The literature on public preferences for health care indicates that responses in stated preference studies are highly influenced by framing effects, and that is exactly what we have seen in this study. We therefore recommend asking questions in more than one way in order to avoid relying on a single question frame, which could produce misleading or unreliable results.

Appendix: Respondent booklet

SCENARIO 1

Consider two different long-term health conditions – condition A and condition B.

With the treatments currently available, patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

With the treatments currently available, patients with **condition B** also live for **5 years** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A** would extend patients' lives by a **further 2 years**. The new treatment for **condition B** would extend patients' lives by a **further 1 year**. The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	5 years
What increase in length of life does the new treatment offer?	+ 2 years	+ 1 year
Do other treatments already exist for this condition?	Yes	Yes

QUESTION 1

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 2

Consider two different long-term health conditions – condition A and condition B.

With the treatments currently available, patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

With the treatments currently available, patients with **condition B** live for **1 year** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for condition A would extend patients' lives by a **further 1 year**. The new treatment for condition B would also extend patients' lives by a **further 1 year**.

The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	1 year
What increase in length of life does the new treatment offer?	+ 1 year	+ 1 year
Do other treatments already exist for this condition?	Yes	Yes

QUESTION 2

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 3

Consider two different long-term health conditions – condition A and condition B.

With the treatments currently available, patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

With the treatments currently available, patients with **condition B** live for **1 year** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A** would extend patients' lives by a **further 2 years**. The new treatment for **condition B** would extend patients' lives by a **further 1 year**. The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	1 year
What increase in length of life does the new treatment offer?	+ 2 years	+ 1 year
Do other treatments already exist for this condition?	Yes	Yes

QUESTION 3

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 4

Consider two different long-term health conditions – condition A and condition B.

Until now, there has been **no treatment available** for **condition A**. Patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

Some **treatments already exist** for **condition B**. With the treatments currently available, patients with **condition B** also live for **5 years** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A**, which is the first treatment available for this condition, would extend patients' lives by a **further 1 year**. The new treatment for **condition B** would also extend patients' lives by a **further 1 year**.

The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	5 years
What increase in length of life does the new treatment offer?	+ 1 year	+ 1 year
Do other treatments already exist for this condition?	No	Yes

QUESTION 4

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**

☐ I **slightly prefer** the treatment of patients with **condition A**

☐ I have **no preference** between the two treatments

☐ I **slightly prefer** the treatment of patients with **condition B**

☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 5

Consider two different long-term health conditions – condition A and condition B.

Until now, there has been **no treatment available** for **condition A**. Patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

Some **treatments already exist** for **condition B**. With the treatments currently available, patients with **condition B** also live for **5 years** from the time of diagnosis, before they die. However, patients have reported that the **existing treatments for condition B are difficult to take** and cause a great deal of inconvenience and disruption to their lives.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A**, which is the first treatment available for this condition, would extend patients' lives by a **further 1 year**. The new treatment for **condition B** would also extend patients' lives by a **further 1 year**. Both of the **new treatments are relatively easy to take** – taking them does not cause much disruption to patients' lives.

The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	5 years
What increase in length of life does the new treatment offer?	+ 1 year	+ 1 year
Do other treatments already exist for this condition?	No	Yes (but difficult to take)

QUESTION 5

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 6

Consider two different long-term health conditions – condition A and condition B.

Until now, there has been **no treatment available** for **condition A**. Patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

Some **treatments already exist** for **condition B**. With the treatments currently available, patients with **condition B** live for **1 year** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A**, which is the first treatment available for this condition, would extend patients' lives by a **further 1 year**. The new treatment for **condition B** would also extend patients' lives by a **further 1 year**.

The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	1 year
What increase in length of life does the new treatment offer?	+ 1 year	+ 1 year
Do other treatments already exist for this condition?	No	Yes

QUESTION 6

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

SCENARIO 7

Consider two different long-term health conditions – condition A and condition B.

Until now, there has been **no treatment available** for **condition A**. Patients with **condition A** live for **5 years** from the time of diagnosis, before they die.

Some **treatments already exist** for **condition B**. With the treatments currently available, patients with **condition B** also live for **5 years** from the time of diagnosis, before they die.

Now suppose there are two new treatments available – one for condition A and one for condition B. The new treatment for **condition A**, which is the first treatment available for this condition, would extend patients' lives by a **further 1 year**. The new treatment for **condition B** would extend patients' lives by a **further 2 years**.

The nature of the patients' conditions is such that further treatment will not be possible if they are not treated today – this is the only opportunity for treatment.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	5 years
What increase in length of life does the new treatment offer?	+ 1 year	+ 2 years
Do other treatments already exist for this condition?	No	Yes

QUESTION 7

Which of the following statements best describes your view? Please tick one box only.

☐ I **strongly prefer** the treatment of patients with **condition A**
☐ I **slightly prefer** the treatment of patients with **condition A**
☐ I have **no preference** between the two treatments
☐ I **slightly prefer** the treatment of patients with **condition B**
☐ I **strongly prefer** the treatment of patients with **condition B**

QUESTION 8

Which of the following statements best describes your view? Please tick one box only.

☐ I think that the NHS should give priority to treating patients for whom there are no other treatments available

☐ I think that the NHS should give priority to treating patients who will get the largest health gain from treatment

QUESTION 9

Which of the following statements best describes your view? Please tick one box only.

☐ I think that the NHS should give priority to treating patients who are severely ill

☐ I think that the NHS should give priority to treating patients who will get the largest health gain from treatment

QUESTION 10

Please re-consider scenario 4, which is repeated below.

	Condition A	Condition B
How long do patients live *without* the new treatment?	5 years	5 years
What increase in length of life does the new treatment offer?	+ 1 year	+ 1 year
Do other treatments already exist for this condition?	No	Yes

Please indicate what percentage of the budget you would prefer to allocate to each treatment, by choosing one of the options listed below. The maximum amount you can allocate to one treatment is 100%, which would mean that the other treatment receives no funding at all. If you have no preference between the two treatments, then you may allocate 50% of the budget to each one. Please tick one box only.

	Proportion to budget to:	
	Treatment for condition A	Treatment for condition B
☐	100%	0%
☐	90%	10%
☐	80%	20%
☐	70%	30%
☐	60%	40%
☐	50%	50%
☐	40%	60%
☐	30%	70%
☐	20%	80%
☐	10%	90%
☐	0%	100%

QUESTION 11

Please tell us your thoughts about the scenario that you just considered, in which only difference between the two options was that until now there has been no treatment available for condition A, whereas some treatments already exist for condition B.

Use the box below to write any comments you have about this particular scenario.

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