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Preferences for cancer investigation: a vignette-based study of primary-care attendees

Jonathan Banks, Sandra Hollinghurst, Lin Bigwood, Tim J Peters, Fiona M Walter, Willie Hamilton

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See Online for an audio interview with Jonathan Banks

School of Social and Community Medicine (J Banks PhD, S Hollinghurst PhD, L Bigwood MA) **and School of Clinical Sciences** (Prof T J Peters PhD), **University of Bristol, Bristol, UK; Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK** (F M Walter MD); **and University of Exeter, Exeter, UK** (Prof W Hamilton MD)

Correspondence to: Dr Jonathan Banks, School of Social and Community Medicine, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, UK **jon.banks@bristol.ac.uk**

Summary

Background The UK lags behind many European countries in terms of cancer survival. Initiatives to address this disparity have focused on barriers to presentation, symptom recognition, and referral for specialist investigation. Selection of patients for further investigation has come under particular scrutiny, although preferences for referral thresholds in the UK population have not been studied. We investigated preferences for diagnostic testing for colorectal, lung, and pancreatic cancers in primary-care attendees.

Methods In a vignette-based study, researchers recruited individuals aged at least 40 years attending 26 general practices in three areas of England between Dec 6, 2011, and Aug 1, 2012. Participants completed up to three of 12 vignettes (four for each of lung, pancreatic, and colorectal cancers), which were randomly assigned. The vignettes outlined a set of symptoms, the risk that these symptoms might indicate cancer (1%, 2%, 5%, or 10%), the relevant testing process, probable treatment, possible alternative diagnoses, and prognosis if cancer were identified. Participants were asked whether they would opt for diagnostic testing on the basis of the information in the vignette.

Findings 3469 participants completed 6930 vignettes. 3052 individuals (88%) opted for investigation in their first vignette. We recorded no strong evidence that participants were more likely to opt for investigation with a 1% increase in risk of cancer (odds ratio [OR] 1·02, 95% CI 0·99–1·06; p=0·189), although the association between risk and opting for investigation was strong when colorectal cancer was analysed alone (1·08, 1·03–1·13; p=0·0001). In multivariable analysis, age had an effect in all three cancer models: participants aged 60–69 years were significantly more likely to opt for investigation than were those aged 40–59 years, and those aged 70 years or older were less likely. Other variables associated with increased likelihood of opting for investigation were shorter travel times to testing centre (colorectal and lung cancers), a family history of cancer (colorectal and lung cancers), and higher household income (colorectal and pancreatic cancers).

Interpretation Participants in our sample expressed a clear preference for diagnostic testing at all risk levels, and individuals want to be tested at risk levels well below those stipulated by UK guidelines. This willingness should be considered during design of cancer pathways, particularly in primary care. The public engagement with our study should encourage general practitioners to involve patients in referral decision making.

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Introduction

More than one in three people in the UK will develop cancer during their lifetime.[1] Although cancer mortality in the UK has improved in the past 15 years,[2] it is still worse than the average across Europe.[3] Several initiatives have been introduced in the UK to address this issue, such as the Cancer Reform Strategy and the National Awareness and Early Diagnosis Initiative.[4] Earlier diagnosis is thought to be one of the main ways to improve survival, mainly by improved selection of patients for further investigation.[5] Almost 90% of patients with cancer are diagnosed after experiencing symptoms, most of whom present to primary-care facilities.[6] Selection of patients for further investigation is not straightforward: over-investigation has clinical and financial costs, and underinvestigation risks a delay in diagnosis and therefore has clinical and medicolegal costs. This selection is made by clinicians, who have largely guided provision of cancer diagnostic services. However, other groups have a legitimate interest in this decision: providers of cancer diagnostic services, governments, taxpayers, insurers, and—most importantly—patients.

Most common symptoms of cancer can also represent benign disease. When deciding whether to investigate for possible cancer, general practitioners use their experience and national guidelines, especially the UK National Institute for Health and Care Excellence (NICE) guidance that was issued in 2005.[7] This guidance also underpins the provision of 2-week-wait clinics, in which patients are guaranteed to be seen within 2 weeks. NICE guidance describes symptoms or combinations of symptoms and signs deemed worthy of investigation. By implication, when investigation is recommended by the guidance, the likelihood of the patient having cancer is high enough to justify it, although no explicit risk threshold warranting investigation for cancer has been reported in the UK or any other national guidance.[8] The percentage of patients referred to 2-week-wait clinics who are subsequently shown to have cancer varies between cancer sites, geographical areas, and general practitioners.[9] However,

only a quarter of cancers in the UK are diagnosed in 2-week-wait clinics, with other patients presenting as emergencies or referred to other specialist services.[10,11] Research in primary care has provided estimates of the risk of cancer for many symptoms, with several symptoms recommended by NICE as indicating a high likelihood of cancer: few of the NICE recommendations equate to risks of less than 5%.[12,13]

NICE referral guidance strongly recommends that the patient participate in decisions about testing,[7] although little research has been done into diagnostic preferences of patients. Previous research has focused on treatment or follow-up options,[14] preferences for screening,[15] predictive investigation,[16] or the sharing of risk information.[17] Patients certainly fear cancer—more so than they do knife crime, Alzheimer's disease, and job loss[18]—but how likely they are to choose investigation for cancer when provided with the relevant information about cancer risk, the details of investigation, and possible outcomes is unknown. We aimed to establish the likelihood that individuals would choose to be tested for cancer at various levels of risk.

Methods

Study design and participants

In a vignette-based study, we recruited 26 general practices in three areas of England (Bristol and south Gloucestershire, Devon, and the east of England) to include a broad range of urban and rural locations and varying levels of socioeconomic status (number of practices and specific practices not prespecified). We compared mean practice size and Index of Multiple Deprivation score with overall means from the National Public Health Observatory, and ethnic origin of patients with 2009 means from the Office of National Statistics.

In these general practices, researchers recruited attendees aged at least 40 years in waiting areas at different times of the day and week between Dec 6, 2011, and Aug 1, 2012. We did a test–retest exercise in one additional practice, with 48 volunteers (of a recruitment target of 50; same inclusion criteria) who agreed to return 2 weeks later, to complete identical vignettes to their first exercise. These participants were offered £10 shopping vouchers.

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

Procedures

We chose to compare colorectal, lung, and pancreatic cancers, because they differ in terms of symptoms, type of test, treatment, and prognosis. We developed 12 separate vignettes (ie, descriptions of hypothetical situations), with four for each of the three cancers (table 1 shows symptoms extracts; appendix shows full description of vignettes). The content of the vignettes was informed by NICE guidelines, qualitative interviews with patients referred for diagnostic tests for the three cancers,[19] and clinical experience.[20–22] Each vignette contained a description of symptoms, the risk that these symptoms might indicate cancer (both numerically and pictorially), information about the relevant diagnostic test, probable treatment, possible alternative diagnoses, and an indication of the prognosis if cancer were identified. The vignette culminated in a brief summary of information and asked the respondent whether they would choose diagnostic testing at that point, or would not want to be tested (the exact wording being "YES—I would choose to be tested" or "NO—I would not want to be tested now"). After this choice, participants were asked for the main reason for their decision with a list of options that were informed by qualitative interviews,[19] questionnaires previously used in cancer research,[23] and the cognitive interviewing phase.

We refined the vignettes in two rounds of cognitive interviewing using the verbal probing method[24] with 18 members of patient groups from three general practices. We asked 13 of these participants whether they understood the questions and the information. We recorded responses systematically and collated them. After redesign, we tested the questionnaire again on five additional participants followed by 1 week of piloting in which the questionnaire was administered as per protocol in a general practice waiting room to check recruitment method, functionality of equipment, and data recording.

Participants could complete up to three vignettes, which were delivered on an electronic touchscreen tablet computer. The software developed for the survey selected the first vignette randomly from all 12 possibilities, the second from the two remaining cancers (eight possibilities), and the third from the remaining cancer (four possibilities). We also gathered information about participant characteristics, such as age, sex, income, education, employment status, ethnic origin, experience of cancer, and convenience of the nearest main hospital.

For **study protocol** see http://www.discovery-programme.org/pdfs/PIVOT%20protocol%20version%201%2001.11.2010.pdf

See **Online** for appendix

	Colorectal cancer	Lung cancer	Pancreatic cancer
1%	Diarrhoea on most days	Coughing on most days Unusually tired	Some stomach pain on most days Lost a few pounds (~1·5–3 kg) in weight
2%	Diarrhoea and stomach pain on most days	Coughing on most days A little out of breath walking up hills Lost a few pounds (~1·5–3 kg) in weight	Some stomach pain on most days Lost half a stone (3·2 kg) in weight
5%	Unusually tired A blood test shows anaemia	Coughing on most days Coughed blood once	Continuous stomach pain Lost half a stone (3·2 kg) in weight
10%	Intermittent bleeding from the back passage (rectal bleeding) A blood test shows anaemia	Coughing on most days Coughed blood a few times Lost half a stone (3·2 kg) in weight	Continuous stomach pain Lost 1 stone (6·4 kg) in weight

All symptoms last 6 weeks.

Table 1: **Symptoms described in the vignettes, by risk level**

	Participants (n=3469)
Age (years)	
40–59	1519 (44%)
60–69	945 (27%)
≥70	988 (28%)
Missing	17 (<1%)
Sex	
Men	1457 (42%)
Women	2004 (58%)
Missing	8 (<1%)
Annual income	
<£10 000	720 (21%)
£10 000–25 000	1166 (34%)
>£25 000	1072 (31%)
Missing	511 (15%)
Ethnic origin	
White British	3096 (89%)
Other	357 (10%)
Missing	16 (<1%)
Highest educational qualification	
None	1001 (29%)
General Certificate of Secondary Education (GCSE) or equivalent	781 (23%)
Vocational or A level	850 (25%)
Degree and higher	756 (22%)
Missing	81 (2%)
Employment	
Retired	1673 (48%)
Not in paid employment	379 (11%)
Working part time	607 (17%)
Working full time	787 (23%)
Missing	23 (1%)
Previously diagnosed with cancer	
Yes	522 (15%)
No	2941 (85%)
Missing	6 (<1%)
Family member or close friend previously diagnosed with cancer	
Yes	2597 (75%)
No	868 (25%)
Missing	4 (<1%)
Convenience of hospital	
Very convenient	1388 (40%)
Quite convenient	1621 (47%)
Quite inconvenient	323 (9%)
Very inconvenient	129 (4%)
Missing	8 (<1%)
Travel time to hospital	
<0·5 h	1759 (51%)
0·5–1 h	1458 (42%)
>1 h	246 (7%)
Missing	6 (<1%)

Data are n (%).

Table 2: **Characteristics of participants**

Statistical analysis

We estimated that 80% of participants given a 10% risk vignette would opt for investigation, and 60% of those given 1% risk would do so. With a two-sided 5% alpha and 90% power, we estimated that we would need 119 participants in each group, or 1428 overall.

In addition to descriptive statistics, we used logistic regression for the main question (ie, whether or not to be tested), with opting for investigation as the outcome variable. The explanatory variables were cancer site, risk level (as a continuous variable), age group, sex, ethnic origin, income band, education, employment, previous diagnosis of cancer, cancer diagnosis in a family member or close friend, convenience of hospital, and travel time to hospital. In this analysis, we used only the first completed vignette from each participant because data were available for all participants, thus avoiding possible differential selection bias for subsequent vignettes.

We then developed separate models for each cancer, using all (first, second, or third) responses for that cancer. Because participants who completed more than one vignette always had a different cancer for the later vignettes, concerns about selection bias in the analysis of each cancer separately were eliminated. Initially, we entered every possible explanatory variable into univariable analysis to establish the strength of the association between it and opting for investigation, and those with a p value of less than 0·2 were retained for multivariable analysis. The first multivariable model contained only variables with a univariable p value of less than 0·05; we then added the other variables sequentially, repeating the process until only variables with p values of less than 0·05 after adjustment for all other variables in the model were present.

A supplementary analysis used k-fold cross validation with risk level as the only predictor variable in the base model and four other explanatory variables as additional predictors. We tested these variables sequentially, omitting variables in turn that did not seem to contribute to the model. We also considered the effect of missing data on the regression models by omitting any variable with more than 5% of missing data and examining the change in results. Our final validation check was to use intracluster correlation coefficients to investigate the degree of clustering of the outcome variable across the 26 practices and the six researchers involved in data collection.

We used Stata (versions 12 and 13) for all analyses. We did the test–retest analysis on the first vignettes and used percentage comparisons for participant characteristics and κ statistics for the vignette components.

Role of the funding source

The sponsors of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all data in the study and had final responsibility for the decision to submit for publication.

	Colorectal cancer		Lung cancer		Pancreatic cancer		All three cancers (first vignette only)	
	Responses	Choose to be tested	Responses	Choose to be tested	Responses	Choose to be tested	Responses	Choose 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%)
All	2291	1951 (85%)	2323	2144 (92%)	2316	2107 (91%)	3469	3052 (88%)

Table 3: **Number of participants who would choose to be investigated, by cancer and risk level**

	Colorectal cancer		Lung cancer		Pancreatic cancer	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Risk	1·08 (1·03–1·13)	0·0001	..	..	..	..
Age (years)		0·0347		<0·0001		<0·0001
40–59*	1	..	1	..	..	..
60–69	1·29 (0·92–1·82)	..	1·32 (0·86–2·03)	..	2·56 (0·94–7·00)	..
≥70	0·81 (0·59–1·11)	..	0·54 (0·38–0·76)	..	0·35 (0·13–0·99)	..
Travel time to hospital (h)		0·0004		0·0032		..
<0·5*	1	..	1	..	..	..
0·5–1	0·78 (0·59–1·03)	..	0·93 (0·67–1·30)	..	..	..
>1	0·39 (0·22–0·68)	..	0·41 (0·25–0·67)	..	..	..
Family member or close friend previously diagnosed with cancer		0·0266		0·0006		..
Yes*	1	..	1	..	..	..
No	0·72 (0·53–0·96)	..	0·55 (0·40–0·77)	..	..	..
Household income		0·0025		..		0·0001
<£10 000*	1	..	..	..	1	..
£10 000–25 000	1·31 (0·95–1·81)	..	..	..	2·63 (0·97–7·16)	..
>£25 000	1·85 (1·26–2·71)	..	..	..	3·80 (1·09–13·26)	..

OR=odds ratio. *Reference category.

Table 4: **Multivariable analysis for each cancer**

Results

The mean number of patients registered in each of the 26 general practices was 11 505 (range 4161–19 597; SD 3477), which is higher than the overall mean number per practice in England in 2011 of 6935.[25] The mean Index of Multiple Deprivation score was 18·3 (range 4·7–39·2; SD 8·0), compared with an overall English mean of 21·7 in 2010.[25] The mean percentage of non-white British patients in each practice was 4·3% (SD 4·4), compared with a mean for England and Wales of 12·1%.[26]

The study was popular and individuals were recruited much more quickly than had been expected. Because our estimated effect sizes were not robust, we continued the study to use our full researcher time. 3469 individuals participated, completing 6930 vignettes. 1415 individuals declined to participate.

The age and sex profiles of our sample (table 2) were similar to that of the consulting population in England.[27] However, the proportion of men aged 40–59 years in our study population (589 [17%]) was lower than in the overall population of England (27%) and the proportion of women aged 60–69 years (526 [15%]) was higher than in the overall population (11%).[28] The proportion of participants aged 70 years or more in our study population (28%; table 2) was also higher than in the overall population (24%).[28] The respondents were largely of white British ethnic origin and nearly half were retired (table 2). 15% had previously been diagnosed with cancer (table 2), which is higher than the estimate of 13% for individuals older than 65 years in the UK (owing to scarce data on this subject, this age group represents the most meaningful comparison available).[29] For most characteristics, only a small proportion of data was missing (table 2).

Overall, 88% of participants opted for investigation in the first vignette (table 3). The proportion was slightly lower in the lowest risk group and higher in the highest risk group (table 3), but the difference was small and could largely be explained by a risk gradient for colorectal cancer (table 3). This pattern was consistent across responses to the first, second, and third vignettes (data not shown).

	Colorectal cancer		Lung cancer		Pancreatic cancer		All three cancers (first vignette only)	
	Responses	Choose to be tested	Responses	Choose to be tested	Responses	Choose to be tested	Responses	Choose to be tested
Age (years)								
40–59	1061	917 (86%)	1076	1004 (93%)	1083	1002 (93%)	1519	1372 (90%)
60–69	641	563 (88%)	638	605 (95%)	640	601 (94%)	945	861 (91%)
≥70	580	463 (80%)	598	524 (88%)	583	496 (85%)	988	805 (81%)
All	2282	1943 (85%)	2312	2133 (92%)	2306	2099 (91%)	3452	3038 (88%)
Travel time to hospital (h)								
<0·5	1204	1052 (87%)	1224	1143 (93%)	1220	1126 (92%)	1759	1586 (90%)
0·5–1	943	798 (85%)	946	874 (92%)	943	853 (90%)	1458	1272 (87%)
>1	143	101 (71%)	150	125 (83%)	149	124 (83%)	246	189 (77%)
All	2290	1951 (85%)	2320	2142 (92%)	2312	2103 (91%)	3463	3047 (88%)
Family member or close friend previously diagnosed with cancer								
Yes	1739	1507 (87%)	1778	1660 (93%)	1769	1625 (92%)	2597	2317 (89%)
No	550	443 (81%)	545	484 (89%)	545	481 (88%)	868	733 (84%)
All	2289	1950 (85%)	2323	2144 (92%)	2314	2106 (91%)	3465	3050 (88%)
Annual income								
<£10 000	450	357 (79%)	445	403 (91%)	443	376 (85%)	720	595 (83%)
£10 000–25 000	759	642 (85%)	770	715 (93%)	746	685 (92%)	1166	1035 (89%)
>£25 000	806	721 (89%)	806	758 (94%)	825	777 (94%)	1072	985 (92%)
All	2015	1720 (85%)	2021	1876 (93%)	2014	1838 (91%)	2958	2615 (88%)

Table 5: **Number of participants who would choose to be investigated, by cancer and variables identified in the multivariable analysis**

The logistic regression analysis, combining all three cancers and controlling for participant characteristics, identified no strong evidence that participants were more likely to opt for investigation with a 1% increase in risk that symptoms indicated cancer (odds ratio [OR] 1·02, 95% CI 0·99–1·06; p=0·189). Compared with colorectal cancer, after adjustment for risk, participants were more likely to opt for investigation for lung cancer (2·66, 95% CI 1·99–3·56, p<0·0001) and pancreatic cancer (1·96, 1·48–2·60, p<0·0001). We recorded no evidence of an overall interaction between risk and cancer site (p=0·183). However, when the types of cancers were analysed separately, risk did have an effect on whether investigation was chosen for colorectal cancer (table 4).

Age had an effect in all three cancer models: participants aged 60–69 years were more likely to opt for investigation for all three cancers than were those aged 40–59 years, and those in the oldest group (≥70 years) were least likely to opt for investigation (table 4). Further investigation into whether attitude to risk was affected by age showed weak evidence of an effect overall ($p_{interaction}$=0·10), with substantial variation across the different cancers. With controlling for all other factors, participants in the youngest age group (40–59 years) were more likely to opt for investigation as risk increased for colorectal cancer (OR 1·07, 95% CI 1·01–1·13) and for pancreatic cancer (1·10, 1·01–1·17). Conversely, participants in the oldest group (≥70 years) were less likely to opt for investigation as risk increased for lung cancer (OR 0·96, 95% CI 0·88–1·04) and for pancreatic cancer (0·93, 0·87–1·01), although the confidence intervals were wide and include the null value. Other variables associated with increased likelihood of opting for investigation were shorter travel times to testing centre (colorectal and lung cancers), a family member or close friend previously diagnosed with cancer (colorectal and lung cancers), and higher household income (colorectal and pancreatic cancers; table 4).

The k-fold cross validation results for all three cancer sites produced final models including the same variables as those in the original models, with almost identical regression coefficients (data not shown). Table 5 shows the distribution of participants' responses for each variable identified in the logistic regression. We examined the potential bias of missing data in relation to income by omitting the variable from the two final models for colorectal and pancreatic cancers in table 4, with almost identical results for risk level and the other variables (ie, omission of this variable from the models made no difference to the models themselves). We noted negligible intracluster correlation of the preference for investigation by general practice and by researcher who enrolled the individual for all vignettes, and for each cancer site separately (data not shown).

The main reasons cited by participants opting for investigation in the first vignette were peace of mind, early detection, and a family history of cancer, with little variation across the three cancers (table 6). The main reasons cited by those choosing not to be investigated

	All three cancers (first vignette only)	Colorectal cancer	Lung cancer	Pancreatic cancer
Main reason for choosing to be tested				
Peace of mind	1255/3052 (41%)	723/1951 (37%)	806/2144 (38%)	832/2107 (39%)
Early detection	1191/3052 (39%)	872/1951 (45%)	890/2144 (42%)	877/2107 (42%)
Family history of cancer	306/3052 (10%)	212/1951 (11%)	204/2144 (10%)	195/2107 (9%)
At risk from age	107/3052 (4%)	63/1951 (3%)	61/2144 (3%)	66/2107 (3%)
No reason given	77/3052 (3%)	47/1951 (2%)	58/2144 (3%)	62/2107 (3%)
Test is straightforward	56/3052 (2%)	10/1951 (1%)	58/2144 (3%)	43/2107 (2%)
Pressure from family or friends	34/3052 (1%)	20/1951 (1%)	22/2144 (1%)	21/2107 (1%)
At risk from lifestyle	26/3052 (1%)	4/1951 (<1%)	45/2144 (2%)	11/2107 (1%)
Main reason for choosing not to be tested				
Low risk of cancer	103/417 (25%)	69/340 (20%)	66/179 (37%)	57/209 (27%)
Low risk at present age	89/417 (21%)	60/340 (18%)	38/179 (21%)	40/209 (19%)
Rather not know	59/417 (14%)	37/340 (11%)	27/179 (15%)	33/209 (16%)
No reason given	51/417 (12%)	41/340 (12%)	18/179 (10%)	26/209 (12%)
Unpleasant test	28/417 (7%)	66/340 (19%)	2/179 (1%)	7/209 (3%)
Early diagnosis would not help	37/417 (9%)	12/340 (4%)	14/179 (8%)	22/209 (11%)
Harmful test	18/417 (4%)	39/340 (11%)	3/179 (2%)	3/209 (1%)
Inconvenient	20/417 (5%)	11/340 (3%)	6/179 (3%)	13/209 (6%)
Difficult to access hospital	12/417 (3%)	5/340 (1%)	5/179 (3%)	8/209 (4%)

Table 6: **Main reasons for choices**

were low risk of cancer, low risk at present age, and would rather not know (table 6). Reasons for opting for no investigation varied between the three cancers (table 6)—eg, much higher proportions cited an unpleasant test or harmful test for colorectal cancer than for lung and pancreatic cancers.

The primary research question of whether the participant chose to undergo diagnostic tests for cancer showed excellent test–retest consistency, with a κ statistic of 0·878 (>0·75 is deemed excellent). Participants' reasons for their choice produced κ statistics of 0·584 for those who would opt for investigation and 0·667 for those who would not opt for investigation, which are both in the fair to good range (0·4–0·75).[30] The social and economic status data showed reliable test–retest consistency: six of ten questions returned higher than 90% agreement, three were between 80% and 89%, and one (hospital travel time) was 69%.

Discussion

To our knowledge, ours is the first study of public preferences for cancer investigation (panel). 88% of participants would opt for investigation when given a realistic scenario of symptoms that could indicate cancer, along with the risk of cancer these symptoms posed, plus a description of the relevant investigation and likely outcomes. Despite the strong preference for testing, the proportion who would opt for testing increased with risk. Although this risk gradient was identified in the analysis incorporating all three cancers, it was primarily driven by the findings for colorectal cancer, for which participants seemed to make a trade-off between the invasiveness of the colonoscopy and the risk of cancer. Age also seemed to affect responses, with the preference for investigation highest in individuals aged 60–69 years and lowest in those aged at least 70 years.

The willingness for testing shown in our study far exceeds what is actually being offered by the National Health Service. Similarly, Slevin and colleagues[31] showed that patients with cancer were more likely to choose chemotherapy than clinicians were, even when benefits were small. Participants in our study might have simply opted for a free test, an idea which is supported by the fact that the proportion opting for investigation did not vary by risk for lung and pancreatic cancer. The vignettes might not have been sufficiently sensitive to different risk levels. However, the differences by risk level for colorectal cancer and by age group suggest that participants considered their responses.

The four vignettes for colorectal cancer were all in line with NICE guidance for urgent referral (because of the 6 weeks of diarrhoea), although many symptoms with a low risk of cancer (1–5%) are not included in NICE guidance.[12,13] For lung cancer, a chest radiograph is recommended by NICE when a patient has a persistent cough (defined as lasting at least 3 weeks). Again, many symptoms of lung cancer fall into the 1–5% bracket, but NICE guidance suggests that tests should be done only if cough is present for 3 weeks.[7,21,32] The pancreatic scenarios used in our study might not be in line with NICE guidance (which largely concentrates on jaundice).

Even with these caveats, the proportion of patients opting for investigation at even a 1% risk of cancer is substantially different from the conversion rate (the percentage of

***Panel:* Research in context**

Systematic review

We searched OvidSP with the MeSH terms "patient preference", "decision making", "cancer", "primary health care", and "early diagnosis" for all reports published before Dec 12, 2013. We did not identify any studies that could be directly compared with our research because none reported patient or community preferences for cancer investigation.

Interpretation

We have shown that members of the public have a clear preference for cancer investigations across a range of potential risk levels. Only in the case of colorectal cancer, with its invasive method of testing, did we record clear evidence of an association between a preference for testing and risk level, but even at the lowest risks, the proportion who would choose testing was more than 80%. Our study emphasises how the public and patients should be allowed to contribute directly to the continuing redesign of diagnostic pathways into and out of primary care for cancer in the UK. The way that people engaged with the survey and the vignettes of cancer symptoms draws attention to public willingness to discuss and contemplate risk of cancer and testing, which could potentially allow a more patient-centred primary-care consultation and decision-making process.

urgent cancer referrals who transpire to have cancer) of 11%[7] in the 2-week-wait clinics. Use of the 11% figure is slightly misleading, because an average conversion rate means that some patients whose risk is below that figure have been selected for investigation. No threshold level of risk warranting urgent investigation of cancer has been published, although the concept of a threshold is implicit in all UK guidance—and must be in excess of 1%.

Our survey is also instructive about the referral process and the relationship between general practitioners and patients. As well as giving referral guidance, NICE guidelines emphasise the value and importance of including the patient in the decision-making process for referral and diagnostic testing for cancer; effective communication is a key dimension of an appropriate referral.[33] The way that participants engaged with our study, the subtle variations in participant preferences, and the high participant numbers suggest that general practitioners should be able to confidently engage in a dialogue with patients about the meaning of symptoms and the risk of cancer. General practitioners can underestimate the degree to which patients want information and to be involved in decision making,[34] and decisions are sometimes made on the basis of a perception of what patients prefer,[35] but our data and experience show that a substantial proportion of the population are willing to think about what symptoms mean, personal risk, and the possibility of cancer. This kind of internal dialogue could be used in the consulting room and turn aspirations about involvement of patients into a reality. Fear of cancer does not necessarily translate into a fear of talking about cancer.

The use of hypothetical vignettes has strengths and weaknesses. Much of the debate around their use centres on the degree to which responses can be used as accurate measures of views and behaviour, with the correlation between vignette response and actual behaviour being questioned.[36] Conversely, several studies—eg, Peabody and colleagues' investigation[37]—have shown that vignette responses are useful indicators of behaviour and compare favourably with other methods of assessments of preferences and intentions. The method has been widely used in the investigation of medical choice and judgment, such as by Jiwa and colleagues.[38] Many participants in our study had not experienced referral for cancer testing and the vignettes provided a way to elicit preferences in the absence of direct experience.

Any questionnaire survey is only useful if the questions are realistic and the responses considered. We tried to ensure the vignettes were as realistic as possible and to make the percentage risk understandable by presenting it numerically and pictorially (see appendix for example), on the basis of suggestions from our two rounds of cognitive interviewing. We cannot know whether the overall high proportion of participants who would opt for investigation was driven by the symptom burden (which worsened with high risk levels) or by the risk level itself, or by a combination, although the last of these interpretations seems to be closest to clinical reality. We were realistic in our description of the three first-line investigations (colonoscopy, chest radiograph, and CT scanning), including their requirements and possible hazards (largely relevant to colonoscopy with its need for bowel preparation and the small risk of perforation). Since our study began, the findings of the SIGGAR study[39] have suggested that CT colonography could be as accurate as colonoscopy; a higher proportion of participants in our study might have opted for investigation had this test been available. We made it clear that early diagnosis might not reduce the chance of death from lung and pancreatic cancers, emphasising that most patients would die of their disease, although prompt diagnosis could allow benefit from palliative care. Regarding the reliability of responses, the test–retest analyses established that responses were consistent. We would also point to the reasons given for responses, which suggested that participants responded reflectively; the subtle variations around the type of test, risk, and the age of respondents showed an engagement with the differing components of the vignette.

Ours was a large study, in which participants were recruited from urban, rural, wealthy, and deprived locations. Recruitment of 71% of individuals asked to participate is good for a questionnaire survey. Although our target population was the general UK population susceptible to cancer (adults aged ≥40 years), we made a pragmatic decision to recruit from waiting areas of general practices as opposed to other community settings. This decision enabled us to access a large group of people directly about a sensitive health-related subject. Moreover, a health-care setting provided the time, space, and privacy for respondents to complete the questionnaire thoughtfully. Reported data for the demographics of the population who attend primary

care are scarce. The proportion with a past history of cancer in our sample (15%) is similar to the estimated proportion in the UK population of individuals older than 65 years (13%). This was not the case for ethnic origin, because the proportion of non-white individuals was clearly smaller than in the overall UK population. The small number of non-white individuals in our study means that the effect of any ethnic variation is beyond the scope of this study.

NICE recommendations and National Health Service provision seem to differ greatly from preferences of patients in terms of cancer diagnostic pathways. Our findings should be considered during the revision of NICE guidance. In terms of clinical practice, our results should prompt careful thought about referral decision making. If more patients can be drawn into a full dialogue about preference, risk, and decision making with their general practitioner, a more effective referral pathway from primary care could be created.

Contributors

All authors contributed to study design, study conduct, and study management. JB, SH, TJP, and WH analysed and interpreted data. JB, SH, LB, and WH wrote the first draft of the report, and TJP and FMW made revisions.

Conflicts of interest

WH is the clinical lead for the continuing revision of the NICE 2005 guidance. His contribution to this Article is in a personal capacity, and should not be interpreted as representing the view of the Guideline Development Group, or of NICE itself. The other authors declare that they have no conflicts of interest.

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