VALUING END-OF-LIFE TECHNOLOGIES, INVESTIGATING THE EXISTENCE OF A 'CANCER PREMIUM' AND METHODOLOGICAL QUESTIONS FOR HEALTH ECONOMICS

Rachel Baker[1], Neil McHugh[1], Helen Mason[1], Gillian Currie[2] and Cam Donaldson[1]

[1] Yunus Centre for Social Business and Health, Glasgow Caledonian University.

[2] Depts of Paediatrics and Community Health Sciences, University of Calgary, Canada.

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AUTHOR FOR CORRESPONDENCE
Rachel Baker
Reader in Health Economics
Yunus Centre for Social Business & Health
Glasgow Caledonian University
Level 3, Buchanan House
Glasgow Caledonian University
Cowcaddens Road
Glasgow G4 0BA

Email: rachel.baker@gcu.ac.uk

BACKGROUND

In resource constrained publicly funded health care systems, decisions about which health care technologies will be provided and, by implication, which technologies will not, are unavoidable. In many advanced economies this has led to the establishment of institutions and processes to evaluate the costs and benefits of new and existing technologies. In England, NICE have adopted a cost-utility-based framework to evaluate health technologies. The Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (AWMSG) have adopted similar evaluative frameworks. Typically, benefits are measured in terms of quality adjusted life years (QALYs) and ratios presented in terms of the incremental cost per QALY gained. However, recommendations about provision also require a judgement to be made regarding the *value* of benefits (i.e. the value of QALYs gained). NICE apply a 'soft' cost-effectiveness threshold such that technologies which cost £20,000-£30,000, or less, per QALY gained are usually recommended for provision by the NHS. Above £30,000, technologies are usually rejected unless a special case can be made for their recommendation (Rawlins and Culyer 2004). An equal weighting is currently applied to all QALYs regardless of the characteristics of the beneficiaries or the types of QALYs (e.g. improvements in quality of life versus extensions in life expectancy). However, the *relative* value of health gains for different groups of people has been a subject of debate since before the inception of bodies such as NICE (Donaldson, Atkinson et al. 1988) and remains a current research question (Dolan, Edlin et al. 2008; Baker, Bateman et al. 2010). There is provision within the

procedures of NICE committees for deliberation and for deviation from the threshold implying that a higher social value may be attached to certain health benefits over others. In their guide to the methods of technology appraisal, NICE state explicitly that the Appraisal Committee will take into account "*Social Value Judgements"* (SVJs) p9 (National Institute for Health and Clinical Excellence 2008).

Supplementary guidance for end of life technologies

Supplementary guidance issued by NICE in 2009 for the appraisal of end of life (EoL) technologies (National Institute for Health and Clinical Excellence 2009) permits their committees to attribute extra weight to health gains for terminally ill patients compared with all other health gains. This move followed a recommendation in the Richards report to the Secretary of State for Health (Richards 2008). Little is known about whether the new guidance reflects societal views regarding health care resource allocation and distributive justice and research is needed to inform policy.

The EoL guidance represents a specific departure for NICE whose committees are now permitted to recommend therapies which have cost per QALY ratios above their standard threshold, subject to specific conditions including: that patients have less than 2 years to live, that the drug is licensed for a relatively small patient group, and that treatments would result in a gain of at least 3 months of increased life expectancy (National Institute for Health and Clinical Excellence 2009). The introduction of such an exception implies that health gains of this type are considered to be of greater social value than other types of health gain, and as such a *weight* is applied to the QALY benefits. The SMC has taken similar steps and include a number of 'decision modifiers' in their Guidance to Manufacturers, which may be called into play when the cost per QALY is relatively high (Scottish Medicines Consortium NHS Scotland 2010). How high the cost per QALY threshold can be pushed is not stated in the NICE guidance, but in an update report in July 2009, reviewing the first four months of implementation, Longson and Littlejohns calculate implicit QALY weights based on the decisions that had invoked the supplementary guidance. They show that the committees had accepted an implicit QALY weight of 1.7. In other words, the health gains in this case were considered by the committee to be 70% more valuable than QALY gains in other cases. Longson and Littejohns requested that the Board support the case for further research: "The supplementary advice highlights that "t*he Institute intends to ensure that the supplementary advice is robust for the long-term and that it achieves its intended purpose" (see paragraph 1.2)* therefore the Board is asked to agree that further research is required to test the assumptions of the EOL advice and to advise on the nature of that research." p5. (Longson and Littlejohns 2009)

If there is general consensus in society that life extensions for those at the end of their life is accorded special value then NICE's supplementary guidance will lead to more efficient use of scarce resources. If, on the other hand, this is not supported then the supplementary guidance will lead to a misallocation of resources. Research is needed to estimate the relative value of health gains generated through EoL technologies versus other uses of NHS funds. Several approaches have been used to estimate relative values, most commonly person trade off (PTO). In this exploratory, pilot study we apply Willingness to Pay (WTP) methods to the elicitation of relative, social values.

OBJECTIVES

1. To design and pilot two different approaches to the elicitation of relative social WTP for expansions to different health programmes.
2. To assess the appropriateness and potential of such methods for eliciting the relative value of EoL technologies compared to other uses of NHS funds.

METHODS

STUDY OVERVIEW

The methods used in this pilot study were devised as a means of exploring two different approaches to eliciting societal WTP values for health programmes, to include technologies for people at the end of life. The first approach we will refer to as "real-world scenarios" and builds on the approach devised by (Olsen and Donaldson 1998) Olsen and Donaldson (1998). The second approach we will call "attribute-based" and is designed such that specific attributes can be varied systematically so that the effect of age, or proximity to death, for example, can be teased out by examining WTP values for scenarios where one attribute is allowed to vary whilst holding others equal. Focus groups and interviews were used to elicit WTP values and to generate qualitative data.

Respondents were invited to take part in the research by a market research company (http://www.researchresource.co.uk/) who recruited members of the public by stopping people in the street and snowball sampling. Although the target sample size (40) is small for this preliminary pilot work, a simple sampling frame was devised to include a balance of respondent characteristics including: age, gender, socio-economic status (based on occupation only) and postcode. A cash payment of £20 was offered to cover travel or other expenses incurred. All respondents took part in focus groups and individual interviews, held at the university (GCU), during November and December 2010.

FOCUS GROUPS

Groups, consisting of 5-7 members of the public were brought together for approximately 45 minutes before participants were each interviewed individually. This study is concerned with citizens' WTP for societal 'goods'. These do not provide direct (hypothetical) health benefits for respondents, but are portrayed as expansions to health programmes described as benefiting a number of patients in respondents' communities (in a sense, like additions to an 'insurance' package within a publicly-funded system). Therefore, respondents and their families may or may not benefit from the expansions if funded. Due to the societal nature of such questions, and based on a growing body of literature that suggests deliberation is important to citizens' valuation (Sagoff 1998), the groups began with discussion around the prospective health programme expansions. Discussions were facilitated by a researcher from the team who began by introducing the notion of scarcity and the need to make difficult choices. The rationale for the pilot study was outlined. Discussions were audio recorded, emphasising assurance of respondent anonymity. Each respondent was given a set of six coloured cards, printed with the 'real-life' scenarios, and labelled L, M, N, O, P and Q (see Appendix A). The scenarios described: laparoscopic surgery for hernias; a new drug for rheumatoid arthritis; an additional drug for leukaemia; an additional treatment for liver cancer; statins for people at risk of heart disease; and a new dementia drug for alzheimers disease, respectively. The scenarios were intended to be as realistic as possible (based loosely on the subjects of NICE technology appraisals) whilst simplifying and summarising information into a small number of key points. Each card included details of: the patient group affected; their disease and symptoms; the type of treatment; and the number of patients that would benefit from extra funding. In an effort to represent a realistic opportunity cost, we set a notional additional budget (arbitrarily set at £500,000) and made a crude calculation of the number of patients who would benefit using available data regarding the per-patient cost of the six technologies. Respondents were not told the size of the additional budget, or the cost per patient, but were asked to imagine that there was a fixed, additional pot of money available in the West of Scotland and that only one of the programme expansions could be funded.

In the first instance, participants were each assigned a different card, L through Q. They were asked to read this card carefully and to describe the scenario described on their card, in turn, to the rest of the group. They were then asked to offer some thoughts about whether or not they thought this was a valuable use of resources. The group were then guided through a discussion of each scenario with open ended prompts from the group facilitator such as "what do you think?", "do you think that is an important area for funding? Why?" The six cards were then arranged in order of importance by each participant individually; their rank orderings were recorded and followed by further guided discussion around the programmes they viewed as most and least important.

WTP – 'real-world scenarios'

The group leader then explained the rationale for WTP methods (as a means of expressing value) and an example of a WTP question was given. Respondents were guided through two WTP questions which were explained to the group, but again completed individually. Two of the six programmes were valued: L (hernia) and O (liver cancer). These were selected because of the differences in terms of the patients treated and the type of health gains possible: L depicts a treatment which impacts the quality of life and speed of recovery for patients who (generally speaking) do not have a life threatening illness. O describes terminally-ill cancer patients with a short life expectancy who may benefit from an additional treatment which extends lives, on average, by 3 months. To elicit maximum WTP, respondents were given a shuffled set of 15 "money cards" printed with values between £1 and £5000 (£1, £2.50, £5, £10, £25, £50, £60, £75, £100, £150, £200, £250, £500, £1000, £5000) and asked to consider, in each case, whether they would pay the amount stated, would not pay, or were unsure, placing the cards into three piles accordingly. They then identified and recorded, on a response sheet, the highest value they "definitely would pay" and the lowest value amongst the values they "definitely would not pay", finally stating their maximum WTP, which may be one of the two amounts recorded or else a figure between.

STRUCTURED INTERVIEWS

Immediately following the focus groups each participant was assigned to an interviewer and taken to a separate room. Interviews were structured according to an interview schedule which included:

WTP 'attribute-based scenarios'

Twelve attribute-based scenarios were devised around three attributes: the age of patients affected (30-40 or 60-70); the type of disease (unlabelled (generic), cancer, heart, lung); and prognosis without treatment (live for 1 or 8-10 years). An example of a generic scenario and a labelled scenario are reproduced in Appendix B. Each scenario describes an expansion to an existing service which would allow 100 additional procedures.

To limit the number of questions facing any individual respondent, there were two versions of the questionnaire. Both versions began with two generic WTP questions (B1 and B2 – see Table 1). Thereafter the versions were split and one half of respondents answered questions relating to 30-40 year olds (version 1: C2, C3, D2, D3 and E2) whilst the other questionnaire version contained WTP questions which related to patients aged 60-70 (version 2: C1, C4, D1, D4, E1). Hence each respondent faced a total of 7 attribute-based WTP questions: 2 generic and 5 disease-labelled scenarios. All respondents answered WTP questions about all three conditions and patients with different life expectancy. Table 1 lists the scenarios devised for this pilot study and the questions appearing in each version of the questionnaire. Although questions B1 and B2 were always presented first, the ordering of the WTP questions for labelled scenarios was varied systematically within questionnaire versions 1

and 2. The elicitation of WTP values took the same form as for the descriptive scenarios. Respondents finished by rank ordering the 5 labelled scenarios.

Qualitative interview

The WTP questions were followed by a short, semi-structured, qualitative interview. This interview was primarily designed to allow for a more in depth understanding of the responses that had been given in the interview and to get feedback on the questions and the overall conduct of the exercise. Respondents were specifically asked to comment on any differences between the WTP values they had given or if they had given the same WTP value for more than one question, why this was. This data has not been analysed as yet and results are not presented in the remainder of this paper.

FINDINGS

In what follows we present the pilot WTP data in as transparent a manner as possible, to enable discussion of responses at an individual level insofar as is feasible. Basic summary statistics are used to describe the findings. Although we draw attention to similarities and differences, we do not draw any inferences about the significance of observed differences. In particular, any observed differences between the values derived from different questionnaire-version sub-samples is as likely to relate to systematic differences between those sub-samples as to indicate genuine differences in valuation.

Pilot participant sample

40 respondents attended 7 focus groups. The demographic characteristics of respondents are presented in Table 2 which also shows the demographic split by questionnaire version. Respondents' gross household income was reported by selecting one of 9 income bands and the midpoint of each income category was used in order to calculate means and medians.

Despite being small, the respondent sample was purposively selected in order to include a balance of socio-demographic characteristics. Nevertheless, there were more males than females and mean income is relatively low. Respondents answering versions 1 and 2 of the questionnaire were broadly similar, although those answering version 1 were, on average, slightly younger with a slightly higher mean income.

'Real-World' Scenarios

Ranking exercise

Table 3 shows the mean and median rank for each scenario. Based on the mean ranks, the scenario describing statins (P) was ranked highest (perhaps because the additional funding would treat 330 people - more than in any other scenario presented - and/or because the treatment is preventive). The additional drug for leukaemia (N) is ranked second on average and the mean rank is very close to that of statins (2.78 and 2.70 respectively). The hernia operation is ranked 6th, on average, and the additional treatment for liver cancer is ranked in 4th position.

Examining the relative ranking of scenarios L and O only, 25 (63%) respondents placed the liver cancer scenario above the hernia scenario and 15 (37%) respondents placed the hernia scenario higher than the liver cancer scenario. On this basis there would appear to be a reasonable degree of heterogeneity between preferences for a treatment that improves quality of life for a relatively large number (100) of patients with a non-life threatening condition versus a treatment which extends the lives of a relatively

small number (5) of terminally ill cancer patients by a short duration. On average, in this sample of respondents, the latter is preferred.

Willingness to Pay

Following the ranking exercises, WTP was elicited for scenarios L and O. Table 4 shows the mean and median WTP for each of these two scenarios.

Mean WTP for O is higher than WTP for L which is consistent with the average rankings shown in Table 3 . A ratio or 'relativity' between the two scenarios can be calculated to indicate the strength of preference for O over L which, based on means is 1.83:1 and, 1.54:1 based on medians. Given that different numbers of patients are treated in each scenario and the size of the health gain is not held equal between scenarios, these ratios are only an indication of the relative strength of preference for one scenario *vis a vis* another. It does not represent a relative weight which could be attached to patients or else QALYs – an issue we return to in the discussion section.

However, examining the WTP data more closely again showed heterogeneity between respondents' preferences for L and O (see Table 5). 21 respondents gave a higher WTP value for O than for L, 8 respondents vice versa and 6 respondents gave the same WTP for L and O.

Qualitative data have not yet been formally analysed, but selected sections of focus group transcripts have been examined for insights into respondents' views of scenarios L and O when ranking the six scenarios. For those who thought the liver cancer treatment was relatively important, rationales differed but clustered around a small number of issues. Some respondents prioritised O for reasons of severity and sympathy for those in need. This was contrasted with the 'new kind of' hernia operation when a treatment is already available:

> ***(in reference to prioritising scenario O – liver cancer)***
> *Well I suppose it is slightly - looking at the figures, you've got a <u>less chance of living</u> than you have with Leukaemia so I think it should be prioritised. I would prioritise it on that basis alone probably, that it's <u>more needed</u> just for the standard of quality of life for the patient for instance.*
>
> ***Ok so what about at the bottom. Out of all the things what would you give lowest priority to?***
> *The hernias.*
>
> ***The hernias. So what is it about the hernias that was…?***
> *Because there is already an operation they can do to fix that, and I think there is much more important. And what I mean is they can already fix it and the money would be better spent.*
>
> **(Excerpt from Group 4 discussion)**

Much of the discussion of scenario O focussed on the limited effectiveness of the liver cancer treatment. There were a few different strands to that view, including: that liver cancer has a very poor prognosis; that patients are going to die soon, even with treatment, and so money may be better spent elsewhere; and that quality of life (not simply life expectancy) at the end of life is very important. Participants often related their views to the experiences of friends and family.

> *F1: … I put at the bottom was O, because as far as I'm concerned with the Liver Cancer as you say if you know somebody which was my husband once it was into the liver that was it. And what they said six to eight*

months and that's what he had, that is a really serious one and there is not a lot they are doing with that yet. I mean even doing that doing things doesn't really help it.

(Excerpt, group 2)

So what do you feel about that treatment? (Referring to liver cancer scenario)
M3: Well I feel it's... My opinion is it's not a priority since the people are obviously not going to live anyway. So I wouldn't prioritise that one at all.
F2: I would agree with that. I don't think it's a priority, not for the few people that are going to benefit for a short time.
F1: I don't think it's worth it for three months. If they were saying three years that might be a different matter, but for three months I don't really think... I think the money again could be better used. I'm sure there are other areas. This is quite interesting.
So it's more because it's the length of life…?
F1: Yes. For three months it's... Again, if you're there I suppose you would think differently but, if you're going to look at it rationally, it's not to my mind, financially a good idea.
F2: Not for three months.

(Excerpt from Group 5 discussion)

R1: Yeah I can imagine but I just wonder if, you know, that, I just wonder if the extra three months in a sense would be worth their while if there's still a tremendous amount of very uncomfortable, pain.
R2: Basically .. another thing - I've had a couple of friends that have died with cancer. You see at the end you're actually relieved because you know there's no going back. They're not in pain and they're at peace. Because it's absolutely horrible to watch somebody...

(Excerpt group 6)

Respondents explicitly discussed trade-offs between aspects of the 'real-life' scenarios when ranking them, between the number of patients treated, severity, prognosis and the size of the health benefits and broader implications such as patients' recovery, return to work and productivity gains. Respondents appear, from their discussions, to have engaged with the scenarios, understood the information presented to them and made informed judgements about their relative value.

Consistency between ranking and WTP responses

As an indication of convergent validity, we examined the concordance between the explicit, relative ranks respondents assigned to scenarios L and O (when ordering the 6 scenarios), and the ranking implied by their WTP values. In other words, were the 21 respondents who gave a higher WTP for O also amongst the 25 who explicitly ranked O above L? Table 6 shows the number of respondents who gave consistent responses. Following (Olsen, Donaldson et al. 2005) we have labelled the respondents who gave the same WTP for both scenarios, but who distinguished between them in the explicit ranking exercise, as "partially consistent". Percentages are based on the 35 respondents who gave complete responses.

22 respondents were consistent in their ranking and WTP for the two scenarios and 7 reversed their responses. 28 (80%) of respondents who gave complete answers were wholly or partially consistent, which is encouraging.

Looking at the 7 inconsistent respondents' ranking and WTP values a little more closely (see Table 7), we can see that for respondent 5 the rank for L and O (4th and 3rd) and WTP (£30 and £25) are very close. Respondents 10 and 13 ranked L and O quite differently and appear to have reversed their preferences in their WTP values. It is possible that they did not comprehend one or the other exercise

fully; or perhaps mistakenly transcribed their rankings in reverse order; made another type of error; or perhaps they altered their preferences between exercises. As mentioned previously, a group discussion took place between the ranking and valuing of scenarios, focusing on the programmes participants viewed as most and least important, so it is plausible that some respondents were persuaded of others' priorities, and their altered views were reflected only in their WTP values.

(Due to a concern over the duration of the focus group, the interview to follow, and participant fatigue, there was no discussion about participants' WTP for L and O. On reflection, discussion could have generated useful insights into preference reversals, or reduced the number of errors occurring.)

Attribute-based scenarios

The results for the attribute-based scenarios were taken from the individual interviews and two respondents did not offer responses. One respondent was a 'protestor' who didn't feel they could answer questions about health and WTP, the other had problems of comprehension and the interview was abandoned. Mean and median WTP and the number of observations for each question are given in Table 8.

Differences in respondents' *individual* WTP based on i) disease type ii) age and iii) prognosis are examined in three short sub-sections below.

i) Disease premiums

Using the attribute-based approach we can select scenarios that vary according to disease type and which are otherwise identical to an unlabelled scenario and estimate a 'disease premium' for each of cancer, heart and lung disease. Since the respondents were split between questionnaire versions two tables follow, Table 9 presents the mean and medians based on 20 respondents who completed version 1 of the questionnaire and so faced WTP questions relating to 30-40 year olds. Table 10 shows equivalent responses derived from 16 participants allocated to version 2 relating to 60-70 year olds.

Two respondents (respondent 1 - version 1 and respondent 6 - version 2) stated higher WTP for the unlabelled scenario than the labelled. This is an unusual response but could potentially be justified if, for example, respondents viewed patients with specific conditions as being in some way responsible for their illness. From the interview transcripts, however, it appears that Respondent 1 found it difficult to justify her responses and, when asked to explain them, repeatedly revised her WTP values. Respondent 6 gave an interesting explanation for reducing her WTP when scenarios were labelled. Her WTP values were £5000 for B1 and C1 and £1000 for D1 and E1. When questioned about her values it transpired that, based on her family history, she believed that 'little could be done for' cancer and lung diseases, but that heart disease could be treated. Her values dropped, therefore, for diseases that she considered incurable. Whilst this is a reasonable justification it raises doubt about whether respondent 6 'believed' the scenarios. Therefore, means and medians have also been calculated excluding these two respondents.

The first column in each table (labelled B2 in Table 9 and B1 in Table 10) shows mean and median WTP values for the generic scenario which is comparable with the labelled scenarios for that questionnaire. In version 1, therefore, since all labelled disease scenarios relate to 30-40 year olds, B2 is the relevant generic comparator scenario. The next three columns (C2-B2, D2-B2 and E2-B2) present the difference in WTP between each disease labelled scenario and the generic (B2). Considering only the mean values in the shaded rows, excluding respondents 1 and 6, there appears to be an overall preference for D

(cancer) over E (lung disease) over C (heart disease). This pattern is not consistent in version 2 as there appears to be a preference for E over D over C. Mean WTP values are very close, however, especially in version 2 and, as mentioned throughout, numbers are small. Median differences are zero for all version 2 scenarios and for the heart disease scenario in version 1.

ii) Age

Preferences for age can be examined in two ways based on our data. Since all respondents gave values for B1 and B2 and since these scenarios differed only in terms of patients' age we can simply look at the mean/median difference between individuals' WTPs for B2 and B1, which is given in Table 11.

Based on these figures there may be a small premium for treating younger people than older people (although the median difference is zero). However, simply taking the mean of the differences between WTP for B2 and B1 may hide the fact that respondents had heterogeneous preferences, i.e. some valued the younger age group more highly but others were willing to pay more for treating older people. Table 12 presents the number of respondents who paid more either B1 or B2 and reveals that almost half the sample gave the same WTP value for both. It would appear from Table 12 that support for an age premium from this sample of pilot respondents is equivocal.

The impact of age on preferences for disease-labelled scenarios, can also be examined *between-samples* and the results of this are presented in Table 13.

WTP values based on the *within-sample* difference between B1 and B2 (the generic scenarios) showed, if anything, a modest, overall preference for younger people. The differences in WTP values, *between-samples,* shown in Table 13 above are somewhat larger, and indicate a preference for treating 60-70 year olds. However, since these differences are derived by subtracting mean values from one sample of respondents from the other sample, little can be said about these figures, except that the differences are consistent across all questions. This could simply indicate a higher willingness or ability to pay *in general* in the sample of respondents allocated to version 2 of the questionnaire. (Mean income is slightly higher in the version 1 group.) In a study designed to detect between-sample differences, large sample sizes and randomisation between versions would help to eliminate differences between groups and would add meaning to differences detected.

iii) Prognosis

The issue of EoL was, in the attribute-based scenarios, presented in terms of two different prognoses. In each scenario, life expectancy for patients, without treatment, is either 1 year or 8-10 years. With treatment, patients gain an additional year of life expectancy. All scenarios have some quality of life component which was described in terms of a proportion of patients being freed from pain (see Appendix B). Table 14 shows the mean difference in WTP for scenarios presenting short life expectancies (C3, C4, D3, D4) and the corresponding scenarios with longer life expectancies (C2,C1, D2, and D1 respectively).

If anything, there appears to be a slight preference for treating people with a longer life expectancy, shown by the positive mean values, except for treating 60-70 year olds with cancer as there is a marginally negative mean (-£2). Median values, however, are zero in every case and, once again, closer examination of the numbers giving higher WTP values for shorter versus longer life expectancies reveals heterogeneity in preferences (Table 15).

More than half responses indicated that equal value is placed on patients with different life expectancies. Of the 36 respondents who gave differential values, 20 gave a higher valuation to the scenario treating patients who had 8-10 years life expectancy without treatment. Qualitative analysis of individual interview transcripts may help to understand this rationale.

Consistency between ranking and WTP responses

Assessing consistency in the attribute-based questions was more complex than in the real-world scenarios where there were only two scenarios subject to WTP valuations. Here, there are 5 WTP questions per respondent, and the same 5 scenarios were also ranked. For simplicity we have looked at the implied and explicit ordering of pairs of scenarios. The results of this are shown in Table 16 and it can be seen that very few respondents were inconsistent, which is, again, encouraging. However, large respondent samples are needed to analyse consistency fully.

To date we have not analysed the qualitative interview data - such analysis may offer insights into the acceptability of real-world versus attribute-based scenarios. The indications from the quantitative, pilot data, are that respondents engaged with both approaches: only two respondents did not offer responses and a small number gave inconsistent responses.

DISCUSSION

Estimating the relative societal value attached to EoL health care is an important, current area for research. In this paper we have described exploratory work which applied social WTP methods to the elicitation of relative values. We have shown that members of the general public can, broadly speaking, engage with the exercises they were presented with. They were able to rank order and value scenarios and present a coherent rationale for their answers. In this discussion we consider: the strengths and limitations of combining group and one-to-one methods to elicit values; heterogeneity and inconsistency in ranking and WTP responses; and, importantly, the interpretation and potential utility (by decision makers) of values generated by our approaches. We finish by highlighting a number of points for wider discussion amongst HESG participants.

i) Group and one-to-one elicitation methods

In order to elicit well-informed preferences, deliberation in focus groups or citizens' juries is often recommended (Sagoff 1998). In this pilot study, the groups functioned well as a means of familiarising respondents with the nature of the study (in terms of scarcity and choice) and with the details of the scenarios to be considered. Discussions were fruitful, generated information about how scenarios were viewed and allowed participants to question one another. For reasons of duration and respondent fatigue, group discussion was limited to certain points in the elicitation process. On reflection, however, potentially useful data (such as respondents' rationales for inconsistent ranking and WTP values in the real-world scenarios) were lost. A final issue to note is the inherent difficulty in connecting audio-recorded comments made in a group setting with values recorded on a response sheet, even when discussions are transcribed carefully. One-to-one interviews are better suited to a combined qualitative/quantitative analysis of this kind.

ii) Heterogeneity and inconsistency in responses

Our findings indicate that, for some health programmes at least, there is likely to be significant heterogeneity in preferences. This has practical implications in terms of analysis as well as higher-level implications in terms of policy. From a practical perspective, the characteristics of

respondents with different preferences should be carefully analysed (specifically with regard to ability to pay – see (Donaldson 1999)). From a policy perspective there are potential issues about decisions based on such values: should mean or median values be applied? When WTP is equal for a large proportion of those surveyed, indicating overall indifference, but a positive premium can be estimated from those with preferences for a specific programme which values should count? How should ranking and WTP be treated when they are not consistent and should a marginal approach to valuation be adopted (Shackley and Donaldson 2002)?

There were relatively low numbers of inconsistent responses, but there may have been more frequent inconsistencies in the real-world scenarios (although a larger sample is needed to confirm this). These were the first questions presented to respondents, which may offer some explanation but there could also be a group effect that might lead to poorer attention/ more frequent errors, or else persuasion and subsequent preference reversal. Attention should always be given to the reasons behind inconsistent responses and we have limited qualitative data to shed light in the real-world scenarios. We may be better placed after analysis of the qualitative interview data from the attribute-based scenarios to explain the small number of inconsistencies. A small amount of respondent error, however, is to be expected in any public survey.

iii) Use of the numbers: interpretation and utility for policy

(Shackley and Donaldson 2000) argue that WTP data should be collected from the public for publicly funded health care programmes. Few studies have applied WTP methods in this way (the exceptions being the Helicopters Hearts and Hips study (Olsen and Donaldson 1998) and the EuroWill project (Donaldson 1998; Luchini, Protiere et al. 2003) and (Onwujekwe, Ojukwu et al. 2006). The interpretation of WTP values is not straightforward for a number of reasons which Shackley and Donaldson discuss, but the design of such studies has the potential to generate values which more closely reflect the decisions facing commissioners and policy makers in the NHS. It does seem clear that these should be interpreted as relative (and not absolute) values that could be used to inform investment and disinvestment decisions at the margin.

In terms of their use by policy makers, facing real decisions about EoL and other technologies, the two approaches piloted have different merits and limitations. On the one hand, the real-world scenarios generate values which are contextualised. This has inherent appeal, not least because there is descriptive warmth to such scenarios which is lost when descriptions are designed on the basis of a limited number of attributes which are systematically varied in a series of (what appear to be) very similar, formulaic questions. But how can values generated by WTP for realistic health programme expansions be interpreted and applied? At the extreme these scenarios could be viewed as so specific that new WTP studies would be needed for all new decisions. A more constructive view would be that such questions can be used to generate *indicative weights*. As such, and by valuing a sufficiently wide range of different scenarios it would be possible, for example, to generate sufficient information to support or refute the existence of EoL QALY weights or a cancer premium. Given a sufficiently in-depth study it may also be possible to gain insight into those aspects of EoL health care that drive such weights (e.g. quality versus length of life, or cancer dread versus other conditions). Policies such as NICE supplementary guidance for EoL technologies or the Cancer Drug Fund are based on assumptions about societal values which need to be underpinned by evidence. Scenarios could be designed which reflect the nature of technologies which are targeted by particular policies.

On the other hand, attribute-based scenarios, designed systematically, generate 'granulated' data. The clear advantage of this is the capacity to estimate the relative value of different scenarios *and* the extent to which different attributes and levels of those attributes drive values. Such an approach could, in principle, generate 'multipliers' for age, disease type, EoL, quality of life, and so on, which could be used to weight QALYs (or health outcomes more generally) to reflect societal preferences. This becomes increasingly complex when consideration is given to the interaction between those attributes and the weight that would be implied by combinations of attributes. A Discrete Choice Experiment (DCE) would be an obvious next step if this was the route taken but there are issues of experimental design which would need to be overcome (Baker, Bateman et al. 2010; Lancsar, Wildman et al. 2011) and choices would inevitably be abstracted from the real-world.

Returning to the real-world scenarios, then, and considering further the use of the numbers. If, as in this example, scenarios are designed to reflect the approximate opportunity cost of investment options, the number of patients treated and the size of QALY gains will vary between scenarios. Mean WTP values represent an indicative social premium attached to the treatment of 5 patients with advanced liver disease compared with 100 hernia patients (£425 versus £233 in our pilot data). In the context of a fixed additional budget, this is useful information. On average the public would prefer to see the additional budget directed towards the liver treatment. But perhaps it would also be helpful to know the relative difference between the scenarios in terms of QALYs or patients?

Following Olsen and Donaldson (1998) we can make crude estimates of the value of a QALY based on these scenarios. The liver cancer scenario, the original NICE submission from which this was taken reported a QALY gain of 0.36 QALYs per person which would result in a 1.8 QALY gain for the programme expansion proposed. Using the WTP values elicited from the participants this would give a value of a QALY of £236 (median £111). For the hernia scenario the QALY gain is 2.89 QALYs per person (health state without treatment is 0.83 and following treatment would return to 1, the gain would last for the remaining 17 years of a patient's life, therefore, each patients gain calculated as ((1-0.83) *17) = 2.89). This would result in a gain of 289 QALYs for the programme expansion which treats 100 people, and based on the WTP value for hernia would give a value of a QALY of £0.80 (median £0.44). The absolute numbers are of less interest than the relative preferences if calculated in this way with a preference for O over L of 286:1. If we instead equalise the numbers of people treated for each programme to 100 assuming that individual's preferences are linear we can multiply the size of the liver cancer programme by 20. Thus WTP would be £8508.4 (median £4000) for the liver programme and remain the same for the hernia programme. This would indicate a strength of preference for the liver programme over the hernia programme of 37:1 (30: 1 based on medians).

This paper presents work in progress and is research we plan to take forward to a grant proposal. With that in mind we would be interested in HESG discussion around the following (and any other) points.

- Which approach has greater appeal, from a theoretical, analytic or policy perspective?
- How could/ should the numbers be used?
- How important is it to set up valuation scenarios which reflect the real opportunity cost of investment options?

WORD COUNT 6659 (excluding tables and references)

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Table 1- Attribute-based scenarios by questionnaire version

CODE/ TITLE	Age 30-40 years	Age 60-70 years	Without Procedure live another 1 year	Without Procedure live another 8-10 years	Questionnaire version (1,2)
B1/ Generic (1)		✓		✓	1,2
B2/ Generic (2)	✓			✓	1,2
C1/ Hearts (1)		✓		✓	2
C2/ Hearts (2)	✓			✓	1
C3/ Hearts (3)	✓		✓		1
C4/ Hearts (4)		✓	✓		2
D1/ Cancer (1)		✓		✓	2
D2/ Cancer (2)	✓			✓	1
D3/ Cancer (3)	✓		✓		1
D4/ Cancer (4)		✓	✓		2
E1/ Lung Disease (1)		✓		✓	2
E2/ Lung Disease (2)	✓			✓	1

Table 2 - Socio-demographic characteristics of respondents by questionnaire version

	Gender			Age*			Income†		
	Male	**Female**	**Total**	**Range**	**Mean**	**Median**	**Mean**	**Median**	**Missing**
Version 1 (%)	14 (61)	9 (39)	23 (100)	18-78	42	39	£17,500	£20,000	4
Version 2 (%)	10 (59)	7 (41)	17 (100)	19-74	45	44	£16,250	<£15,000	1
Total (%)	24 (60)	16 (40)	40 (100)	18-78	44	44	£16,900	<£15,000	5

* 2 respondents did not provide information about their age

† 5 respondents did not report their income. (19 of the remaining 35 selected the lowest income bracket (<£15,000): 9 respondents in version 1 and 10 in version 2.)

Table 3 - Mean and median rank for each 'real-world' scenario

	L Hernia op	M RA drug	N Leukamia drug	O Liver cancer	P Statins	Q Alzheimers drug
Mean rank	***4.18***	3.95	2.78	***3.75***	2.70	3.40
Median rank	***5.0***	4.0	2.5	***4.0***	2.5	3.5
Total rank	***6***	5	2	***4***	1	3

Table 4 - Willingness to pay for Hernia Operation (L) and Liver Cancer Treatment (O) scenarios

	WTP	
	Hernia L	**Liver Cancer O**
Mean	£232.92	£425.42
Median	£130	£200
N	37	36
Refusal	1	1
Missing Values	2	3
Total Sample Size	40	40

Table 5 - WTP for O and L respectively

	WTP O> WTP L	**WTP L> WTP O**	**WTP L = WTP O**	**Missing**	**Total**
n	21	8	6	5	40
(%) Of responses	(60)	(23)	(17)		

Table 6 - Consistency between explicit ranking and implied ranking based on WTP for L and O

	Number (%)
Consistent	22 (63)
Inconsistent	7 (20)
Rank L>O, WTP - Equal	3 (9)
Rank O>L, WTP - Equal	3 (9)
Missing Values	5
Total	40

Table 7 - Inconsistent responses 'real-world' scenarios

Respondent ID (group number)	**Rank L (hernia)**	**Rank O (liver cancer)**	**WTP L £**	**WTP O £**
5 (1)	4	3	30	25
10 (2)	2	6	130	160
13 (3)	1	6	200	1000
26 (5)	6	5	100	25
29 (5)	2	4	50	1000
33 (6)	5	6	250	1000
34 (6)	5	3	100	25

Table 8 - Mean and Median WTP for all attribute-based scenarios

Scenario description	Mean WTP £	Median WTP £	n =	Mean WTP £ (respondent 1 & 6 excluded)	Median WTP £ (respondent 1 & 6 excluded)	n=
B1/ Generic (1)[1]	£302.38	£100	38	£152.51	£100	36
B2/ Generic (2)	£320.67	£100	38	£171.82	£100	36
C1/ Hearts (1)	£521.76	£200	17	£241.88	£175	16
C2/ Hearts (2)	£209.29	£100	21	£182.25	£100	20
C3/ Hearts (3)	£207.62	£100	21	£168.00	£87.50	20
C4/ Hearts (4)	£464.41	£200	17	£180.94	£150	16
D1/ Cancer (1)	£288.24	£200	17	£243.75	£163	16
D2/ Cancer (2)	£245.71	£100	21	£208.00	£87.50	20
D3/ Cancer (3)	£199.29	£100	21	£159.25	£87.50	20
D4/ Cancer (4)	£289.71	£200	17	£245.31	£175	16
E1/ Lung Disease (1)	£290.94	£200	17	£246.63	£200	16
E2/ Lung Disease (2)	£427.14	£100	21	£198.50	£100	20

Tables 9 and 10 - Differences in mean and median WTP based on disease type

Disease Premium (30 – 40 years old) – Version 1				
	B2	**C2 – B2**	**D2 – B2**	**E2 – B2**
Mean	£360.24	-£150.95	-£114.52	£66.90
Median	£75.00	£0.00	£0.00	£0.00
n	21	21	21	21
Mean (respondent 1 excluded)	£128.25	£54.00	£79.75	£70.25
Median (respondent 1 excluded)	£75.00	£0.00	£17.50	£20.00
n	20	20	20	20

Disease Premium (60 – 70 years old) – Version 2				
	B1	**C1 – B1**	**D1 – B1**	**E1 – B1**
Mean	£470.32	£51.44	-£182.09	-£179.38
Median	£200	£0.00	£0.00	£0.00
n	17	17	17	17
Mean (respondent 6 excluded)	£187.22	£54.66	£56.53	£59.41
Median (respondent 6 excluded)	£160	£0.00	£0.00	£0.00
n	16	16	16	16

Table 11 - Difference in WTP based on age in generic scenarios

Age Premium (Generic)	
	WTP B2 – WTP B1
Mean	£18.29
Median	£0.00
n	38
Mean (respondents 1 & 6 excluded)	£19.31
Median (respondents 1 & 6 excluded)	£0.00
n	36

[1] **Mean and median values for B1 and B2 are the combined values for both version 1 and version 2 as the Generic scenarios are the same in both versions.

Table 12- Number of respondents expressing WTP B2>B1

Age Premium (Generic) – Total		
	(n)	**B2- B1 (%)**
WTP more for 30-40 yr olds	15	39
WTP more for 60-70 yr olds	6	16
WTP Equal	17	45
No Info	2	
Total	40	

Table 13 - Differences in WTP, between samples, based on age within different disease scenarios

WTP	Mean	Median	Sample Number	Questionnaire version
C1 (hearts 60-70)	£241.88	£175	16	2
C2 (hearts 30-40)	£182.25	£100	20	1
C1 – C2	***£59.63***	***£75***	***26***	
C3 (hearts 30-40)	£168.00	£87.50	20	1
C4 (hearts 60-70)	£180.94	£150	16	2
C4 – C3	***£12.94***	***£62.50***	***26***	
D1 (cancer 60-70)	£243.75	£163	16	2
D2 (cancer 30-40)	£208.00	£87.50	20	1
D1 – D2	***£35.75***	***£75.50***	***26***	
D3 (cancer 30-40)	£159.25	£87.50	20	1
D4 (cancer 60-70)	£245.31	£175	16	2
D4 – D3	***£86.06***	***£87.50***	***26***	
E1 (lungs 60-70)	£246.63	£200	16	2
E2 (lungs 30-40)	£198.50	£100	20	1
E1 – E2	***£48.13***	***£100***	***26***	

Table 14 - Difference in individual WTP for expansions to health programmes for patients with 1 year and 8-10 years life expectancy

	Version 1			**Version 2**	
	C2 – C3	**D2 - D3**		**C1 – C4**	**D1 – D4**
Mean	£1.67	£46.43		£57.35	-£1.47
Median	£0.00	£0.00		£0.00	£0.00
N	21	21		17	17
Mean (respondents 1 & 6 excluded)	£14.25	£48.75		£61	-£2
Median (respondents 1 & 6 excluded)	£0.00	£0		£0.00	£0.00
N	20	20		16	16

Table 15 - WTP for scenarios treating patients with shorter versus longer life expectancy

Prognosis	Version 1		Version 2		Total responses (%)
	C2 – C3 (%*)	D2 – D3 (%)	C1 – C4 (%)	D1 – D4 (%)	
Higher WTP for 8-10 years LE	5 (24)	5 (24)	7 (41)	3 (19)	20 (26)
Higher WTP for 1 year LE	6 (29)	4 (19)	2 (12)	4 (19)	16 (21)
WTP equal	10 (48)	12 (57)	8 (47)	10 (63)	40 (53)
Missing data	2	2	0	0	4
Total	23	23	17	17	80

* % of complete responses, excluding missing data

Table 16 - Consistency between ranking and WTP responses between pairs of attribute based scenarios

	D2 v C2		D2 v E2		C2 v E2		D1 v C1		D1 v E1		C1 v E1	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Fully Consistent	11	52	9	43	16	76	9	53	8	47	10	59
Partially Consistent	7	33	8	38	5	24	6	35	6	35	5	29
Inconsistent	3	14	4	19	0	0	2	12	3	18	2	12
Total	21	100	21	100	21	100	17	100	17	100	17	100
Missing data	2		2		2		0		0		0	
Sample Total	23		23		23		17		17		17	

APPENDIX A

L

IMPROVED OPERATION FOR HERNIAS

PATIENT GROUP

- Hernias mainly affect men over 60, although they can occur in younger people and in women.
- They sometimes follow strenuous activity such as heavy lifting.

DISEASE & SYMPTOMS

- A weakness in the wall of the abdomen results in a bulge or swelling. It causes discomfort which can affect daily activities.
- In rare cases it can be life threatening (if the bowel becomes strangulated or blocked).

TREATMENTS

- Open surgery is the main treatment for hernia. It is one of the most common operations performed by the NHS.
- A new technique (called 'laparoscopic' surgery) means that patients can recover more quickly and have fewer symptoms (less pain and numbness), improving their quality of life.

Additional funding would mean that 100 patients in the West of Scotland would benefit from this new technique in the next year.

M

NEW DRUG FOR RHEUMATOID ARTHRITIS (RA)

PATIENT GROUP

- Rheumatoid arthritis is three times more likely to affect women than men.
- Generally the age of onset is between 40 and 70.

DISEASE & SYMPTOMS

- The symptoms are pain and swelling of the joints and it disrupts patients' lives. Over time the joints become damaged. After 10 years one third of patients are classed as disabled.
- Life expectancy is shorter for patients with RA (for a 50 year old woman with RA life expectancy is 4 years shorter than a 50 year old without RA).

TREATMENTS

- There is an additional drug available which **reduces pain and swelling** and may slow down progression of disease. It is taken intravenously (by needle into the vein) once a month.

Additional funding would mean that the new drug could be provided to 5 patients in the West of Scotland in the next year.

N

AN ADDITIONAL DRUG FOR LEUKAEMIA (CLL)

PATIENT GROUP

- Chronic Lymphocytic Leukaemia (CLL) is an adult form of leukaemia and mostly occurs in people over 55.

DISEASE & SYMPTOMS

- CLL is a slow growing cancer of the white blood cells which stops normal blood cells from working properly.
- Patients who are diagnosed early can live for more than 10 years and will often not require treatment for some time. Those with advanced disease are likely to live for 1-3 years.
- On average, with current treatments, patients with moderate to advanced CLL can expect to live without the disease progressing **for** 32 months**.**

TREATMENT

- With this additional treatment, on average, patients live an extra 7 to 10 months without disease progression. This means that the cancer does not grow during that time, patients feel better, and may live longer.

Additional funding will mean that 5 patients in the West of Scotland can benefit from this new drug in the next year.

O

ADDITIONAL TREATMENT FOR ADVANCED LIVER CANCER

PATIENT GROUP

- Primary liver cancer affects more men than women. The average age of diagnosis is 66.

DISEASE & SYMPTOMS

- 'Primary Liver cancer' means that the cancer starts in the liver and has not spread from another cancer.
- Life expectancy for patients with primary liver cancer is, on average, 6 to 8 months.

TREATMENT

- This is treatment for people who are not eligible for surgery. It is given in tablet form administered orally 4 tablets per day for as long as benefit is seen.
- Results of treatment vary but on average patients live for an additional 3 months.

Additional funding will mean that 5 patients in the West of Scotland can be treated with this drug in the next year.

P

'STATINS' FOR PEOPLE AT RISK OF HEART DISEASE

PATIENT GROUP

- Heart disease and narrowing of the arteries can lead to a heart attack, angina (pain /discomfort in the chest) or stroke amongst other things.

DISEASE & SYMPTOMS

- These diseases are the most common causes of death in the UK and have a major impact on quality of life.

TREATMENT

- Drugs called 'Statins' are used in people who have, or are at risk of having, diseases of the heart and blood vessels. Statins lower cholesterol and are used to help prevent heart disease. They are taken daily, in tablet form.The health benefits of statins occur in the future. People with risk factors who take statins, on average, have fewer heart attacks, chest pain and strokes, and fewer people die from heart attacks and strokes.

Additional funding would mean that 330 'at risk' people in the West of Scotland would be provided with Statins reducing their risk of heart attack and stroke.

Q

NEW DEMENTIA DRUG FOR ALZHEIMERS DISEASE

PATIENT GROUP

- Azheimers disease mainly affects adults over the age of 65 and is more common in people over the age of 80.

DISEASE & SYMPTOMS

- Dementia is a disorder of the brain that affects functions including memory, thinking and orientation.
- People with dementia become confused, and frequently forget the names of people, places, and recent events. They may experience mood swings or feel scared and frustrated by their increasing memory loss

TREATMENT

- This drug may slow down the progression of the disease and help to reduce some of the symptoms of dementia in some people.

Additional funding would mean that 50 people in the West of Scotland would be treated with this drug in the next year.

APPENDIX B

Example of a generic 'attribute-based scenario

CARD B1

Investment in a Medical Centre

100 more procedures per year, in addition to the 400 per year currently done in the West of Scotland, could be provided, benefiting men or women **aged 60-70 years** who have chest pain and breathe heavily when strained.

The procedure will make 75% of the patients completely **free from pain** for the rest of their lives. Without the procedure the patients are expected to **live another 8-10 years**. With the procedure they will on average **live for an extra 1 year on top of this.**

Example of a labelled 'attribute-based' scenario

CARD C3 (Heart)

Investment in a Heart Unit

100 more heart procedures can be provided each year in addition to the 400 which are currently done in the West of Scotland, benefiting men and women **aged 30-40 years** who have chest pain and breathe heavily when strained.

The procedure will make 75% of the patients completely **free from pain** for the rest of their lives. Without the procedure the patients are expected to **live another 1 year**. With the procedure they will on average **live for an extra 1 year on top of this.**