What influences men’s decision to have a prostate-specific antigen test? A qualitative study

Tanvi Rai, Alison Clements, Colleen Bukach, Brian Shine, Joan Austoker and Eila Watson


**Background.** Current UK policy recommends informed decision making for prostate-specific antigen (PSA) testing. The process by which men decide to be tested warrants further investigation.

**Objective.** To determine the important influences on men’s decision to have a PSA test.

**Methods.** Semi-structured interviews with 20 men who had raised the issue of testing for prostate cancer with their GP and undergone the PSA test.

**Results.** Men wanted to be tested primarily because they believed in the benefits of early diagnosis. Triggers for consulting the GP were the personal experiences of friends with prostate cancer, a desire to be proactive about health, media reports, a family history or ongoing urinary symptoms. Before consulting the GP, men’s awareness was largely based on personal accounts and media stories and did not include much familiarity with the potential limitations of testing. Many had decided they wanted to be tested by the time they consulted their GP and this decision remained largely unaffected by the consultation. Men varied in the value they placed on receiving information about the benefits and limitations of PSA testing from their GP.

**Conclusions.** Men who consult their GP about testing are often already committed to having the test. When information about the benefits and limitations of PSA testing is provided, at that stage it may be too late for it to play a part in their decision. Making balanced information available to men in the community may be a more effective way to promote informed decision making and to facilitate more useful discussions with the GP.

**Keywords.** Decision making, patient information, prostate cancer screening, prostate-specific antigen, qualitative research.

**Introduction**

The National Screening Committee has recommended that currently there is insufficient evidence to introduce a prostate cancer screening programme in the UK.¹ The findings from two ongoing randomized controlled trials² are still awaited to provide a true assessment of the impact of prostate-specific antigen (PSA) testing on subsequent cancer mortality. However, in response to growing public anxiety about prostate cancer, the Department of Health introduced the Prostate Cancer Risk Management Programme (PCRMP) in 2001. Central to the programme is the premise that ‘any man who wishes to have a PSA test should have access to the test, provided he has been given full information regarding the possible benefits and limitations associated with receiving a test’.³

To facilitate implementation of the programme, all GPs were issued with an evidence-based information pack,⁴ containing summary information to assist discussions with men, and a pack of tear-off information sheets to be given to men considering a PSA test. The main issues identified by the PCRMP that men should be aware of before undertaking testing, irrespective of whether or not they have lower urinary tract symptoms (LUTS), are described in Box 1. LUTS are common in older men,⁵ and while debate continues regarding the merits of PSA testing for men with such symptoms,⁶,⁷ there is consensus that these men should be fully counselled prior to testing.
Previous studies evaluating the impact of providing information about the benefits and limitations of having a PSA test to men in the general population demonstrate that it can increase men’s knowledge and lead to more realistic expectations. Similar effects have been observed following information provision in relation to other medical screening decisions.

Our study aimed to investigate the process by which men who had raised the issue of testing for prostate cancer with their GP decided to have a PSA test, and to determine the role of evidence-based information about the potential benefits and limitations of the test in that decision.

Methods

Study design
Individual, semi-structured face-to-face interviews were conducted with men who had recently had a PSA test. We interviewed a purposive sample of men who had raised the issue of testing, excluding those where the initiative to test lay solely with the GP. Ethics committee approval was obtained.

Sampling strategy
Men were recruited from practices in the Oxfordshire area during 2005. They were identified on the basis of their GP’s request for a PSA test, as recorded by the Department of Clinical Biochemistry, John Radcliffe Hospital. These GPs were asked to complete a short questionnaire for each man referred and to state if they would be willing to forward an invitation to their patient to participate in our study. They also indicated on the questionnaire if the patient had raised the issue of PSA testing.

Seven hundred and forty-four questionnaires (44.5%) where they had indicated that PSA testing had been raised by the patient. We received consent to take part in an interview from 38 patients, corresponding with 36 referring GPs. On initial telephone contact, 14 men showed no recollection of PSA testing and/or mentioned that the issue was raised by the GP and were excluded prior to interview. A further four men were excluded after interview for the same reasons. The final sample available to us was 20 men, corresponding with 19 referring GPs. Interviews took place as soon as possible after consent was obtained. All the men were interviewed within a year of having a PSA test, and most within a few months.

Interviews
Semi-structured interviews were conducted and audio-taped (with consent from the man) by TR and EW, either in the man’s home or at the university. A schedule was used to elicit men’s motivations for wanting to be tested, any discussion they had with their GP about the benefits and limitations of testing, to explore how they reached the decision to proceed with the test and the role of information in this process. Twenty interviews were fully transcribed.

Analysis
Thematic analysis was undertaken by TR, EW and AC using the framework approach. The authors read the transcripts to obtain a detailed knowledge of the content of the interviews and identify the key issues. Coupled with questions from the aims of the study, a preliminary coding framework was developed. Sections of text were coded using this framework (using the software package Atlas.ti to assist in the management of the data) and new codes were added as more themes emerged from subsequent transcripts. The coded themes were examined by all three researchers across the different transcripts as well as within the context of each interview. Regular discussions during the analysis period ensured that the results that emerged were based on a joint perspective.
Results

Participants’ age ranged from 45 to 75 years and all were White British. Although there was some variation, men tended to be affluent and/or well educated. Some men had been experiencing symptoms such as urinary frequency and difficulty in urination. All men in our sample had completed testing and had received a ‘normal’ PSA value.

Reasons for wanting a test for prostate cancer

Men in this study had wanted to be tested for prostate cancer because either they perceived that an early diagnosis would increase their chances of successful treatment or they sought reassurance that they did not have prostate cancer.

... every man has a prostate [sic] problem of some kind, some degree and if you can catch it early um you give yourself a damn good chance of getting away with it. ... Whereas if you let it run that’s you know can be curtains. ... And I’m not ready for curtains yet. [laughs] ID6, 58 years

There were several triggers for men becoming concerned about prostate cancer and the impetus to consult their GP was often a mixture of different factors.

Having friends with prostate cancer was a significant stimulus for men becoming anxious about their own risk of prostate cancer.

... you know when you see friends uh with it who have a pretty healthy life style uh you think “Oh blimey am I, am I in that bracket?” ID10, 69 years

Some men were reflective about getting older and worried about their general health declining. Having medical tests like the PSA test helped them feel like they were acting responsibly and taking some control of their health. Additionally, men had often read in the popular press that prostate cancer was a common disease with a high death rate. Having relatives with prostate cancer also played a part in raising one man’s concerns.

Some men in our sample reported experiencing chronic symptoms such as urinary frequency and nocturia before they consulted the GP. A few among them also mentioned erection problems. Many of these men said they had wanted an explanation and/or treatment for their symptoms and were concerned about the possibility of having prostate cancer. However, it was not just the presence of symptoms but symptoms combined with the factors described above that prompted the consultation.

Men’s awareness of PSA-testing issues

Before GP consultation. At the point of consulting the GP, men had known about prostate cancer mainly from previous exposure to media stories and accounts from friends with the disease. They had all felt that prostate cancer was a very real concern.

Some men had heard anecdotal reports about the discomfort associated with having a biopsy, the potential for prostate cancer to take an indolent course and the morbidity associated with some of the treatment options. Very few men had more detailed knowledge about the issues surrounding PSA testing (see Box 1) before their GP consultation, which they had gained from previous discussions with a GP on this topic.

Information gained from GP consultation. One man’s GP had discussed PSA testing in great detail and as a consequence he had a good level of understanding of the issues. Another man’s GP gave him an information sheet that he studied carefully along with other literature from professional sources. Thus, only a few men were well informed at the point of testing.

Of the remainder, many men had some level of discussion with their GP, with a few also receiving written information to supplement the discussion. As a result, they became conscious of the unreliability of the PSA result, with some of them recalling being told about false positives and false negatives. Some learnt that the next stage in diagnosis was a prostate biopsy and in a few cases the GP had mentioned that prostate cancer could be indolent. Rarely was any information given about treatment options for prostate cancer. Some men received no discussion or written information about PSA testing from their GP, and thus remained poorly informed even after the consultation.

The role of information about the benefits and limitations of testing in making a decision to have a PSA test

Information has limited value to decision. Most men had not placed much importance on information about the benefits and limitations of testing in their decision to have a PSA test. They had been happy to receive some information from their GP, but they had already made their minds up to do something to alleviate their concerns about prostate cancer by the time they saw their GP, and this desire to ‘do’ something had remained unaltered.

And he said “Well we don’t recommend it, it’s not reliable, uh quite a lot of times ... the result isn’t the correct result,... he went on for some time giving me this spiel and then said “Well,” did I want to have one and I said “Yes,” ... because I’d rather if it’s 80% reliable, that 80% could be my life (…) I was very happy with what, ... was given to me [information]. And to be honest I had already made up my mind that I would [have the test] because I had had sufficient outside advice that men over 50 ought to have the test. ID6, 58 years
The reasons given by men to account for their views on the limited role of information were frequently related to their original reasons for wanting the test. For example, by the time this man received information from his GP about the uncertainty associated with the test, he had already been through a period of deliberation and was then reluctant to revisit his decision to be tested in case he regretted it later:

... it wasn’t just like “Oh I’m walking down the road I’ll pop in,” do you know what I mean? ... It was like a conscious decision after some thought and stuff. ... You would feel awfully silly wouldn’t you in two years from now ... if you had got all the way in to the doctors’ surgery (…). I got the information that I wanted from him ... as much as I needed to make a decision, and I had pretty much made the decision when I went in. ID5, 47 years

Another man had gone to see his GP for a PSA test because he had been experiencing mild symptoms of urinary nocturia that were similar to a friend’s symptoms who had been diagnosed with prostate cancer. His wife persuaded him to get tested and after doing some of his own research on the Internet beforehand, he went to his GP expecting to have the test:

I wanted it done there and then ... I had gone down ... to explain the problem and to find out what to do about it next, ... and when she came out with this stuff [information about pros and cons of testing] I was quite comfortable with just carrying on. ... I didn’t need time to think about it, I didn’t need anything like that at all. ID13, 58 years

**Information causes anxiety.** A minority of men, who were also committed to testing by the time they consulted their GP, spoke about being wary of ‘too much’ information and wanting to keep the decision simple. These men felt that information would only make them anxious:

... it’s nice to have the information but sometimes ... it’s too much information ... it can put you on the worry, I feel quite happy that uh I had the blood test and if there was anything wrong I have always put my faith in doctors and the Health Service. ID12, 61 years

These men often talked about ‘trusting’ or ‘having faith’ in their GP, as an explanation for why they personally did not need to engage with the information about the pros and cons of PSA testing. However, when prompted, this stated trust in the GP did not always accommodate the GP suggesting not having the test—the same man replied:

I think I would have believed him but ... I would have probably gone somewhere to have got a test (...) And fortunately he said “Yes”.

**Information is not relevant at the stage of the PSA test.** Another reason why men said they had been indifferent to, or uncomfortable about, receiving detailed information at the time of the test was because they felt it was premature. They had seen testing as a staged process and information about the ‘later stages’ as being redundant at the PSA-testing stage. So, receiving information about the unreliability of PSA results, and in some cases, even that a high PSA could be followed by a biopsy was more acceptable than information about indolent cancers and prostate cancer treatments and their associated side effects.

I would have wanted probably information if I had got a stage further. ... So it’s not that I don’t want to know what the situation is. ... I just didn’t feel there was any call at that stage ... I think I’m quite pragmatic about life and unless I know there is a need to think about the next stage then I don’t ... I don’t worry. ID8, 66 years

**Information is important to decision.** A minority of men demonstrated a greater incorporation of information about the benefits and limitations of PSA testing in their decision. These men had not consulted their GP with an expectation of having a test. They had deliberated over the information, weighing up the pros and cons of testing for themselves, and then decided that they would go ahead with the test, despite its limitations.

... we talked it through, the pros, the cons, the complications, what would happen if the PSA test proved to be positive, how would I feel, how would I react. ... the doctor discussed possible treatment ... and the subsequent consequences of the treatment, incontinence ... etcetera, etcetera ... all that was discussed quite openly, in a very relaxed manner. And uh I had no qualms to go for the subsequent PSA test. ID11, 47 years

However, even in this group of men, personal experiences had continued to impact on their decision to be tested. Knowing friends who had been through the process of diagnosis and treatment for prostate cancer had an enduring influence on men’s beliefs about the appropriate health behaviour for themselves, and these views survived even after taking on board information about the potential problems associated with diagnosis and treatment. This is exemplified by a man...
who had discussed PSA testing with his GP in the past and chosen not to be tested, but subsequently had seen three friends diagnosed with prostate cancer following a PSA test:

my friends who had raised PSA levels did have prostate cancer. ... So in my mind it was absolutely clear: you’ve got a raised PSA level, 90% chance, I mean all three of them ... had raised PSA levels, all three of them had prostate cancer, all three of them had to have treatment ... and so I wanted to get this out of the way you know. ID10, 69 years

Discussion

The fear of cancer, often coupled with prevailing urinary symptoms, the experiences of friends or family with prostate cancer and/or media influences prompted men to consult their GP about testing for prostate cancer. Prior to consulting the GP, most men had limited awareness of the issues surrounding PSA testing and prostate cancer, but firmly believed identifying prostate cancer at an early stage to be important. Even after the GP consultation, only a few men had developed a good understanding of the potential limitations of the test; some men had received no discussion or written information from their GP and had proceeded to testing with minimal awareness; the remainder had gained some degree of awareness of the issues from the GP consultation.

It emerged that many men were already committed to testing by the time they saw their GP, and since the ‘new’ information received from the GP would necessitate revisiting their decision, it diminished its value. Others said they did not want detailed information about testing as this would only have made them anxious. These few men preferred to put their trust in their GP, and this may be why GPs adopted a more doctor-centred role. However, they would have felt uncomfortable if the GP recommended not having the test.

Men’s attitude towards using information to aid their decision was affected by the individual contexts from which their concerns had first arisen. Personal anecdotes and media accounts continued to have a strong influence on their views even after the GP consultation. Even men’s prior knowledge about how prostate cancer can be slow growing did not temper their faith in the benefits of early detection. These findings are consistent with those of Sheridan et al.,\textsuperscript{14} who concluded that the strongest predictor of men’s interest in screening after viewing a decision aid was men’s interest in screening prior to the decision aid. In another study,\textsuperscript{17} where participants were assessed before and after a counselling intervention, men viewed the counselled information as being ‘unfavourable towards PSA’ and their underlying beliefs remained strong enough for them to dismiss it. Similar results emerge even further down in the process, as described by Denberg et al.,\textsuperscript{18} where men’s treatment preferences for localized prostate cancer were based less on the physician-provided information about the numerical risks of the various outcomes and more on emotions like fear (with a desire for rapid treatment), continuing misconceptions about cancer and treatment and the anecdotal accounts of others with prostate cancer.

Some men felt that information relating to the possibility of indolent prostate cancer and the controversies around treatments was redundant until there was a confirmed diagnosis of prostate cancer. These reservations about receiving information about the limitations find resonance in other cancer screening studies.\textsuperscript{19} The general optimism expressed by men about the benefits of PSA testing could be a function of the vigorous manner in which cancer screening has traditionally been promoted, both by health authorities and in the popular press.\textsuperscript{20} There may be a need for some flexibility in information provision, which includes the options of following the guidance of a doctor or recognized health authority and having access to more detailed information.\textsuperscript{21} We also need to find a way to enable men to recognize why an understanding of both the limitations and benefits of PSA testing could be valuable to them, and why there is currently no prostate cancer screening programme. Our study suggests that men often want the PSA test despite the current absence of evidence of its benefits. If the trial evidence does not find PSA screening to be effective, then it may prove difficult to scale back a technology for which public enthusiasm is high. This suggests the need for caution to be exercised before introducing other programmes where the benefits of a screening test are unproven.

Many of the previous studies that have considered the role of information in decision making regarding PSA testing\textsuperscript{8–11,13,14} have focussed on the general population, where most men would not have actively been considering PSA testing. The strength of this study is that the participants were men who had specifically consulted their GP on this issue. These men are also the target group for the PCRMP. One limitation of the study is that all the men in our sample had a test and we did not capture the views of men who decided not to proceed with testing following the GP consultation. Undoubtedly, interviewing this category of men would help illuminate the process of decision making where discussion with the GP results in a decision ‘not’ to proceed with testing. It would be interesting to explore the extent to which these men’s decisions are based on being fully informed, relative to the effect of a recommendation from the GP. Further, it would be useful to establish the size of this population
as compared with those who have the test. However, the methodological difficulties of trying to recruit men purely on the basis of them having initiated a discussion with their GP about PSA testing within our study period led us to base our recruitment around test completion records. Also, our sample did not include men who were found to have a raised PSA. These are clearly important areas for future research. As all the men in our sample had received a normal PSA result, they may have been less inclined to question the quality of information upon which they made their decision to be tested.

While it may be that the time delay between the GP consultation and our interview affected the detailed recall men had of the content of the consultation, we were still able to explore their views about the consultation and the extent to which they had actually absorbed the information given to them. We also recognize that many of our study participants were relatively affluent and well educated and that men from different backgrounds may have expressed different views. Finally, while we interviewed all the men available to us through our sampling strategy and uncovered a wide range of opinions, further interviews may have provided greater insight.

Conclusions

Relying solely on the GP to provide men with balanced information regarding the benefits and limitations of PSA testing may not be the most successful strategy to promote informed decision making. The findings from this study indicate that GPs do not always provide men with the prescribed information and, more significantly, many men have already decided they want to be tested by the time they consult the GP. Hence, making balanced information available to men in the community, i.e. at an earlier stage, may be necessary to facilitate informed decision making. Perhaps this could occur within the context of education about general prostate health. Men would then have the opportunity to consider this information before they develop a heightened concern about prostate cancer, and it would allow for more informed discussions with the GP. This approach would also require GPs to be fully conversant with the potential benefits and limitations of testing and be able to portray this information in a balanced fashion.

Acknowledgements

We would like to thank the GPs who assisted with recruiting the men for this study and all the men who took time to participate. We would also like to thank Professor Adrian Edwards for helpful discussions regarding the design of this study.

Declaration

Funding: Cancer Research UK; NHS Cancer Screening Programmes [Grant number: C73/A2983]. Ethical approval: Trent MREC.

Conflicts of interest: The authors have stated that there are none.

References

17 Farrell MH, Murphy MA, Schneider CE. How underlying patient beliefs can affect physician-patient communication about
What influences men’s decision to have a PSA test?


