

## Ethnic differences in patients' preferences for prostate cancer investigation:

a vignette-based survey in primary care

### Abstract

#### Background

Minority ethnic groups in the UK have worse outcomes for some cancer types compared with the white majority. Black males have worse staging at diagnosis of prostate cancer and often present as emergencies, suggesting possible delays in the diagnostic pathway. Delay may arise from lower awareness of cancer symptoms, reluctance to report symptoms, reduced desire for investigation, or a combination of these. Reduced desire for investigation was examined in this study

#### Aim

To investigate whether black males in the UK would choose to be tested for prostate cancer compared with the white majority.

#### Design and setting

A vignette (hypothetical scenario)-based, electronic survey of male patients aged  $\geq 40$  years from four general practices in Bristol, UK.

#### Method

The vignettes described possible prostate cancer symptoms (equating to risk levels of 2%, 5%, and 10%), investigative procedures, and possible outcomes. Participants indicated whether they would choose investigation in these scenarios. Analysis used logistic regression, with preference for investigation as the outcome variable and ethnicity as the main explanatory variable.

#### Results

In total, 449 (81%) of 555 participants opted for investigation, regardless of risk levels; of these, the acceptance rate was 94% (251 out of 267) among white males and 70% (198 out of 285) among black males. In multivariable analyses, preference for investigation was lower in black males, even after controlling for relevant confounding factors including specific risk level (odds ratio 0.13; 95% confidence interval = 0.07 to 0.25;  $P < 0.001$ ).

#### Conclusion

Black males are less likely to opt for investigation at any risk level of prostate cancer compared with white males. This may explain some of their late-stage presentation at diagnosis and subsequent poorer outcomes.

#### Keywords

ethnic groups; primary health care; prostate cancer.

### INTRODUCTION

When compared with white males, black males have higher incidence and worse outcomes of prostate cancer. In the US where routine screening with prostate specific antigen (PSA) is widespread, African-Americans are around 1.6 times more likely to be diagnosed with prostate cancer and are more than twice as likely to die from the disease than their white counterparts.<sup>1</sup> In the UK, where PSA screening is not recommended, prostate cancer incidence is approximately three times higher,<sup>2</sup> and case-specific mortality rates are 35% greater in black males compared with white males.<sup>3</sup> These ethnic differences in mortality, in addition to possible biological differences, may arise at several points in the diagnostic and treatment pathways.<sup>4</sup>

The present study focuses on diagnosis. Some of the differences in black versus white mortality rates may be linked to diagnostic delay, although existing, albeit weak, UK studies found no evidence of such a relationship.<sup>5</sup> Black males also have worse staging at diagnosis<sup>6</sup> and are 1.7 times more likely to present as an emergency.<sup>4</sup>

Prostate cancer diagnosis is generally preceded by symptoms (although the possibility of cancer may not be recognised), followed by presentation to primary care, where initial assessment may lead to investigation or referral.<sup>7,8</sup> The first interval is pre-presentational; patients may delay

presenting to primary care due to fear of cancer. Non-recognition or misattribution of cancer symptoms, comorbidity, socioeconomic deprivation, and self-medication may also affect this process. In minority ethnic groups, stigma, cultural and religious preferences, language and communication barriers, as well as racial discrimination, are additional possible contributory factors to delay.<sup>9</sup>

Once patients present to primary care, however, the decision regarding whether or not to investigate for cancer is determined, in the main, by GPs. National guidance recommends shared decision making between doctor and patient,<sup>10</sup> but it is unknown to what extent this is achieved in reality. Lower urinary tract symptoms, such as urgency and hesitancy, are common, and none is particularly suggestive of malignant, as opposed to benign, disease.<sup>11</sup> Both digital rectal examination and PSA testing have false positives and false negatives. Furthermore, prostate cancer treatments may lead to complications, such as incontinence or impotence; men knowing this may decline testing.

Patient views on testing for cancer have rarely been investigated. In a vignette (hypothetical scenario)-based study in 2014, Banks *et al* reported that patients in the UK preferred to be investigated for lung, pancreatic, and colorectal cancer, even at low risk levels.<sup>12</sup> That study was not powered to identify any ethnic differences

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## How this fits in

Black males have worse outcomes in several cancer types, including prostate cancer, and they present more frequently to primary care before diagnosis when compared with white males. It is not certain whether black males have different attitudes to testing for cancer, which could explain this. This vignette-based study showed a considerably lower preference for testing in black males. Furthermore, their preference for testing was lower at the lowest risk level.

in the preference for cancer investigation. To address this, the current study adopted a similar approach to investigate whether the preference for prostate cancer investigation in black patients is comparable with that of white patients.

## METHOD

### Design and participants

This was a vignette-based survey of primary care patients, performed between January 2014 and April 2014. Participants were males aged  $\geq 40$  years, attending four general practices in Bristol, UK. Selected practices (selected from 10 potentially eligible general practices) were those located in areas with a high concentration of minority ethnic groups; these were recruited through the local Primary Care Research Network.

The survey was administered via a tablet computer (iPad) and gathered basic information on participants' sociodemographic characteristics, including:

- age;
- ethnicity (defined using the 2001 UK Census groupings);
- income;
- level of education;
- employment status;
- previous history of cancer (personal, family, or close friends);
- travel time to hospital; and
- convenience of the nearest main hospital.

Three different vignettes each included a description of prostate cancer symptoms, or symptom combinations, and the estimated risk of prostate cancer (2%, 5%, and 10%); symptoms were portrayed numerically and pictorially. The selection of symptom profiles was based on clinical experience,

primary care evidence, and guidelines from the National Institute for Health and Care Excellence (NICE).<sup>10,11</sup> Table 1 outlines each vignette; Appendix 1 shows the screens and exact wording seen by the participants. The vignettes also gave information about physical examination, relevant tests, and differential diagnoses with an approximate prognosis should prostate cancer be detected.

Finally, the vignettes summarised all the information and requested participants to indicate whether or not they would choose diagnostic investigation if they had the symptoms in question. Participants were subsequently asked to choose from a predefined list of reasons for choosing or declining investigation. Extensive piloting of vignettes and the technology had been performed for a previous study, including two cycles with patient representatives;<sup>12</sup> the piloting in this extension involved informal testing of terminology relating to urinary symptoms and risk with black community groups.

### Procedure

Participants awaiting their primary care appointment were approached opportunistically by one researcher, who had the study information on the iPad screen and on paper. Patients who appeared to be  $< 40$  years of age were avoided because prostate cancer is rare in younger males. Before completing the survey, selected participants gave or declined oral informed consent, supplemented by a consent screen on the iPad. Occasionally, the practice's bilingual link worker or professional interpreters helped clarify/translate the vignette. Participants could complete up to two vignettes, selected at random and at different risk levels. In addition, they were able to exit the survey at any stage if they desired or were called into their consultation.

### Statistical analysis

The aim was to survey at least 572 males (286 of each ethnicity), providing 90% power at the 5% significance level to detect a difference between the groups in preference for investigation, 80% versus 90%, with the latter figure being the outcome in the earlier study.<sup>12</sup>

Black males in this study were those who self-identified as black-black British African or black-black British Caribbean, while white males were self-identified white British. Males who identified with ethnic groups other than the above categories were classified as 'other groups' and were

**Table 1. Prostate cancer symptoms and associated risk levels, as described in the vignette**

Prostate cancer symptom(s) <sup>a</sup>	Risk level, %
Hesitancy (difficulties starting to urinate)	2
Frequency/urgency (needing to rush to the toilet to urinate) Hesitancy	5
Weight loss Frequency/urgency Hesitancy	10

<sup>a</sup>All symptoms last 6 weeks.

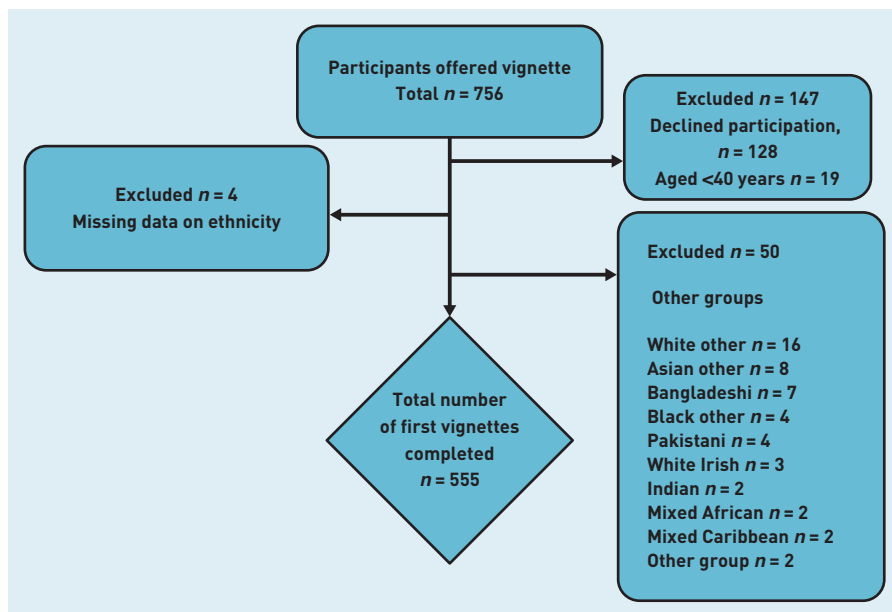


Figure 1. Participant selection process.

omitted from the analyses due to small numbers.

Table 2. Participants' (n = 555)<sup>a</sup> characteristics by black (n = 286) and white (n = 269) males

Characteristics	Black males, %	White males, %
<b>Age, years</b>		
40–59	74	39
60–69	11	28
≥70	15	33
<b>Income, £</b>		
<10 000	41	44
10 000–25 000	54	52
25 000–40 000	5	5
<b>Highest educational qualification</b>		
None	29	30
GCSE/equivalent	36	33
Vocational or A-level	17	27
Degree or more advanced	18	10
<b>Employment status</b>		
Retired	21	51
Not in paid employment	22	14
Working part time	15	16
Working full time	42	19
<b>Convenience of hospital</b>		
Very convenient	69	82
Quite convenient	26	16
Quite inconvenient	4	2
Very inconvenient	2	0
<b>Travel time to hospital, hours</b>		
<0.5	93	95
0.5–1	7	5
<b>Previously diagnosed with cancer</b>	3	4
<b>Family or close friend previously diagnosed with cancer</b>	39	59

<sup>a</sup>The lowest sample size was 552 of a maximum of 555. GCSE = General Certificate of Secondary Education.

Participant characteristics were summarised using simple descriptive statistics. Few participants completed a second vignette, so analyses of preferences for investigation were restricted to the first. Logistic regression was used to compare the binary outcome preference for investigation (opting for investigation versus not doing so) between white and black groups, firstly without adjustment and, secondly, adjusted for potential confounders, including age, employment status, convenience of hospital, previous history of cancer, and prostate cancer risk. As a second test of the possible effect of age on the main outcome, a stratified analysis was performed using three age groups. However, as expected from the main analysis, this was insignificant; as such, the results have been omitted. All analyses were conducted using Stata (version 13).

## RESULTS

### General practices

Ten potentially eligible general practices expressed interest in participation, of these, four were selected, one had data on patients' ethnicity, with 2.5% of the practice patients reported as being black.<sup>13</sup> This practice was selected despite having a relatively low percentage of black males, to increase generalisability. The remaining three were located in areas with a high concentration of black African or black Caribbean people (40%, 40%, and 17%, respectively) when compared with an overall figure of 3.3% for England and Wales.<sup>14</sup>

The mean number of patients registered in the practices was 12 567 (range 5176–18 035); the average practice size in England is 7041.<sup>13</sup> All four practices were in areas of considerable socioeconomic deprivation, when compared with the average Index of Multiple Deprivation (IMD) score for England in 2012. The mean IMD score for the four practices was 36.9 (range 29.6–43.5), compared with an average of 21.8 for England in 2012.<sup>13</sup>

### Patients' characteristics

In total, 756 males were asked to participate; 147 either declined (n = 128) or were <40 years of age (n = 19). Four omitted the questions on ethnicity, and 50 self-identified with other ethnic groups therefore were excluded; this left 555 participants for analysis. Figure 1 shows the participant selection process and the number of vignettes completed. Table 2 shows participants' characteristics by ethnic group.

**Table 3. Preference for testing in black males and white males**

Level of risk, %	Black males, % (n)	White males, % (n)	COR	AOR <sup>a</sup>	95% CI	P-value
2	44 (40/90)	91 (98/108)				
5	82 (79/96)	97 (83/86)				
10	80 (79/99)	96 (70/73)				
All	70 (198/285)	94 (251/267)	0.15	0.13	0.07 to 0.25	<0.001

AOR = adjusted odds ratio. COR = crude odds ratio. <sup>a</sup>Adjusted for participants' age, employment status, convenience of hospital, previous history of cancer (none of which was independently associated with opting for investigation), and prostate cancer risk level.

Of the 555 participants entering analysis, 286 (52%) self-identified as black males and 269 (48%) as white males. Black males were younger (74% aged 40–59 years) and a greater percentage were in full-time employment compared with their white counterparts (42% versus 19%). Just over half of the group of white males had retired. More white males (59%) than black males (39%) had a family member or friend with a history of cancer.

**Preference for investigation**

Overall, 81% of the participants opted for investigation. Participants' preferences for investigation differed by ethnicity with 94% of white males opting for investigation regardless of risk levels and 70% of black males doing so. The difference between

the groups was most marked at the lowest risk level: just 44% of black males opted for investigation compared with 91% of white males (Table 3).

After controlling for participants' age, employment status, convenience of hospital, and previous history of cancer (none of which was independently associated with opting for investigation), plus prostate cancer risk level, the odds of opting for investigation remained significantly lower in black males (odds ratio [OR] 0.13; 95% confidence interval [CI] = 0.07 to 0.25; *P*<0.001) (Table 3). A test of interaction showed little evidence that the OR differed by level of risk (*P* = 0.41).

**Reason for choice**

Although the main reason cited by males of both groups was early diagnosis, a much higher proportion of white males selected this option. In black males, peace of mind was almost as important (Table 4).

Fewer white males than black males gave their reasons for declining investigation although, again, differences were significant (Table 4).

For males in both groups, the main reason cited for declining investigation was low risk of cancer; however, a considerably higher proportion of black males stated that they did not want to know if they had cancer (Table 4).

**DISCUSSION**

**Summary**

In this study, it was found that black males opt for investigation for possible prostate cancer less frequently than white males; this did not appear to be related to any specific, recorded, patient characteristic. This lower preference for investigation in black males was particularly marked when the risk of cancer in the vignette was low: less than half of black males opted for investigation when the risk of prostate cancer was the lowest value offered (namely 2%). In contrast, white males had a very high preference for investigation, including at the 2% risk level.

Several factors were not significantly associated with black males' preferences for investigation, including age, income, employment status, convenience of the nearest main hospital, or a family history of cancer.

**Strengths and limitations**

To the authors' knowledge, this is the first study to examine ethnic differences in the desire to be tested for prostate cancer. This study built on a previous, successful

**Table 4. Main reasons cited for investigation preferences in black males and white males**

Main reason for choosing investigation	Black males, %	White males, %	P-value <sup>a</sup>
	n = 197	n = 251	
Having the cancer test would give me peace of mind	41	15	0.001
Having the cancer test would allow cancer to be found early	45	72	
If the test is offered I'll take it	11	9	
Having the test would be easy	1	0	
My family/friends would want me to have the cancer test	1	0	
At my age, I think a cancer test is worthwhile	1	3	

Main reason for declining investigation	Black males, %	White males, %	P-value <sup>a</sup>
	n = 85	n = 14	
The risk of cancer is not very high	45	43	<0.001
I would rather not know I have cancer	37	14	
The cancer test sounds unpleasant	12	7	
The cancer test can cause damage	1	7	
The cancer test would be too inconvenient	0	0	
Getting to hospital for the cancer test would be difficult	0	0	
At my age, a cancer test is not worthwhile	2	29	
If I have cancer, early diagnosis would not help	4	0	

<sup>a</sup> $\chi^2$  test P-value.

project that was not powered to explore ethnic differences; as a result, much of the design and piloting for this study had already been performed, and procedural problems overcome.

The vignettes were realistic and used primary care data to provide estimates of the actual risk of prostate cancer.<sup>11</sup> In addition, the electronic nature of the questionnaire minimised missing data and was accepted by 80% of patients who often have a long waiting time, with few or no distractions. The response rate of >80% was excellent, and there was no obvious difference by ethnic groups in those declining to participate.

However, some limitations are present. Black male patients (who have a higher incidence rate for prostate cancer) were compared with white male patients; as a result, the findings cannot be generalised beyond these two groupings. In addition, two black ethnicities (black-black British African and black-black British Caribbean) were grouped together; there are many different black ethnic groups, which may have different views on the advantages of testing for prostate cancer.

A further limitation is that only prostate cancer was studied so it is not possible to determine whether the lower preference for investigation in black males would also be found for other cancers, or in black females. Furthermore, the sample population comprised GP attenders. Although conducting the study in the GP practice offered the major advantage of providing translation where needed, and being the setting where initial investigation for prostate cancer takes place, it is not possible to determine whether a true community sample, or a sample in other cities, would have yielded different results. That said, there is no reason to think this would be the case.

The final consideration is whether vignettes give valid answers. This was discussed relatively widely in Banks *et al*'s recent study: most, but not all, studies considered vignettes to provide meaningful responses.<sup>12</sup>

#### Comparison with existing literature

Overall, 81% of the sample participants opted for investigation in the first vignette. This proportion is lower than the 88% reported in Banks *et al*'s study (although 89% of participants in that study were white British); the differences by risk groups in that study were also slightly larger. In the study reported here, 94% of white males opted for investigation; this may reflect the different cancer site: prostate, as opposed to colon, pancreas, or lung. Prostate cancer

is generally found in older males, has lower mortality rates, and is relatively more common in black males; all of these factors make it somewhat atypical.

There was a general increase in the preference for investigation with higher risk of cancer in black males; a finding reported by Banks *et al*,<sup>12</sup> although in that case it was largely driven by their colorectal findings. The rationale appears logical; it was not seen in white males but this could be a result of their high overall preference for investigation.

This study's findings of a lower preference for investigation in black males, compared with white males, could perhaps indicate why it has been found that emergency presentations are increased, and mortality and staging at diagnosis are worse, in black males.<sup>3,4,15</sup> The current findings are based on a vignette that presupposed entry into health care, and strictly does not extrapolate on the decision to seek health care when a man has symptoms; however, it is plausible that a lower desire for investigation may also engender a lower desire to seek help.

Black males have been reported to have a worse fear of prostate cancer when compared with white males.<sup>4,16</sup> They fear that the disease could be terminal and that its treatment could lead to severe sexual disorders (such as erectile dysfunction, sterility, and decreased sex drive), which, in turn, may change their close relationships with their spouses.<sup>16,17</sup> Several (mainly US) studies have highlighted fear as a major deterrent to black males' medical help-seeking, even when experiencing lower urinary tract symptoms.<sup>16</sup> This factor may explain some of the views expressed by black males in this study rather than assuming that they were making accurate judgement of their cancer risk. It is also well recognised that black males do not like visiting doctors and may be influenced in their healthcare seeking by family members;<sup>18,19</sup> interestingly, however, a specific family history of cancer did not appear to be important in the current study.

Conversely, patients' knowledge of prostate cancer signs and symptoms, investigative procedures, and possible outcomes of treatments may influence their willingness for investigation.<sup>17,20</sup> Males of both ethnicities have similar knowledge of prostate risks and symptoms,<sup>4</sup> although black males tend to underestimate their personal risk of the disease,<sup>21</sup> and are often less conversant with the PSA and rectal examination procedures, and may abstain from investigation altogether due to

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### Ethical approval

Ethical approval was obtained from Camden and Islington National Research Ethics Service Committee (ref 13/LO/1823).

### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

William Hamilton is the clinical lead for the continuing revision of the 2005 guidance published by the National Institute for Health and Care Excellence (NICE). His contribution to this article is in a personal capacity and should be interpreted as neither representing the view of the Guideline Development Group nor that of NICE. The other authors declare no competing interests.

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this.<sup>17,20</sup> Some black males perceive rectal examination as a threat to their masculinity and consider it an undignified test.<sup>17,20</sup> They are also more likely to be too embarrassed about lower urinary tract symptoms and generally less comfortable seeing their GPs compared with their white counterparts.<sup>4,22</sup> These factors, in addition to language or communication barriers, stigma, and socioeconomic deprivation may provide an alternative explanation to black males' reluctance for prostate cancer investigation when symptomatic.

Models of behavioural change (for example, the health belief model and self-regulatory models) have been used to explain patients' attitudes towards cancer screening and early diagnosis.<sup>23,24</sup> The questionnaire in this study did not collect specific information to assess this, although the main reasons cited by participants for choosing or declining investigation provide useful insights in this regard. In total, 86% of those declining prostate cancer investigation were black males, around half of whom cited low risks as the main reason for their choice. This is consistent with the findings of a US study, which reported moderate perceived susceptibility and perceived severity of prostate cancer in black males.<sup>24</sup> Worryingly, 37% of those who declined indicated that they would rather not know they have cancer; this, again, echoes their fears of the disease and perceived negative consequences of it being diagnosed.

In both groups who opted for investigation, early detection of prostate cancer was the main reason cited for their decision, and black males cited peace of mind almost as frequently. White male reasoning in this situation may be interpreted in line with their perceived benefits of treatment and curability of the disease, while black males'

views may, again, reflect their greater fear of prostate cancer diagnosis and possible treatment outcomes.

### Implications for practice

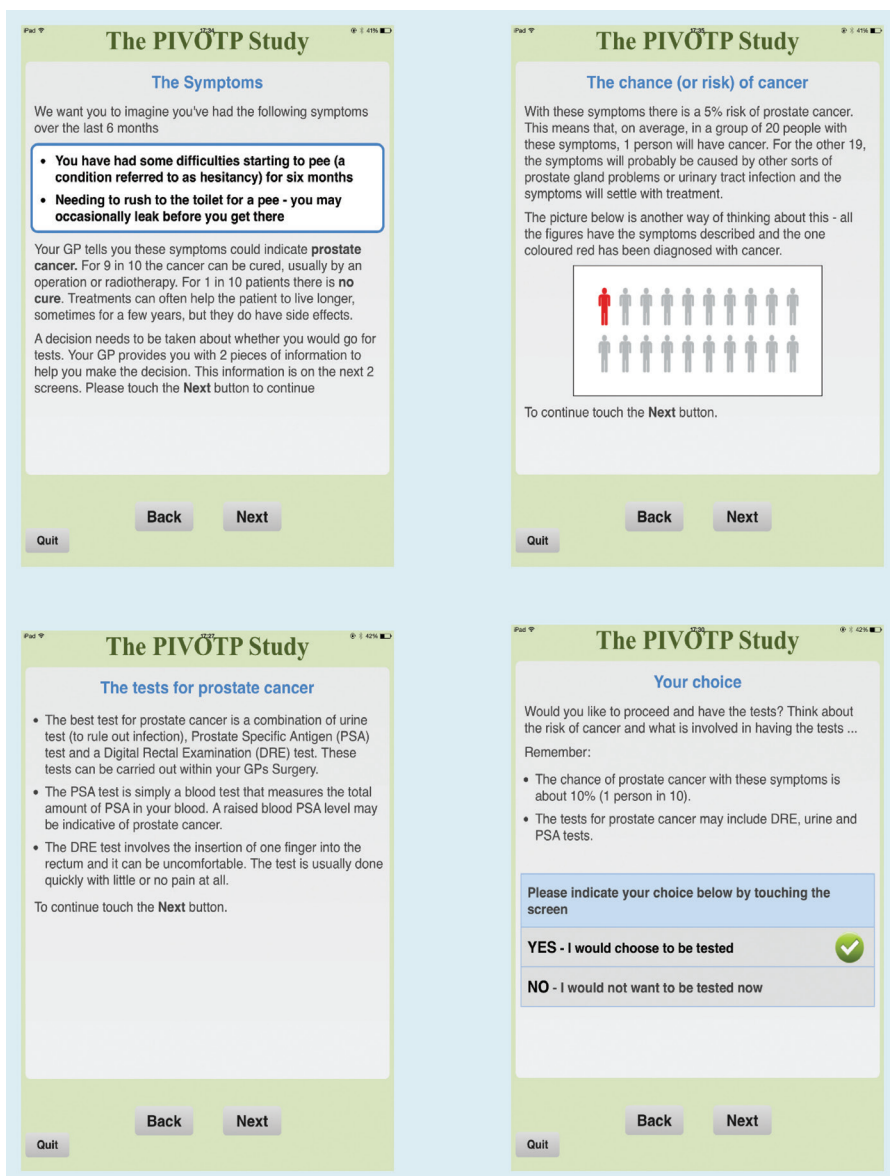
The pathway to diagnosis of symptomatic prostate cancer is complex, the success of which depends largely on prompt presentation of symptoms to primary care and prompt referral to secondary or specialist care. Both stages may be influenced by patients' preference for diagnostic investigation. GPs should be aware of the reduced appetite for testing in black males (which is possibly linked to fear and perceived negative outcomes of a prostate cancer diagnosis) and may consider being proactive in discussing the subject. This is particularly important as a study has suggested lower self-initiated discussion with the doctor about prostate cancer in black Caribbean males (as measured in native-born and foreign-born black males in the US).<sup>25</sup>

Prostate cancer awareness campaigns currently targeting black males may prove less effective where patients are unwilling to take up diagnostic investigation. Campaigners may consider including information about testing procedures and promote the benefits of early diagnosis. This is especially relevant as black community groups are increasingly keen to see PSA screening become available. If such campaigns could also incorporate encouragement for symptomatic testing, the differences reported in this study may narrow.

Black males, who have a higher incidence of prostate cancer and a higher mortality from it, are less inclined than white males to be tested for the disease. Education targeted at the black community and the health professionals who treat them may help to address this.

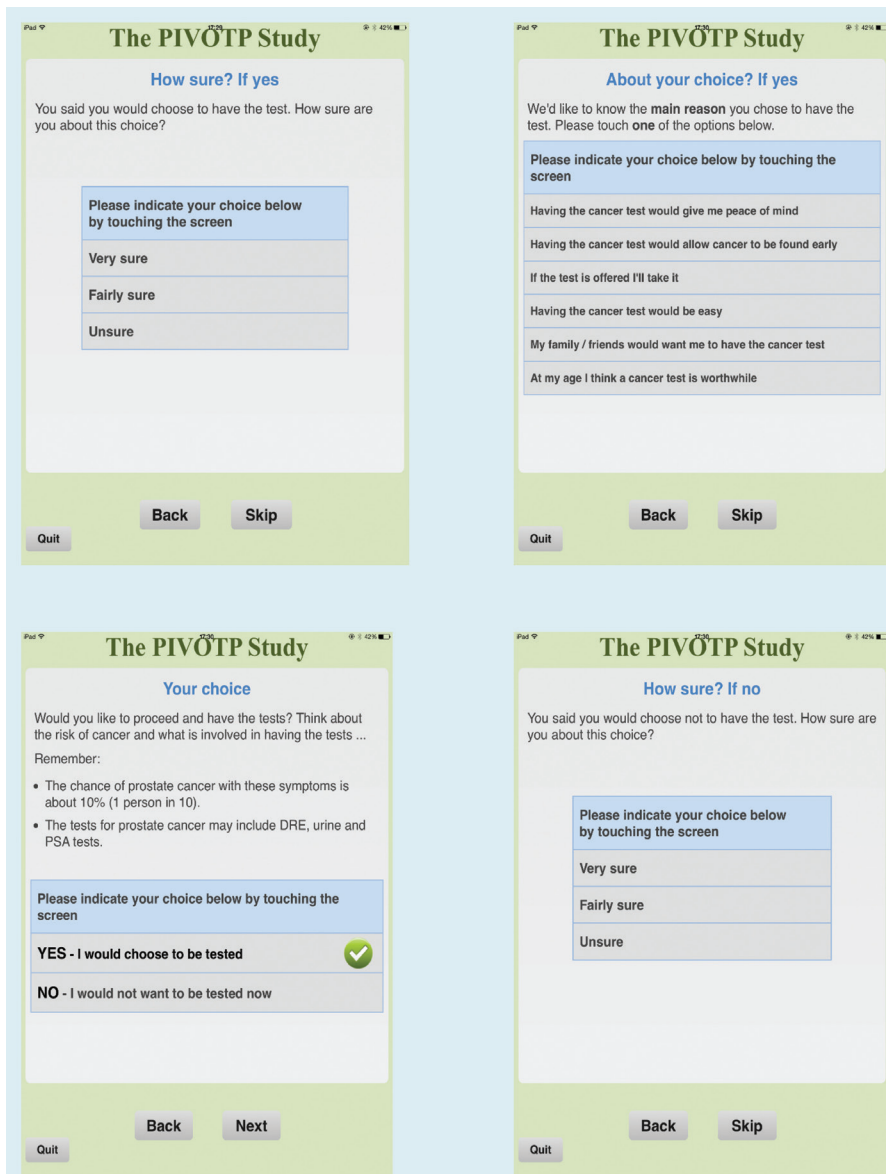
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Appendix 1. The vignette as viewed by participants.





Appendix 1 continued. The vignette as viewed by participants.



Appendix 1 continued. The vignette as viewed by participants.