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Using willingness-to-pay to establish patient preferences for cancer testing in primary care

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Abstract:	<p>Background Shared decision making is a stated aim of several healthcare systems. In the area of cancer, patients' views have informed policy on screening and treatment but there is little information about their views on diagnostic testing in relation to symptom severity.</p> <p>Methods We used the technique of willingness-to-pay to determine public preferences around diagnostic testing for colorectal, lung, and pancreatic cancer in primary care in the UK. Participants were approached in general practice waiting rooms and asked to complete a two-stage electronic survey that described symptoms of cancer, the likelihood that the symptoms indicate cancer, and information about the appropriate diagnostic test. Part 1 asked for a binary response (yes/no) as to whether they would choose to have a test if it were offered. Part 2 elicited willingness-to-pay values of the tests using a payment scale followed by a bidding exercise, with the aim that these values would provide a strength of preference not detectable using the binary approach.</p> <p>Results A large majority of participants chose to be tested for all cancers, with only colonoscopy (colorectal cancer) demonstrating a risk gradient. In the willingness-to-pay exercise participants placed a lower value on an X-ray (lung cancer) than the tests for colorectal or pancreatic cancer and X-ray was the only test where risk was clearly related to the willingness-to-pay value.</p> <p>Conclusion Willingness-to-pay values did not enhance the binary responses in the way intended; participants appeared to be motivated differently when responding to the two parts of the questionnaire. More work is needed to understand how participants perceive risk in this context and how they respond to questions about willingness-to-pay. Qualitative methods could provide useful insights.</p>	
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Dear Editor

Research article

Using willingness-to-pay to establish patient preferences for cancer testing in primary care

Thank you for your positive response to our manuscript. We have now edited the 'Declarations' section to include all that are required. We do not feel a list of abbreviations is necessary for this paper.

Please let us know if any other edits are needed before publication can be completed.

Yours faithfully,

Sandra Hollinghurst

on behalf of Jonathan Banks, Lin Bigwood, Fiona M Walter, Willie Hamilton and Tim J Peters

[Click here to view linked References](#)

1 1 **Using willingness-to-pay to establish patient preferences for cancer**
2 2 **testing in primary care**

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42 **Abstract**

43 *Background*

44 Shared decision making is a stated aim of several healthcare systems. In the area of cancer, patients'
45 views have informed policy on screening and treatment but there is little information about their
46 views on diagnostic testing in relation to symptom severity.

47 *Methods*

48 We used the technique of willingness-to-pay to determine public preferences around diagnostic
49 testing for colorectal, lung, and pancreatic cancer in primary care in the UK. Participants were
50 approached in general practice waiting rooms and asked to complete a two-stage electronic survey
51 that described symptoms of cancer, the likelihood that the symptoms indicate cancer, and
52 information about the appropriate diagnostic test. Part 1 asked for a binary response (yes/no) as to
53 whether they would choose to have a test if it were offered. Part 2 elicited willingness-to-pay values
54 of the tests using a payment scale followed by a bidding exercise, with the aim that these values
55 would provide a strength of preference not detectable using the binary approach.

56 *Results*

57 A large majority of participants chose to be tested for all cancers, with only colonoscopy (colorectal
58 cancer) demonstrating a risk gradient. In the willingness-to-pay exercise participants placed a lower
59 value on an X-ray (lung cancer) than the tests for colorectal or pancreatic cancer and X-ray was the
60 only test where risk was clearly related to the willingness-to-pay value.

61 *Conclusion*

62 Willingness-to-pay values did not enhance the binary responses in the way intended; participants
63 appeared to be motivated differently when responding to the two parts of the questionnaire. More
64 work is needed to understand how participants perceive risk in this context and how they respond to
65 questions about willingness-to-pay. Qualitative methods could provide useful insights.

66

67 **Keywords:** willingness-to-pay; cancer; diagnostic tests; primary health care

68

69 **Background**

70 Shared decision making is a stated aim of several healthcare systems [1,2]. Involving patients in
71 critical decisions about their care is regarded as not only ethically correct but also as a way of
72 improving quality and “avoiding unwanted and costly medical interventions” [3]. In the UK the
73 philosophy of “no decision about me, without me” has been promoted by the Department of Health
74 [4] and has been applied to many aspects of patient care. However, fully shared decisions can only
75 be made if the asymmetry of information between clinicians and patients is more balanced.
76 Recently, the current imbalance has begun to shift, encouraged by a greater will on the part of
77 clinicians and an increase in readily available information accessible to patients, both from the
78 National Health Service (NHS) and elsewhere.

79

80 One notable area where shared decision making has been adopted actively is cancer. Research on
81 patients’ views has informed policy on screening [5] and treatment [6] in accordance with referral
82 guidelines developed by the National Institute for Health and Care Excellence (NICE) [7]. Such
83 information is important, as care plans that incorporate patients’ preferences are more likely to be
84 successful in terms of acceptability and may lead to more efficient use of resources. However, one
85 gap in the evidence is information about patients’ views on testing for cancer with respect to risk:
86 how serious do symptoms have to be, in terms of indicating cancer, for patients to consider a
87 particular test to be worthwhile? The lifetime prevalence of cancer in the UK is more than 30% [8]
88 and despite falling death rates the fear of cancer is known to be high among the general population
89 [9]. Early diagnosis may improve survival [10] but many early symptoms of cancer, for example,
90 cough, diarrhoea, and headache, far more often indicate a benign condition. General practitioners
91 are faced with the challenge of deciding which patients with such symptoms to refer for diagnostic
92 testing, relying largely on their expertise and limited national guidelines [7]. The risk of failing to

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2 93 investigate a potentially serious symptom has to be weighed against the need to avoid unnecessary
3 94 anxiety, inconvenience, side-effects and cost from inappropriate investigation.

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7 96 The study described here is part of a larger study reported more fully elsewhere [11], which used a
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9 97 survey of primary care attenders to investigate preferences for cancer investigation. Three
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11 98 contrasting cancers were chosen as exemplars - colorectal, lung and pancreas – because of their
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13 99 variation in symptoms, type and accessibility of test, treatment, and prognosis. Here, we describe a
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15 100 willingness-to-pay component of the survey, which was designed to enhance the results of the main
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17 101 survey: if the same number of participants opted to be investigated for a particular cancer
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19 102 irrespective of risk level, could the values offered in the willingness-to-pay exercise be used to refine
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21 103 these responses and identify a threshold risk level below which testing was not regarded as
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23 104 worthwhile.
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30 106 Willingness-to-pay has been used extensively to obtain patient and public valuations for a variety of
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32 107 goods and services in many diverse settings.[12] Despite considerable methodological research into
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34 108 the use of different willingness-to-pay techniques [13] no consensus has emerged as to best practice
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36 109 and it is likely that different methods suit different situations and patient groups [14, 15]. The
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38 110 simplest form of value elicitation is to use an ‘open-ended’ approach whereby the respondent is
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40 111 asked to provide a valuation without any prompting or context; more sophisticated, is a ‘payment
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42 112 scale’ approach where a list of feasible values is offered and the respondent chooses from the list. A
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44 113 bidding approach, which is more refined, has generally come to be preferred to both of these. [16,
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46 114 17] This method requires the respondent to accept or reject a starting bid (value), which is increased
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48 115 or decreased according to the response and the process continues until a final value is determined.
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50 116 Although this is often a preferred method there is evidence suggesting that responses in a bidding
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52 117 approach tend towards the point at which the bidding starts (starting point bias) [18, 19, 20]. This
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54 118 can lead to biased results.
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2 120 The aim of this study was to develop and administer a willingness-to-pay questionnaire that could be
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4 121 used to elicit the relative values that patients place on diagnostic testing for lung, pancreatic and
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6 122 colorectal cancers. We aimed to identify a risk threshold for each cancer that would indicate when
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9 123 patients choose to be tested in preference to watchful waiting.

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16 126 **Methods**

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19 127 *Study design*

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21 128 We developed a vignette-based survey with a willingness-to-pay component to determine the
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23 129 likelihood that patients would choose to be tested for colorectal, lung, and pancreatic cancer, using
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25 130 various levels of risk. The key question of what proportion of the population would choose to be
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27 131 tested at each risk level for each cancer was addressed using a simple 'yes'/'no' alternative. Those
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29 132 responding 'yes' to a test proceeded to a willingness-to-pay exercise with the aim of identifying a
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31 133 strength of preference around the binary choice. Cookson suggests that willingness-to-pay exercises
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33 134 that aim to elicit true, absolute values are unreliable because of "budget constraint bias", where the
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35 135 value given is inflated because of the close focus placed on a particular service [21]; comparative
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37 136 willingness-to-pay may be a way of avoiding this. This study adopted the latter technique, with the
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39 137 aim of identifying relative values to differentiate between 'yes' responses by risk level. The survey
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41 138 was designed specifically for this study and was administered using an electronic touch screen tablet
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43 139 computer (an iPad). The iPad application software was custom built, which gave us considerable
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45 140 scope and flexibility in the design. We obtained ethics approval from the South West (Southmead)
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47 141 National Research Ethics Service committee (ref 11/SW/0055). Participants provided oral informed
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49 142 consent.

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145 *Survey design*

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2 146 The survey contained three components. The first section asked for information about participant
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4 147 characteristics, including age, sex, income, education, employment status, ethnicity, experience of
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7 148 cancer (self and family member or close friend), and convenience of the nearest main hospital.

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9 149 Screen shots showing details of the way these questions were asked are included in Appendix A.
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14 151 Secondly, we used vignettes to ascertain participants' attitudes towards testing for cancer. We
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16 152 developed twelve separate vignettes, one for each combination of the three cancers (colorectal,
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19 153 lung, and pancreas) and four different risk levels (1%, 2%, 5%, 10%). The content of the vignettes
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21 154 was informed by current guidelines and clinical experts on the team. We also undertook qualitative
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23 155 interviews with patients referred for symptoms suspicious of cancer [22], and these were used to
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26 156 validate the vignettes' depiction of the three diagnostic pathways as experienced by patients. Each
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28 157 vignette contained a description of symptoms, the chance that these might indicate cancer –
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31 158 presented as a percentage, ratio, and pictorially – information about the diagnostic test that would
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33 159 be used, likely treatment, and an indication of the prognosis. The information provided in the
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36 160 vignettes is summarised in Table 1. For each participant, one of the twelve vignettes was generated
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38 161 randomly, thus avoiding any ordering effect, and the respondent was asked to imagine they were in
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40 162 the situation described in the scenario. They were then asked whether they would choose to have
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42 163 the diagnostic test if it were offered.

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47 165 Following a 'yes' response to the question about testing, participants proceeded automatically to the
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49 166 third section of the survey – the willingness-to-pay exercise. The design of this part of the survey was
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52 167 informed by experts in the team and with reference to published costs of tests. The survey and the
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54 168 values included were tested on a sample of participants using the technique of verbal probing [23] to
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57 169 check that respondents interpreted the question correctly, and understood why it was being asked.

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59 170 Two rounds of verbal probing were carried out, the first on 13 participants and the second on five.
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171 Further pilot testing ensured that the exercise would not be too burdensome. Feedback from the
172 verbal probing was used to refine the content: data from the first round indicated that respondents
173 did not fully understand the concept of opportunity cost so the wording was changed to convey the
174 idea of sacrifice. Subsequent testing in round 2 showed this change was successful. To mitigate
175 starting point (or anchoring) bias we designed a two-part exercise in which respondents were first
176 presented with a payment scale and the response to that question established the starting point of a
177 bidding process. The starting point was generated randomly from a selection within the range of the
178 scale chosen, and the participants could then bid up or down from the starting point. This
179 mechanism is illustrated in Figure 1, using an example where a participant selects the payment scale
180 £101 to £300. The starting point for the bidding is randomly selected by the software from £125,
181 £200, £250 and £300; in this example £200 is selected. The participant is then able to bid up as far as
182 £300 or down to below £125, with five possible end points. In total, 18 end points were used, five for
183 each of the lower three bands (£1 to £100, £101 to £300, and £301 to £700) and three for the “more
184 than £700” band. Within each band, the difference between each end point and the one
185 immediately higher increased as the value increased so that proportional differences were roughly
186 similar [24].

187
188 At the beginning of the task, when presenting the payment scales, we used reference goods to help
189 participants think about the value of a diagnostic cancer test (see Figure 2). We chose a selection of
190 ‘lifestyle’ goods and services, seen as being ‘desirable’ though not essential, and which could
191 conceivably be sacrificed to pay for healthcare. Wording was carefully chosen to encourage them to
192 think in terms of sacrifice – that is, what they might be prepared to give up or go without in order to
193 have a test [25].

194
195 It is known that some individuals find it hard to place a value on healthcare, particularly in the
196 context of a system of universal coverage as in the UK, and moreover some individuals feel it is

197 unethical to expect them to provide a valuation. To accommodate these views the payment scale
198 offered an option of “I would not pay anything for the test”. If this was selected they were then
199 asked a further question about their reason for this view with the choices of “I cannot afford
200 anything extra”, “I do not believe I should pay for healthcare”, and “It is too difficult to put a value
201 on health”.

202
203 Throughout the development of the survey we piloted the wording and layout of all components
204 with a patient and public involvement group using the technique of verbal probing [23]. Feedback
205 from these sessions was used to refine and improve the content.

206

207 *Survey Administration*

208 The survey was administered by researchers in general practice waiting areas. We targeted a
209 susceptible population – that is, those at greater risk of cancer who would be likely to seek health
210 care help and advice (GP attenders aged 40 and over). General practices in three geographical areas
211 (Bristol & South Gloucestershire, Devon, and the East of England) were included and practices were
212 purposively sampled to achieve an overall mix of urban and rural, and a range of socio-economic
213 statuses. Data collection took place at 26 practices at different times of the day and week between
214 December 2011 and August 2012.

215
216 Participants could complete up to three vignettes, one for each cancer. The first vignette was
217 randomly generated from all 12 possibilities (three cancers, four risk levels), the second from the
218 eight that related to the two remaining cancers, and the third from the four relating to the final
219 cancer.

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221 When data collection was complete we conducted a test-retest exercise in a different practice using
222 a convenience sample of 48 volunteers who agreed to return two weeks later. The random

1
2 223 generation of vignettes was removed from the survey for the second stage of this exercise to ensure
3 224 the two tests were identical.

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7 226 *Analysis*

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9 227 Data were electronically downloaded directly from the iPads at the end of each session. Participant
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11 228 characteristics were explored descriptively and the age/sex profile was compared with that of
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13 229 England as a whole and general practice attenders. Responses to the choice of whether to be tested
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15 230 were analysed descriptively and using logistic regression to establish the extent to which risk played
16
17 231 a part in participants' decisions.

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21 233 The data from the willingness-to-pay exercise were analysed to explore whether they could be used
22
23 234 to inform the strength of preference about the simple 'yes'/'no' choice. We therefore investigated
24
25 235 the extent to which willingness-to-pay values differed according to risk. We explored this
26
27 236 descriptively using means and medians, and tested the relationship between the willingness-to-pay
28
29 237 values and risk using regression analysis. A one-way analysis of variance, with three degrees of
30
31 238 freedom, was conducted to investigate the difference in mean willingness-to-pay across all risk
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33 239 levels, for each cancer.

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37 241 Analysis was carried out using Stata v13.1 statistical software and Microsoft Office Excel 2013.

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41 243 **Results**

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43 244 *Participant characteristics*

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45 245 A total of 3,469 participants took part, completing 6,930 vignettes. The characteristics of the
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47 246 participants are shown in Table 2. The age/sex profile of responders is similar to that of the
48
49 247 consulting population in England [26]. As expected, when compared with the general population of
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51 248 England the sample was under-represented in terms of younger men (17% vs 27% aged 40-59), and

249 over-represented in respect of older women (15% vs 11% aged 60-69), and for all elderly people
250 (29% vs 24% aged 70 and over) [27]. The respondents were: largely white British; nearly half were
251 retired; 15% had previously been diagnosed with cancer; and 75% had a family member or close
252 friend who had experienced cancer.

253

254 *Binary responses*

255 Detailed results of the responses to the 'yes'/'no' question about whether to opt for a test have
256 been reported elsewhere [11]. Table 3 shows the number of participants choosing to be investigated
257 at each risk level for each cancer. A large majority (88%) of participants chose to be referred for a
258 test; this was slightly lower in the low risk (1%) group and higher in the high risk (10%) group, but the
259 difference was very small (87% vs 89%). Colonoscopy (colorectal cancer) had a lower uptake than
260 chest X-ray (lung cancer) and ultrasound/CT scan (pancreatic cancer) and displayed the greatest risk
261 gradient. These observations were confirmed by the results of the logistic regression analysis, which
262 controlled for patient characteristics.

263

264 *Willingness-to-pay*

265 The results of the willingness-to-pay exercise are presented in Tables 4-6. Table 4 gives the number
266 and percentage of participants who selected each payment scale, by cancer and by risk level and
267 Table 5 gives the values indicated in the bidding exercise. Results for each cancer separately are
268 based on all responses, but because participants could respond to up to three vignettes, results for
269 all cancers together use each participant's first response so as to reduce differential selection bias.
270 Responses covered the entire payment range offered for all cancers and all risk levels, though 68% of
271 participants bid up to the highest value within the range of the payment scale chosen.

272

273 The results show that participants placed a lower value on an X-ray for lung cancer than the tests for
274 colorectal or pancreatic cancer; the regression analysis in Table 6, which shows the best-fit logistic

1 275 regression models, indicate that controlling for other factors there was a difference of about £51
2 276 (95% CI: £14 to £87) in the mean willingness-to-pay between an X-ray and a colonoscopy and slightly
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4 277 less between an X-ray and the tests for pancreatic cancer. In general, testing was valued more highly
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7 278 when risk was high than when it was low, though the increase is not monotonic in the case of
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9 279 colorectal and pancreatic cancers (Tables 5 and 6). This may be related to the lack of a clear gradient
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11 280 for these two, as evidenced by testing for a difference in mean willingness-to-pay by risk level (p-
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13 281 values: colorectal 0.71; pancreas 0.91).

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18 283 Around one fifth of respondents chose “I would not pay anything” when completing the payment
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20 284 scale exercise. Of these, one half said they did not believe they should pay for health care and one
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22 285 third said they could not afford to pay. Comparing the lowest risk level (1%) with the highest (10%),
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24 286 more individuals reported not being able to pay at the higher level (32% vs 26%) and more said they
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26 287 did not think they should pay at the lower level (59% vs 52%).

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31 32 33 289 *Factors influencing responses to individual cancers*

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35 290 Previous analysis of responses to the ‘yes/no’ question of whether participants chose to be tested
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37 291 indicated that age was an important factor in all three cancer models [11]. Other variables affecting
38
39 292 this decision were travel time to nearest hospital (colorectal and lung), whether a family member or
40
41 293 close friend had previously been diagnosed with cancer (colorectal and lung) and income (colorectal
42
43 294 and pancreas). The willingness-to-pay exercise indicated a rather different set of variables
44
45 295 influencing the values placed on the tests: age did not appear as a factor in any of the three models
46
47 296 and neither did travel time (Table 6). Three variables did however contribute to the willingness-to-
48
49 297 pay values in all three tests: those with a higher income, particularly those in the highest bracket,
50
51 298 were prepared to pay more for testing, as were the more highly educated, and a previous diagnosis
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53 299 of cancer increased the valued placed on a test by between £63 (95% CI: £13 to £114) (lung) and £73
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55 300 (95%CI: £22 to £124) (colorectal). Additionally, the values placed on an X-ray for lung cancer were
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2 301 affected by a family member or close friend having been diagnosed with cancer and employment
3 302 status. Males were prepared to pay more for testing for pancreatic cancer than were women.

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7 304 *Test-retest*

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9 305 Analysis of the test-retest data suggested a good level of agreement in terms of the binary choice

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11 306 question: 47 (99%) of the 48 who took part gave the same response as to whether they would

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13 307 choose to be tested. The level of agreement for both parts of the willingness-to-pay element was

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15 308 lower. Forty-three of the 48 respondents entered the willingness-to-pay exercise on both occasions

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17 309 and chose a payment scale. Of these, 25 (58%) chose the same band on both occasions. Forty-two

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19 310 participants gave two valid willingness-to-pay values from the bidding process and 14 (33%) gave the

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21 311 same exact value at re-test.

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25 313 **Discussion**

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27 314 *Key findings*

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29 315 The aim of this willingness-to-pay exercise was to enhance the responses to a simple 'yes'/'no'

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31 316 question about testing for cancer, by indicating a strength of preference. We hypothesised that we

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33 317 might be able to identify a threshold level of risk below which patients would prefer to wait and see

34
35 318 how symptoms develop before being referred for further investigation. Although the overwhelming

36
37 319 majority of respondents opted for testing for the three cancers at all levels of risk included, the

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39 320 responses to the willingness-to-pay exercise did not augment the results of the binary question as

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41 321 anticipated; in fact the results suggest that participants treated the two parts of the survey rather

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43 322 differently. The 'yes'/'no' component of the survey indicated a risk gradient in the case of colorectal

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45 323 cancer, which was not seen in the willingness-to-pay values given to pay for a colonoscopy, but there

46
47 324 was evidence that risk influenced willingness-to-pay values for testing for lung cancer. Furthermore,

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49 325 the participant characteristics that affected the decision to opt for a test were different than those

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51 326 affecting the willingness-to-pay values.

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328 *Explanations for the findings*

329 In general, the willingness-to-pay values obtained did not differentiate across risk levels as much as
330 hypothesised. It is possible that the known “fear of cancer” may have contributed to this, indeed this
331 was indicated in the yes/no part of the questionnaire where results suggested that patients would
332 opt for testing even at very low levels of risk.

333 The willingness-to-pay values obtained suggest that risk is an important consideration when patients
334 are deciding whether to accept the offer of a test for cancer of the lung but not colorectal or
335 pancreas, a finding at odds with those of the binary ‘yes’/‘no’ decision, where risk was only evident
336 in colorectal cancer. Colorectal cancer involves the most invasive test, which may explain this
337 finding, but it would seem that in the willingness-to-pay exercise participants may have
338 discriminated according to neither the burden of the test nor the prognosis (pancreatic cancer
339 having the worst likely outcome), but possibly their perception of the cost of the test. They valued a
340 chest X-ray more highly if the risk of cancer was high (£365 at 10% risk) and lower if the risk was low
341 (£305 at 1% risk) and there was a clear gradient (p-value 0.049). This was not the case with the more
342 expensive tests where there was no evidence of an overall gradient despite the value placed on a CT
343 scan for pancreatic cancer at the 10% risk level being somewhat higher than the value at 1%. The
344 tests were described in detail in the vignettes so it is possible that many participants recognised that
345 a chest x-ray is less costly than a colonoscopy and a CT scan. This confirms the belief that willingness-
346 to-pay questions tend not to be sensitive to the size or scope of benefits [28] but is counter to the
347 finding that people tend to state a similar amount for any reduction in risk of death or injury [29].

348

349 This raises the question of what people are actually valuing when they answer a willingness-to-pay
350 question. Our hypothesis was that the willingness-to-pay exercise could be used to discriminate
351 between cancers and risk levels more sensitively than a binary choice of whether to be tested or not.
352 However, it would seem that participants viewed the two parts of the questionnaire separately and

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353 differently: the initial choice of whether to be tested appears to have been driven by the burden
354 placed on them in undergoing the diagnostic test, illustrated by greater reservation about agreeing
355 to a colonoscopy than the other tests, whereas the willingness-to-pay component appears to reflect
356 people's perception of the cost burden of the test, as a chest X-ray is by far the least expensive of
357 the three. While the main aim of our study was to make comparisons across cancers and risk levels it
358 is useful to reflect on the absolute levels of the willingness-to-pay values in comparison to those
359 found in similar studies. Marshall et al [5] compared physician and patient preferences for different
360 methods of screening for colorectal cancer in Canada and the US. The values obtained ranged from
361 US\$111 (equivalent to £245 inflation adjusted) to C\$232 (£662) depending on the type of test and in
362 another US-based study to determine the value of time and discomfort of a colonoscopy, Jonas et al
363 [30] reported a mean value of US\$263 (£563). In the UK Frew et al [31] compared different methods
364 of eliciting the willingness-to-pay for a faecal occult blood (FOB) test and a flexible sigmoidoscopy
365 (FS) for colorectal cancer screening with results ranging from £86 (£136, inflation adjusted) for FS to
366 £130 (£205) for FOB. In comparison to this, Nuemann et al [32] obtained somewhat higher values in
367 their US study for predictive testing: for breast and prostate cancer these ranged from US\$508
368 (£904) for an imperfect test for breast cancer when the risk is 10% to US\$622 (£1007) for a perfect
369 test for prostate cancer when the risk is 25%. Our results of £305 to £393 across all cancers and risk
370 levels fall towards the lower end of these, closer to the UK study results than those from North
371 America.

373 *Methodological considerations*

374 A variety of willingness-to-pay methods have been used in different settings and different patient
375 groups [12]. In this study we used a bidding approach; furthermore, to mitigate the effect of any
376 possible starting point bias we employed a two-part approach with each participant effectively
377 selecting their own starting point. To our knowledge, this is a novel approach, made possible
378 because of the mode of administration and the electronic nature of the questionnaire. However, in

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379 avoiding one methodological difficulty we have arguably introduced another. The bidding exercise
380 was designed to restrict participants to the boundaries of the payment scale they chose in the first
381 part of the willingness-to-pay exercise. This decision was largely driven by concern over ethics: it was
382 considered ‘unfair’ to allow respondents to bid above/below the top/bottom value of the scale they
383 had chosen. In fact, we found that 68% of participants bid up to the highest value, leaving the
384 unanswered question of what would have happened if they had been allowed to go beyond that
385 value. This, in part, may explain the poor result in the relevant part of the test-retest exercise
386 because once the participant had chosen a different payment scale in the retest, which 40% did, it
387 was impossible for them to identify the same final value as in the initial exercise.

388
389 In designing our study we were conscious of the phenomenon of ‘prominent’ numbers and we felt
390 that the two-part design might mitigate this. In fact, analysing the results of the test-retest exercise
391 we found that all participants who chose exactly the same value on both occasions had chosen a
392 ‘prominent’ number: £0, £100, £300, £700 or £1000. This highlights the need for a better
393 understanding of the role of ‘prominent’ numbers in such studies and has implications for the design
394 of future studies.

395
396 We included reference goods in the payment scale exercise to help participants think about the
397 value of a test. The verbal probing exercise did not throw up any consensus concerns about the use
398 of reference goods or the choice of goods but there were some interesting individual comments:
399 *“You are given a few ideas to give you the value of the cost”, “I think health is more important than*
400 *material things” and “At my age we already have most things we need – furniture etc.”* However,
401 when asked how easy or hard it was to put a value on the test none of the respondents mentioned
402 that the reference goods helped. Whilst it seems useful to have benchmark reference goods for
403 respondents to use our experiences suggest these are not essential; if they are included they must
404 be chosen carefully and must be relevant to the population being surveyed.

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7 408 *Limitations*

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9 409 The technique of willingness-to-pay is a conceptually attractive method of eliciting valuations and

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11 410 preferences. If responses reflect the true value that a population places on an intervention such as

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13 411 diagnostic testing the value can be compared with cost in a 'purer' way than any other outcome and

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15 412 used to make decisions about allocative efficiency. However, the results of this study show that

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17 413 many people find it difficult to think in terms of the value of benefit offered rather than what the

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19 414 intervention involves, and this is likely to be particularly true in a system of universal health

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21 415 insurance such as the NHS in England. While we were unable to use the results of this study as

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23 416 intended, they do reveal interesting unanswered questions which should be explored further.

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25 417 Qualitative methods could be employed to understand more about the thought processes and

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27 418 motivation of respondents as they complete such a survey; although some limited work has been

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29 419 done in this area [24, 33] there is a clear gap in our knowledge that needs to be closed in order to

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31 420 successfully exploit the full potential of willingness-to-pay as a technique for eliciting true valuations.

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35 422 **Conclusion**

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37 423 The willingness-to-pay exercise reported here successfully obtained valuations for cancer testing

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39 424 from a large and diverse sample of the UK consulting population. A risk gradient was found only in

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41 425 the case of an X-ray for lung cancer, with higher values reflecting greater risk. This was inconsistent

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43 426 with responses to the question of whether to be tested or not, which suggested risk affected testing

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45 427 preferences only in the case of colorectal cancer. More investigation is needed to understand how

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47 428 patients perceive and respond to risk in this context, and how best to develop the use of willingness-

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49 429 to-pay techniques, which have the potential to provide good quality evidence which could enhance

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51 430 decision making in the provision of health care services.

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433 **Declarations**

434 **Ethics approval and consent to participate**

435 Ethical approval was obtained from the South West (Southmead) National Research Ethics Service
436 committee (ref 11/SW/0055). Participants provided oral informed consent.

437
438 **Consent to publish**

439 Not applicable

440
441 **Availability of data and materials**

442 The datasets generated and analysed during the current study are available from the corresponding
443 author on reasonable request.

444
445 **Competing interests**

446 WH is the clinical lead for the ongoing revision of the NICE 2005 guidance on suspected cancer. His
447 contribution to this article is in a personal capacity, and is not to be interpreted as representing the
448 view of the Guideline Development Group, or of NICE itself. The remaining authors have no
449 competing interests relevant to this research paper.

450
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456
457 **Authors' contributions**

1 458 WH and SH conceived of the study; JB, TP and FW contributed to the design. LB collected the data
2 459 under the supervision of JB and SH. SH and TP carried out the statistical analysis and all authors
3
4 460 contributed to the interpretation of the results. SH drafted the manuscript, with contributions from
5
6
7 461 all other authors. All authors read and approved the final manuscript.
8

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569 Table 1. Summary of content of 12 vignettes: one for each combination of cancer and risk level

570

	Colorectal	Lung	Pancreas
symptoms for 1% risk	Diarrhoea on most days	Coughing on most days...unusually tired	Some stomach pain on most days...lost a few pounds (~1.5-3kg) in weight
symptoms for 2% risk	Diarrhoea and stomach pain on most days	Coughing on most days...a little out of breath walking up hills...lost a few pounds (~1.5-3kg) in weight	Some stomach pain on most days...lost half a stone (3.2kg) in weight
symptoms for 5% risk	Unusually tired...blood test shows anaemia	Coughing on most days...coughed blood once	Continuous stomach pain...lost half a stone (3.2kg) in weight
symptoms for 10% risk	Intermittent bleeding from the back passage (rectal bleeding)...blood test shows anaemia	Coughing on most days...coughed blood a few times...lost half a stone (3.2kg) in weight	Continuous stomach pain...lost 1 stone (6.4kg) in weight
test/ investigation	Colonoscopy	Chest x-ray	Ultrasound scan followed by CT scan
treatment	Surgery and chemotherapy	“Difficult to treat”	“Difficult to treat”
prognosis/outlook	Early diagnosis may improve outcome	Early diagnosis may improve outcome	Early detection does not necessarily improve survival

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574 Table 2. Participant characteristics

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Characteristic	Category	n	%
<i>Age group</i> n=3452	40-59	1519	44.0
	60-69	945	27.4
	70+	988	28.6
<i>Sex</i> n=3461	male	1457	42.1
	female	2004	57.9
<i>Income</i> n=2958	<£10,000	720	24.3
	£10,000 - £25,000	1166	39.4
	£25,001 - £40,000	581	19.6
	£40,001 - £75,000	319	10.8
	>£75,000	172	5.8
<i>Ethnicity</i> n=3453	White British	3,096	89.7
	White Other	159	4.6
	Mixed	40	1.2
	Asian or Asian British	90	2.6
	Black or Black British	46	1.3
	Chinese	10	0.3
	Other Ethnic Group	12	0.4
<i>Education</i> n=3388	None	1,001	29.6
	GCSE or equivalent	781	23.1
	Vocational / 'A' level	850	25.1
	Degree and higher	756	22.3
<i>Employment</i> n=3446	Retired	1,673	48.5
	Not in paid employment	379	11.0
	Working part time	607	17.6
	Working full time	787	22.8
<i>Cancer diagnosis – self</i> n=3463	Yes	522	15.1
	No	2941	84.9
<i>Cancer – family/ close friend</i> n=3465	Yes	2597	75.0
	No	868	25.1
<i>Convenience of hospital</i> n=3461	Very convenient	1,388	40.1
	Quite convenient	1,621	46.8
	Quite inconvenient	323	9.3
	Very inconvenient	129	3.7
<i>Travel time to hospital</i> n=3463	<0.5 hour	1,759	50.8
	0.5 – 1 hour	1,458	42.1
	>1 hour	246	7.1

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577 Table 3. Number (%) choosing to be investigated by cancer and risk level

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	Colorectal		Lung		Pancreas		All three cancers (first vignette only)	
Risk level	Number of responses	Number (%) choosing to be tested	Number of responses	Number (%) choosing to be tested	Number of responses	Number (%) choosing to be tested	Number of responses	Number (%) choosing to be tested
1%	572	462 (81%)	581	533 (92%)	582	525 (90%)	898	782 (87%)
2%	569	485 (85%)	571	531 (93%)	580	527 (91%)	838	738 (88%)
5%	580	496 (86%)	589	543 (92%)	572	526 (92%)	873	764 (88%)
10%	570	508 (89%)	582	537 (92%)	582	529 (91%)	860	768 (89%)
	2291	1951 (85%)	2323	2144 (92%)	2316	2107 (91%)	3469	3052 (88%)

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1 581 Table 4. Number and percentage of respondents selecting each willingness-to-pay band by
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 3 582 cancer (all responses) and by risk level (first response only).

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	Colorectal	Lung	Pancreas	All three cancers (first response only)
£1-£100	630 (35%)	774 (39%)	691 (36%)	1,030 (37%)
£101-£300	382 (21%)	400 (20%)	397 (20%)	541 (20%)
£301-£700	186 (10%)	180 (9%)	197 (10%)	262 (9%)
over £700	287 (16%)	278 (14%)	312 (16%)	405 (15%)
would not pay	311 (17%)	346 (17%)	340 (18%)	527 (19%)
	1,796	1,978	1,937	2,765
	1%	2%	5%	10%
£1-£100	295 (42%)	244 (36%)	242 (36%)	252 (36%)
£101-£300	139 (20%)	127 (19%)	129 (19%)	146 (21%)
£301-£700	58 (8%)	71 (10%)	62 (9%)	71 (10%)
over £700	83 (12%)	102 (15%)	102 (15%)	118 (17%)
would not pay	124 (18%)	137 (20%)	146 (21%)	120 (17%)
	699	681	681	707

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588 Table 5. Mean (SD) and median (IQR) willingness-to-pay values, by cancer and risk level

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	n	Mean (SD) £	Median (IQR) £
Colorectal			
1%	354	380 (348)	300 (100 to 700)
2%	351	393 (351)	300 (100 to 700)
5%	373	367 (351)	270 (100 to 700)
10%	385	367 (343)	270 (100 to 700)
	1463	377 (348)	300 (100 to 700)
p-value		0.71	
Lung			
1%	401	305 (326)	100 (100 to 300)
2%	403	339 (336)	270 (100 to 503)
5%	399	360 (349)	270 (100 to 700)
10%	412	365 (346)	270 (100 to 700)
	1615	342 (340)	224 (100 to 670)
p-value		0.049	
Pancreas			
1%	389	371 (355)	224 (100 to 700)
2%	405	367 (336)	300 (100 to 700)
5%	378	375 (352)	270 (100 to 700)
10%	401	385 (358)	300 (100 to 700)
	1573	374 (350)	270 (100 to 700)
p-value		0.91	
all cancers (first response only)			
1%	567	312 (327)	100 (100 to 300)
2%	534	366 (347)	270 (100 to 700)
5%	529	360 (347)	270 (100 to 700)
10%	573	377 (351)	270 (100 to 700)
	2203	353 (344)	224 (100 to 700)
p-value		0.0075	

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592 NOTE: p-values were obtained from the one-way analysis of variance, with three degrees of

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594 freedom, conducted to compare the effect of risk level on willingness-to-pay.

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Table 6. Logistic regression: factors influencing the value of willingness-to-pay. Best fit logistic regression models for each cancer separately and all cancers together.

£	All cancers together ^a			Colorectal (colonoscopy)			Lung (chest x-ray)			Pancreas (Ultrasound / CT scan)			
	Variable (reference category)	Coeff (se)	p-value	95% CI	Coeff (se)	p-value	95% CI	Coeff (se)	p-value	95% CI	Coeff (se)	p-value	95% CI
	Cancer (colorectal)		0.0012										
	Lung	-50.80 (18.67)	0.0070	(-87.43 to -14.18)									
	Pancreas	8.56 (19.37)	0.6590	(-29.44 to 46.55)									
	Risk (1%)		0.0206										
	2%	65.53 (21.07)	0.0020	(24.21 to 106.85)									
	5%	49.71 (21.29)	0.0200	(7.95 to 91.47)									
	10%	88.15 (20.93)	<0.0001	(47.10 to 129.20)									
	Household Income (<£10,000)		<0.0001			<0.0001			<0.0001			<0.0001	
	£10,000 - £25,000	46.96 (22.22)	0.0350	(3.39 to 90.53)	23.06 (27.35)	0.3990	(-30.58 to 76.71)	48.75 (26.63)	0.0670	(-3.48 to 100.99)	42.47 (27.29)	0.1200	(-11.05 to 96.00)
	>£25,000	153.42 (25.43)	>0.0001	(103.55 to 203.30)	132.99 (28.73)	<0.0001	(76.62 to 189.36)	150.42 (29.83)	<0.0001	(91.90 to 208.93)	145.28 (28.86)	<0.0001	(88.66 to 201.90)
	Education		<0.0001			<0.0001			0.0208			<0.0001	
	GCSE or equivalent	-21.07 (23.59)	0.3720	(-67.33 to 25.20)	-9.85 (28.87)	0.7330	(-66.50 to 46.79)	-0.22 (27.73)	0.9940	(-54.61 to 54.17)	-41.75 (28.49)	0.1430	(-97.64 to 14.14)
	A-level or equivalent	21.48 (22.91)	0.3490	(-23.46 to 66.43)	33.44 (28.13)	0.2350	(-21.75 to 88.62)	35.68 (27.42)	0.1930	(-18.10 to 89.46)	-17.51 (28.02)	0.5320	(-72.47 to 37.45)
	Higher education	95.22 (24.36)	<0.0001	(47.44 to 143.01)	133.53 (29.96)	<0.0001	(74.74 to 192.31)	72.97 (29.08)	0.0120	(15.93 to 130.01)	86.06 (29.78)	0.0040	(27.64 to 144.49)
	Cancer diagnosis (yes)		0.0033			0.0048			0.0138			0.0092	
	No	-63.48 (21.67)	0.0030	(-105.98 to -20.98)	-73.04 (25.93)	0.0050	(-123.92 to -22.17)	-63.63 (25.92)	0.0140	(-114.47 to -12.79)	-70.71 (27.18)	0.0090	(-124.02 to -17.39)

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Employment (Retired)		0.0137			0.0488		
Not in paid employment	-76.57 (27.55)	0.0060	(-130.60 to -22.53)		-82.45 (32.22)	0.0100	(-145.64 to -19.25)
Working part time	-40.55 (21.33)	0.0570	(-82.37 to 1.27)		-43.00 (25.33)	0.0900	(-92.70 to 6.70)
Working full time	-3.39 (21.22)	0.8730	(-45.01 to 38.23)		-20.24 (23.86)	0.3960	(-67.05 to 26.57)
Family cancer (yes)						0.0276	
No					-46.89 (21.36)	0.0280	-88.78 to - 5.00)
Sex (male)							0.0298
Female						-40.09 (18.49)	0.0300 -76.37 to - 3.81)

^a Based on first response only to avoid more than one response from each participant

1 Figure 1. Schema illustrating the two-part willingness to pay exercise. Choice of payment scale
2 leads to a bidding process with the starting point randomly generated from four values within
3 the band.
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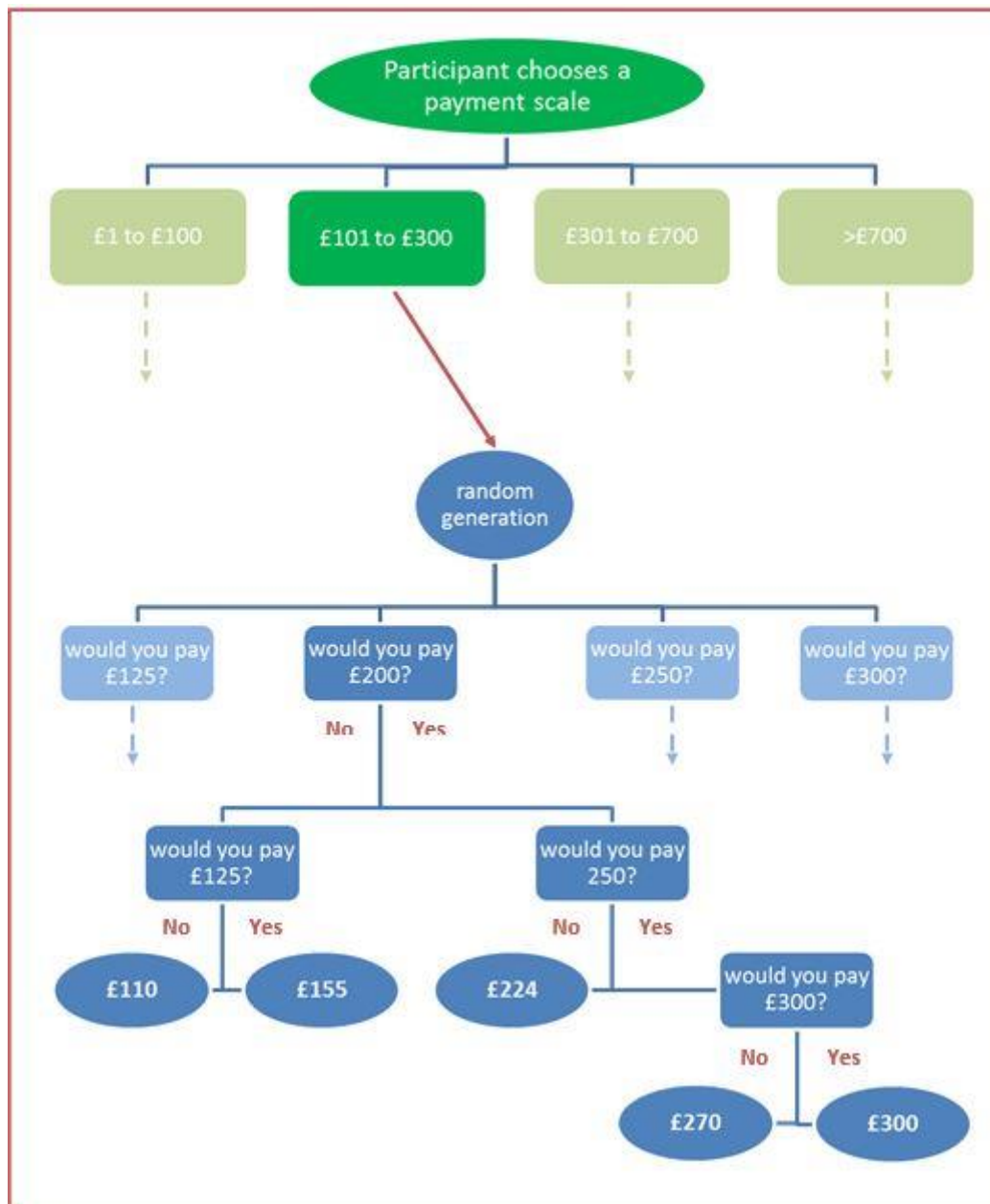
18 Figure 2. Screen shot of the payment scale exercise showing the use of reference goods.
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Appendix A. Screen shots showing questions about participant characteristics.



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The screenshot shows a mobile application interface for 'The PIVOT Study'. The title bar at the top is green and contains the text 'The PIVOT Study'. Below the title bar, the main content area has a light green background. At the top of this area, the text 'Traveling to your nearest main hospital' is displayed in blue. Below this, a light blue box contains the question: 'Thinking about your **current nearest main hospital**, how long would it normally take you to get there, using your usual method of transport?'. Underneath the question, there are five radio button options, each in a light grey box: 'Less than ½ hour', 'Between ½ hour and 1 hour', 'Between 1 and 2 hours', 'Between 2 and 3 hours', and 'More than 3 hours'. At the bottom of the screen, there are three buttons: 'Quit' on the left, 'Back' in the center, and 'Skip' on the right.



Pad 13:31 79%

The PIVOT Study

The value of the test

How much would the cancer test be worth to you? In other words what is the most you would be prepared to pay to have the test? You may find it useful to think about the goods and services you would be prepared to give up or go without.

Please indicate your choice below by touching the screen

	What else costs this amount?
Between £1 and £100	<ul style="list-style-type: none">• CD or DVD• Cinema trip• Meal out
£101 and £300	<ul style="list-style-type: none">• Camera• Kitchen appliance
£301 and £700	<ul style="list-style-type: none">• Furniture• Short break
Over £700	<ul style="list-style-type: none">• Holiday• Home improvement
I would not pay anything for the test	

Quit Back Skip