




# BMJ Open What can patient-reported experience measures tell us about the variation in patients' experience of prostate cancer care? A cross-sectional study using survey data from the National Prostate Cancer Audit in England

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## ABSTRACT

**Objectives** A national survey aimed to measure how men with prostate cancer perceived their involvement in and decisions around their care immediately after diagnosis. This study aimed to describe any differences found by socio-demographic groups.

**Design** Cross-sectional study of men who were diagnosed with and treated for prostate cancer.

**Setting** The National Prostate Cancer Audit patient-reported experience measures (PREMs) survey in England.

**Participants** Men diagnosed in 2014–2016, with non-metastatic prostate cancer, were surveyed. Responses from 32 796 men were individually linked to records from a national clinical audit and to administrative hospital data. Age, ethnicity, deprivation and disease risk classification were used to explore variation in responses to selected questions.

**Primary and secondary outcome measures** Responses to five questions from the PREMs survey: the proportion responding to the highest positive category was compared across the socio-demographic characteristics above.

**Results** When adjusted for other factors, older men were less likely than men under the age of 60 to feel side effects had been explained in a way they could understand (men 80+: relative risk (RR)=0.92, 95% CI 0.84 to 1.00), that their views were considered (RR=0.79, 95% CI 0.73 to 0.87) or that they were involved in decisions (RR=0.92, 95% CI 0.85 to 1.00). The latter was also apparent for men who were not white (black men: RR=0.89, 95% CI 0.82 to 0.98; Asian men: RR=0.85, 95% CI 0.75 to 0.96) and, to a lesser extent, for more deprived men.

**Conclusions** The observed discrepancies highlight the need for more focus on initiatives to improve the experience of ethnic minority patients and those older than 60 years. The findings also argue for further validation of discriminatory instruments to help cancer care providers fully understand the variation in the experience of their patients.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A very high response rate (73%) resulted in a very large data set including almost 33 000 men.
- ⇒ The survey was very well completed with a 93%–99% completion rate for individual items on the questionnaire.
- ⇒ This study was able to add a great deal of information compared with most experience surveys, by linking individual data on the diagnosis and treatment of each man, as well as their socio-demographic characteristics.
- ⇒ Similar to other comparable surveys, there were fewer respondents in some patient groups, especially younger men, more deprived men or men in ethnic minority groups; this might mean that some differences found might be an under-estimate.
- ⇒ There may also be some survivor bias, however, these patients are very likely to survive well over 18 months post-treatment after which the survey was sent.

## INTRODUCTION

A positive experience of care is a vital dimension of care quality, alongside patient safety and clinical effectiveness. Measures of patients' experience of care focus on aspects of the 'humanity' of care received and have been highlighted as a way to improve care quality.<sup>1</sup> In addition, a key ambition of most health systems worldwide is to put patient experience on par with patient outcomes.<sup>2</sup> Studies have shown some association between patient experience and outcomes<sup>3–5</sup> and the importance to patients of being involved in decision-making has been shown to be associated with patient satisfaction,<sup>6</sup> leading to less



regret around those decisions, even if a patient experiences side effects of treatment.<sup>4,7</sup>

In England, an independent investigation demonstrated that despite reports of good experience overall: 'there is significant variation across the country and between different population groups'. It also pointed to the lack of 'knowledge and understanding that we have about the experiences of different groups of patients' (p.10<sup>8</sup>). Another UK-based project reported variation in experience and challenges in treatment decision-making, for example, linked to receiving inadequate information about side effects.<sup>9</sup>

To monitor and gain insights into patients' experience of cancer services, the National Cancer Patient Experience Survey (NCPES) has been carried out in the English National Health Service (NHS) since 2010 (<https://www.ncpes.co.uk/>).<sup>10</sup> The National Prostate Cancer Audit (NPCA) evaluates the care and outcomes of all men in England and Wales with newly diagnosed prostate cancer in the NHS. The NPCA sent a survey to men diagnosed between April 2014 and September 2016. This survey was designed to gather reports of functional outcomes and to determine the views of patients with non-metastatic prostate cancer about their experience of care following diagnosis and treatment. The questionnaire included selected questions from the NCPES, such as the information patients received about their prostate cancer diagnosis and treatment options, the treatment options offered, how the decision for their initial treatment was made and patients' overall rating of care.<sup>11,12</sup>

The NPCA reports high overall ratings of care but with some relatively regional variation, similar to findings from the NCPES.<sup>13,14</sup> 91% of men rated their care at 8 out of 10 or above (range across regions 73%–100%), and 87% of men reported that they were given the name of a clinical nurse specialist (CNS) (81%–100%).<sup>14</sup>

The high ratings are heartening despite the regional variation, but it is unclear how discriminatory the questions are: in this study, we explore whether experiences are as positive for all patients with prostate cancer. We have also explored the variation of services on offer following an organisational survey and the impact these might have.<sup>15</sup> Therefore this paper focuses on individual characteristics and whether these made a difference to men's perceptions of care.

Previous papers from the NPCA have focused on functional outcomes for men, such as urinary incontinence and sexual function using the patient-reported outcome measures (PROMs) in the bespoke NPCA Patient Survey.<sup>11,12,16–18</sup> This paper takes the patient-reported *experience* measures (PREMs) from the same survey. The experience measures allow us to further describe the variation in how care was experienced by men of different ethnic and socioeconomic backgrounds and different ages, all of whom have been shown to have varying treatments and outcomes.<sup>16,19</sup> By exploring these patterns, we aim to determine whether the provision of information to men with prostate cancer, and their perception of involvement

in decisions about their treatment, varied according to the patients' characteristics.

## METHODS

Details of the NPCA patient survey data collection have been described elsewhere.<sup>11,12</sup> The cohort of patients in this study comprised men diagnosed in England between 1 April 2014 and 30 September 2016 (n=44791). Men diagnosed with non-metastatic prostate cancer, who underwent or who were candidates for radical treatment were identified from the NPCA data set. In the first year of the survey, the questionnaire was only sent to men who underwent radical treatments. From the second year onwards (for a 1.5 year period) all men were included who underwent, or who were candidates for, radical treatment.

Questionnaires were posted to the homes of men at least 18 months after they were diagnosed with prostate cancer, with two reminders sent to non-responders: the final response rate was 73% for this cohort. The survey response data were individually linked to records from the NPCA database and Hospital Episodes Statistics (HES), an administrative database of all admissions to the NHS in England.<sup>20</sup> This data linkage is done using pseudonymised identifiers after the HES and NPCA data are received from National Cancer Registration and Analysis Service.

98% of respondents to the survey questionnaire provided self-reported ethnicity, which was supplemented, where it was missing, with data on ethnicity from the NPCA database and then HES records. As a result, records of only 0.1% (n=44) of respondents had no ethnicity information. Ethnicity was self-reported using the categories from the UK 2011 Census, and collapsed into four categories due to small numbers: white, black/black British, Asian/Asian British and mixed/other.<sup>21</sup> The NPCA database was the data source for age at diagnosis, tumour characteristics according to TNM scores (T-tumour, N-node, M-metastasis), Gleason biopsy score and serum prostate-specific antigen (PSA). The HES data set was used to determine the number of comorbidities<sup>22</sup> and socioeconomic deprivation, the latter measured by the Index of Multiple Deprivation (IMD), based on where the individual men lived at the point of diagnosis (Lower Super Output Areas: small geographical areas with population of ~1500 people).<sup>23,24</sup> These areas were grouped into five categories according to national quintiles of the IMD ranking, with higher scores indicating greater deprivation.

Men's prostate cancers were classified as being low-risk localised, intermediate-risk or high-risk/locally advanced based on their TNM stage, Gleason score and PSA level, according to a previously developed algorithm,<sup>25</sup> which uses the D'Amico classification adapted by the NPCA.<sup>25</sup>

### Questions included in this analysis

Five questions from the patient experience part of the survey were included in this analysis, as they were relevant to all men regardless of their risk group (Appendix A). The proportion of men responding as indicated in parentheses below was determined for each of the following questions:

- ▶ How much information were you given about your condition and treatment? (The right amount)
- ▶ Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have? (Yes definitely)
- ▶ Were the possible side effects of treatment(s) explained in a way you could understand? (Yes definitely)
- ▶ Were you involved as much as you wanted to be in decisions about your care and treatment? (Yes definitely)
- ▶ Overall how would you rate your care? Please circle a number (from 0 very poor to 10 very good) (8 and above out of 10).

For comparison purposes, the responses were split into binary categories: the response indicated in the parentheses versus all other responses. For example,

Were you involved as much as you wanted to be in decisions about your care and treatment? 1 = “Yes definitely”; 0=any other response (“Yes, to some extent”, “No, but I would have liked to have been more involved”, “Not sure/can’t remember”).

As responses to this questionnaire are generally positive, the most favourable response for each question was chosen. By restricting to the most definite answer, for example, ‘yes, definitely’ only (rather than combining with ‘yes, to some extent’ for instance) as has been done for studies using the NCPES in the past,<sup>10</sup> we can have more confidence in examining whether this truly positive experience varies between groups.

### Statistical analyses

As the patient survey is sent to all men diagnosed with non-metastatic prostate cancer in the English National Cancer Registry, it was possible to compare the characteristics of non-responders to responders. The distribution of patient responses by age, ethnic group and deprivation was then descriptively analysed for each of the five questions.

Some of the treatment options available, their experience of their care and thus the responses given, might additionally be explained by the risk group of a man’s disease, or by the comorbidities that they may have, and so a multivariable logistic regression was undertaken for each question separately. These multivariable analyses examined the factors associated with responding ‘yes, definitely’. Results are presented as the ‘relative risk’ of a positive response. Records with missing data were dropped from the multivariable analysis. For each survey question, a multivariable Poisson regression model was used to estimate the rate of positive responses relative

to the baseline category of each covariate. The statistical significance of the factors included was assessed using the likelihood ratio test of nested Poisson models.

### Patient and public involvement statement

Patients have been involved in this research since conception. The NPCA relies on its patient and public involvement (PPI) Forum for advice, guidance and contribution to its ongoing research programme.

When the original survey was first done, a poster was sent to Trusts about how results would be used and a website address was given to anyone interested. The NPCA has published Patient Summaries of the audits every year they have been published to make results as accessible as possible—these included results of the PROMs investigations in 2018 and 2020. The results were reviewed and commented on at the NPCA PPI Forum. Further to a suggestion from one of the members, slide sets summarising the results were prepared to aid dissemination and discussion within local support groups attended by the PPI members

Two of the PPI Forum members are coauthors of this paper, having advised on the design and conduct of the study, helped to interpret the findings and contributed, with other PPI members, to the comments in our ‘Patients’ Perspective’ section below (Box 1).

## RESULTS

### Participants

44 791 men were sent a survey, and of these 32 796 men responded (73.2%). Responders’ characteristics are shown in [table 1](#). Responders were similar in age to non-responders overall (responders’ mean age was 68.0 years vs non-responders’ 67.1 years). However, more men at the extremes of the age range did not respond (around one-third of those under 60 and of those over 80 years of age). Responders were more likely to have fewer comorbidities (80.0% vs 73.1% with no comorbidities), be less deprived (50.6% vs 39.4% in the two least deprived national quintiles), be in the high-risk/locally advanced risk group (48.1% vs 42.1%) and have had treatment (81.9% vs 66.6%). They were also more likely to be from a white ethnic background (95.1% vs 81.6%)—notably around a quarter (23.9%) of this group did not respond, but around 50% of men from the other ethnic backgrounds did not respond (47.7% black, 50.4% Asian, 51.6% mixed/other) (online supplemental table 1 (Characteristics of responders vs non-responders)).

### Distribution among those responding ‘Yes definitely’ to questions (unadjusted)

All responses to the selected questions, broken down by three of the patient characteristics: age, ethnicity and socioeconomic deprivation, are shown in online supplemental table 2 (all responses by patient characteristics). [Figure 1](#) shows how the most positive responses were distributed. For all questions presented, there is a

**Table 1** Characteristics of men responding to the survey

	Number of men (%)
Total	32 796 (100.0)
Age, mean (years)	68.0 (SD=7.34)
<60	4106 (12.5)
60–69	14 066 (42.9)
70–79	12 989 (39.6)
80+	1635 (5.0)
Ethnic group	
White	31 180 (95.1)
Black/black British	842 (2.6)
Asian/Asian British	439 (1.3)
Mixed/other	291 (0.9)
Missing	44 (0.1)
Charlson comorbidity score	
0	26 248 (80.0)
1	4586 (14.0)
2+	1962 (6.0)
Deprivation category	
1—least deprived	8471 (25.8)
2	8139 (24.8)
3	7045 (21.5)
4	5300 (16.2)
5—most deprived	3841 (11.7)
Risk group	
High-risk/locally advanced	15 768 (48.1)
Intermediate	14 387 (43.9)
Low-risk	1613 (4.9)
Missing	1028 (3.1)
Type of treatment	
External beam radiotherapy only	14 721 (44.9)
Radical prostatectomy only	8247 (25.1)
Brachytherapy only	1257 (3.8)
Other treatment*	2636 (8.0)
No treatment	5935 (18.1)

\*Including multimodal treatments, and cryotherapy and HIFU (High-Intensity Focused Ultrasound).

gradient of decreasing positivity with increasing deprivation category, but the difference between the highest and lowest deprivation is small at 3%–7% depending on the question.

There is a noticeable difference for men in different ethnic groups. Asian men consistently reported the least positive experience. Their responses were similar to black men for most questions, but in particular, fewer Asian men felt their views were taken into account (yes definitely: 69.0% in white men, 66.4% in black men, 59.2% for Asian

men); and fewer felt they had side effects explained to them (yes definitely: 69.4% in white men, 62.8% in black men, 56.7% for Asian men).

Older age groups responded less positively about having their views considered compared with younger men (51.4% in the 80+ age group vs 72.7% in those under 60 years old), having side effects explained (69.6% vs 57.4%) and being involved in decisions (63.5% vs 74.8%) but responded similarly to younger (<60-year-old) men about being given the right amount of information and for their overall rating of care.

### Multivariable analysis of factors associated with the most positive responses

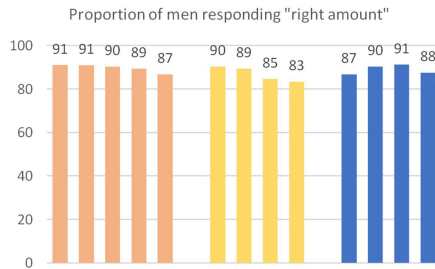
Table 2 shows the relative risk of men responding 'yes, definitely' to the selected questions depending on their characteristics. Univariate relative risks were very similar and are shown in online supplemental table 3 (univariate regression analysis).

There was little evidence of a difference in the most positive responses for any of the groups as to whether they felt they were given the right amount of information before treatment started. When asked if side effects were explained in a way they could understand, the absolute differences in positive responses were not large, but the oldest men over 80 years of age (relative risk (RR)=0.92, 95% CI 0.84 to 1.00), and those in Asian (RR=0.86, 95% CI 0.76 to 0.98) and black (RR=0.91, 95% CI 0.83 to 0.99) ethnic groups were significantly less likely to respond 'yes, definitely'.

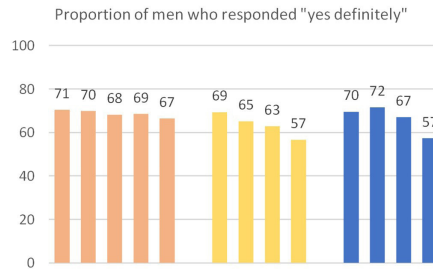
Older men were also less likely to feel their views were considered. Positive responses decreased with increasing age with men over 80 years old being 21% less likely to respond 'yes, definitely' compared with men less than 60 years old (RR=0.79, 95% CI 0.73 to 0.87). Other characteristics were not significantly associated with a positive response to this question except for the risk group which showed that men in the intermediate and low-risk groups were more likely to feel they definitely had their views considered compared with men in the high-risk group ( $p<0.001$ ; intermediate risk group: RR=1.14, 95% CI 1.11 to 1.17).

There was good evidence that the tendency to feel involved in decisions as much as they wanted to be differed by patient characteristics. Older men were less likely to respond 'yes, definitely' (men 80+ RR=0.92, 95% CI 0.84 to 1.00 with men <60 as the baseline), as were men in ethnic minority groups: Black men were 11% (RR=0.89, 95% CI 0.82 to 0.98) and Asian men 15% (RR=0.85, 95% CI 0.75 to 0.96) less likely than white men to respond 'yes, definitely' ( $p=0.004$ ). There was slightly less likelihood of a positive response with increasing deprivation ( $p=0.058$ ; most deprived group: RR=0.94, 95% CI 0.90 to 0.99) and for those with more comorbidities ( $p=0.009$ ; those with 2+ comorbidities RR=0.94, 95% CI 0.89 to 1.00). Men in the lower-risk groups were again more likely to feel adequately involved in decisions than men in the high-risk

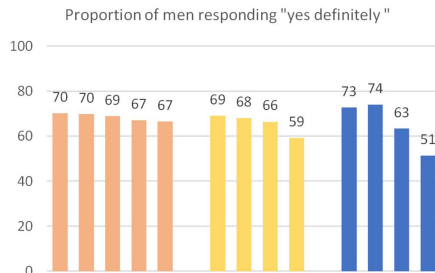
How much information were you given about your condition and treatment?



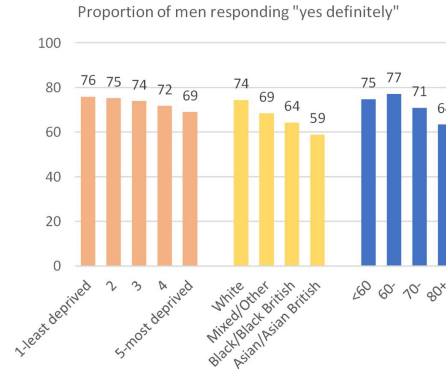
Were side effects adequately explained?



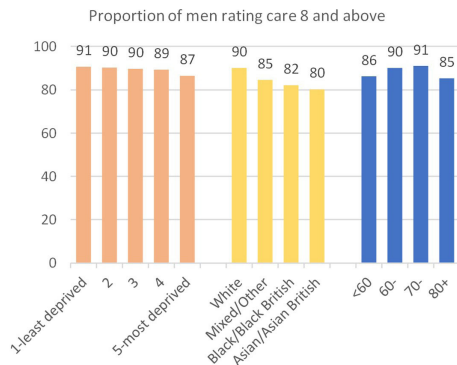
Do you think your views were taken into account?



Were you involved as much as you wanted to be in decisions about your care and treatment?



How would you rate your care?



**Figure 1** Responses to selected patient-reported experience measures questions by age, ethnicity and deprivation category of the respondents (unadjusted).

group ( $p < 0.001$ ; intermediate risk group:  $RR = 1.10$ , 95% CI 1.07 to 1.13).

Finally, for the overall rating of care, there was little evidence of differences across characteristics. Although Asian men were 10% less likely to give a rating of 8 or above compared with white men ( $RR = 0.90$ , 95% CI 0.81 to 1.01), this did not reach statistical significance after adjustment ( $p = 0.075$ ).

## DISCUSSION

This study in the English NHS demonstrates that the experience of care reported by patients with prostate cancer, including patients' perceptions of the provision of information and their involvement in decisions about their treatment, varies according to certain patient characteristics. Older men (especially those over 80 years old) and men in Asian and black ethnic groups reported a

poorer experience of care in these respects. This was also true to a lesser extent for men living in areas of higher socioeconomic deprivation. Although the absolute differences in responses were not large in most cases, they varied similarly across several questions. The overall high rate of positive responses to questions about the experience of prostate cancer care can hide significant variation in response between patients with different characteristics which cancer care providers should be aware of. This was particularly true for the questions about whether side effects were adequately explained and if men felt as involved as they wanted to be in decisions about their care.

### Themes for particular patient groups

#### Men with high-risk disease

Most men with high-risk diseases did feel that they were given the right amount of information before treatment



**Table 2** Multivariable regression analysis of responses to selected questions in the NPCA patient survey (all variables mutually adjusted)

	Right amount of info			Side effects explained			Views considered			Felt involved in decisions			Overall rating of care 8+		
	No.	Adj RR (95% CI)	P value	No.	Adj RR (95% CI)	P value	No.	Adj RR (95% CI)	P value	No.	Adj RR (95% CI)	P value	No.	Adj RR (95% CI)	P value
<b>Total</b>	<b>28849</b>			<b>21 546</b>			<b>21 491</b>			<b>23 025</b>			<b>26 526</b>		
Age			0.259			0.002			<0.001			<0.001			0.069
<60	3726	1		2893	1		3030	1		3113	1		3406	1	
60–69	13 033	1.03 (0.99 to 1.07)		10 039	1.03 (0.99 to 1.07)		10 381	1.03 (0.99 to 1.07)		10 786	1.03 (0.99 to 1.07)		12 004	1.04 (1.00 to 1.08)	
70–79	11 003	1.03 (1.00 to 1.07)		7914	0.99 (0.95 to 1.03)		7455	0.91 (0.87 to 0.94)		8357	0.97 (0.93 to 1.01)		10 152	1.05 (1.01 to 1.09)	
80+	1087	1.00 (0.93 to 1.07)		700	0.92 (0.84 to 1.00)		625	0.79 (0.73 to 0.87)		769	0.92 (0.85 to 1.00)		964	0.99 (0.92 to 1.06)	
Ethnic group			0.765			0.020			0.353			0.004			0.075
White	27 528	1		20 634	1		20 533	1		22 082	1		25 426	1	
Black/black British	714	0.97 (0.90 to 1.05)		507	0.91 (0.83 to 0.99)		536	0.95 (0.87 to 1.04)		518	0.89 (0.82 to 0.98)		590	0.93 (0.85 to 1.01)	
Asian/Asian British	358	0.96 (0.87 to 1.07)		230	0.86 (0.76 to 0.98)		240	0.91 (0.80 to 1.03)		240	0.85 (0.75 to 0.96)		303	0.90 (0.81 to 1.01)	
Mixed/other	249	1.01 (0.90 to 1.15)		175	0.97 (0.84 to 1.12)		182	1.01 (0.88 to 1.17)		185	0.96 (0.83 to 1.11)		207	0.94 (0.82 to 1.08)	
Charlson comorbidity score			0.436			0.028			0.135			0.009			0.217
0	23 230	1		17 545	1		17 471	1		18 747	1		21 414	1	
1	3951	0.98 (0.95 to 1.02)		2820	0.96 (0.92 to 1.00)		2844	0.97 (0.93 to 1.01)		3019	0.95 (0.92 to 0.99)		3606	0.98 (0.95 to 1.02)	
2+	1668	0.98 (0.93 to 1.03)		1181	0.95 (0.89 to 1.01)		1176	0.96 (0.90 to 1.02)		1259	0.94 (0.89 to 1.00)		1506	0.96 (0.91 to 1.01)	
Deprivation			0.601			0.804			0.681			0.058			0.614
1—least deprived	7492	1		5679	1		5639	1		6103	1		6987	1	
2	7205	1.00 (0.97 to 1.03)		5413	1.00 (0.96 to 1.03)		5402	1.00 (0.97 to 1.04)		5839	1.00 (0.96 to 1.03)		6648	1.00 (0.96 to 1.03)	
3	6230	1.00 (0.97 to 1.03)		4569	0.98 (0.95 to 1.02)		4631	1.00 (0.96 to 1.04)		4947	0.98 (0.95 to 1.02)		5686	0.99 (0.96 to 1.03)	
4	4654	0.99 (0.96 to 1.03)		3459	0.99 (0.95 to 1.04)		3392	0.98 (0.94 to 1.02)		3625	0.97 (0.93 to 1.01)		4243	0.99 (0.95 to 1.03)	
5—most deprived	3268	0.97 (0.93 to 1.01)		2426	0.97 (0.93 to 1.02)		2427	0.98 (0.93 to 1.03)		2511	0.94 (0.90 to 0.99)		2962	0.97 (0.92 to 1.01)	
Risk group			0.654			0.091			<0.001			<0.001			0.130
High-risk/locally advanced	14 333	1		10 738	1		9933	1		10 893	1		13 313	1	
Intermediate	13 109	1.00 (0.98 to 1.03)		9884	1.03 (1.00 to 1.06)		10 521	1.14 (1.11 to 1.17)		11 001	1.10 (1.07 to 1.13)		11 967	0.99 (0.97 to 1.02)	
Low-risk	1407	0.98 (0.93 to 1.04)		924	0.98 (0.91 to 1.05)		1037	1.05 (0.99 to 1.12)		1131	1.06 (0.99 to 1.12)		1246	0.94 (0.89 to 1.00)	
Adj RR, adjusted relative risk; NPCA, National Prostate Cancer Audit.															

and that potential side effects were explained to them in a way they could understand. However, they were less likely, than those with intermediate or low-risk diseases, to respond positively to whether they felt their views were considered or whether they felt as involved as they wanted to be in decisions around their care. Men with higher risk diseases tend to have fewer choices available to them regarding their treatment options, which may explain this difference. However, some men with high-risk localised disease may still be offered prostatectomy as part of multimodal therapy and high dose rate brachytherapy is indicated as a boost to other treatments. Patients' expectations regarding potential side effects from treatment may be better managed if they feel fully informed about them during pretreatment discussions and the potential options for managing these should they develop.<sup>426</sup> Clinicians should ensure that men with higher risk diseases are informed as to why certain treatments are being advocated to them.

### Older men

Although older men are more likely than men less than 60 years old to have multimorbidity which could lead to specific clinical decisions or recommendations for treatment, even with adjustment for comorbidities, age remained a factor in reducing positive responses to several of these questions. A study using the NCPES sent to all patients with cancer in the English NHS also found fewer positive responses from the oldest patients.<sup>27</sup> Other studies in the UK and elsewhere have highlighted different treatments given to men seemingly based on chronological age rather than fitness for treatment.<sup>28–30</sup> Although age is rarely mentioned in clinical guidelines for treatment decisions,<sup>31</sup> geriatric assessment is increasingly seen as vital. Older but fit men should receive the same treatment options as younger men, according to the International Society of Geriatric Oncology.<sup>32</sup> Some hospitals have developed a geriatric oncology liaison service for this purpose, but a recent survey of NHS hospitals in England and Wales found that only 11% of hospitals had an onco-geriatric service onsite.<sup>33</sup>

Unconscious ageism may still creep into clinical assessment<sup>34–36</sup> but it could also be that clinicians are sensitive to issues with a patient's hearing or vision, or early signs of their cognitive decline leading to a lowering of a patient's ability to take on board the complex information being given before individual decision-making.

### Ethnic minority groups

Studies have also found worse experiences reported by patients from ethnic minority groups.<sup>27 37 38</sup> The differences in experiences of care reported in these studies and the current study may be the result of conscious or unconscious bias on the part of healthcare professionals. It may also be a genuine language barrier for some patients.

In some population groups with a lower incidence of prostate cancer, men may have fewer contacts with relatives and others who have had the disease. This may be

the case for Asian men for whom the incidence of prostate cancer is 8% compared with around 30% in black men, according to a study carried out in England.<sup>39 40</sup> This may lead to less familiarity with what to expect in the situation and potentially lead to less satisfactory interactions during their own diagnosis and treatment experiences. For black men, their experience of diagnosis and treatment has been found to be affected by 'a complex of intersecting factors' including their ethnicity.<sup>41</sup> While it has been shown in research carried out in the UK that many black men have a variety of adjustment strategies with which to cope with these experiences,<sup>42</sup> there may also be a reticence to follow-up problems likely to be caused by prostate disease.<sup>43</sup>

### Cross-cutting themes

In general, there was little variation by characteristics in how positive men felt about whether they had received the right amount of information and yet, whether side effects had been explained in a way they could understand was rated much lower and it varied by both age and ethnic group. This is an important finding as a critical part of patient-centred shared-decision making is communication about possible side effects, of a procedure or treatment in a way patients can understand, especially in light of the known significant (and often life-long) side effects that radical treatments can cause.<sup>11 12 44</sup> Patients' expectations regarding potential side effects from treatment may be better managed if they feel fully informed about them during pretreatment discussions and the potential options for managing these should they develop.<sup>426</sup>

A reduced feeling of involvement in decisions was common across the subgroups of men in this study. Some men may not want to be very involved and would rather leave all decisions to the clinical team, but this questionnaire asked if they were 'as involved as they wanted to be' and so this reduction highlights an unmet need for some patient groups. This might be connected to the perception of not being given enough information which has been shown to reduce patients' desire to participate in clinical decisions.<sup>45 46</sup> As information exchange is one of the cornerstones of shared decision-making, if patients do not feel adequately informed, they are unlikely to feel adequately involved either.<sup>47</sup> Tools have been developed to try to involve and inform patients more about aspects of their care, for instance <https://prostate.predict.nhs.uk/>.

The reduced perception of involvement might also be due to a variety of linguistic, but also cultural and religious factors. Evidence suggests that patients who feel well informed about the harms and benefits of their treatment options also feel that they received patient-centred care more than those who feel incompletely informed.<sup>46</sup>

### Strengths and limitations

A key strength of this study is how much information we can add compared with most experience surveys, given the linkage to patients' diagnosis and treatment data, as well

**Box 1 The patients' perspective**

Comments from patients:

Patients' stories

"I had radiotherapy, I had three and half years of treatment which finished a year ago. Side effects are a long-term issue, and you are asked to prioritise: I put survival at the top, so other things feel less important, weeks or months in the future [when the survey is sent]."

"It's just my personal view but why is everyone so keen on 'choice' in medical settings? I would have said that it is not that high up my priorities. I don't want choice, I want to be told and then be given the best treatment. It's one situation in which you do want to be told. I don't want to have choice, I want my hospital to be as good as the best."

"As a result of my father dying of metastatic prostate cancer I was advised to have PSA tests. After my third annual test, when I was asymptomatic, the PSA levels had been rising and my GP arranged a consultation with a urologist. My first thoughts, as a result of my family history, were that I was going to die from cancer. The consultant was excellent and he arranged an MRI scan. This failed to indicate anything. He then carried out a biopsy. After discussing the biopsy results with me he said that cancer was present in quite a few cores. We discussed treatment options and when I found that salvage surgery, in the case of recurrence post-radiotherapy was not straightforward, I decided upon surgery. My negative thoughts then progressed to "I will die under the anaesthetic". The surgeon told me at my first consultation post-surgery that the cancer was contained within the prostate and was grade 7. I burst into tears with relief."

Responses to the survey results:

"Any survey will produce a range of results, as a result of the participants' experiences, perceptions and expectations. If research on patient experiences of their health care identifies regular patterns of concern, it is essential that further work is essential to clarify these concerns and, if possible to address them."

"When it comes to asking questions, looking back on a time when you've just been given a cancer diagnosis, it's quite traumatic. Prostate cancer is not one of the bad ones, but that doesn't change the fact that you've got cancer. It happens fairly quickly over a few weeks. Thinking back I don't think things could have been done much differently. It's difficult to go back and think back. All this stuff after the event [surveys], it's reassuring to know that the NHS does these things, and I assume somebody is making sure the treatment across hospitals is as good as can be, but at the time it's happening to you, you don't have any interest in it – you're just in the hands of the medics. You're in a different frame of mind, you're not thinking about it, looking back."

"It may be that for the most elderly men that the clinician's viewpoint is that some treatments are inadvisable. Clinicians may be cautious about some treatment options for the elderly. This means that the clinicians, therefore, probably just don't discuss all options or treatment details with the older men. For older men, [differences in responses to the survey] therefore due to age and because they have more co-morbidities therefore some options have been automatically ruled out? Might a decline in the elderly patient's hearing, vision, or cognitive abilities affect their comments?"

"Some of the ethnic differences might be due to different cultural, linguistic or religious factors. For example, I have often heard from meetings re prostate cancer that there is often a reticence amongst black men to follow up problems likely to be caused by prostate disease. In Asian men is the chance of prostate cancer 1 in 13? Could this result in their having had fewer contacts with relatives etc who had the disease, and, therefore, these patients have less idea of what to expect in the situation? Also not all medical staff may understand cultural sensitivities

Continued

**Box 1 Continued**

- especially if they practice in an area of little ethnic diversity, and hence they will not take this into account."

"It is not surprising to me that men in the higher risk group responded less favourably to the questions on whether their views on treatment were taken into account and whether they were involved as much as they wanted in care and treatment decisions. They would have felt less involved because, in order to attempt a cure, their clinicians would have lent towards those treatments which were likely to result, in their opinion, in a better outcome."

as socio-demographic characteristics. Another important strength is the high response rate achieved to the NPCA patient survey, which at 73% improves on the 65% of the NCPES national survey.<sup>48</sup> The survey responses also had a high completion rate: 93–99% across individual items.

Although the response rate was high, there were fewer respondents from some patient groups, which is similar to other studies,<sup>49</sup> and a well-known issue for survey response. The lower response from younger, more deprived men and those in ethnic minority groups suggests that our findings might underestimate the extent of the differences in response that we have highlighted here.

We must be aware, therefore, that those who were willing to respond may be more likely to be fluent English speakers, and so language difficulties may not fully explain the less positive experiences for ethnic minorities reported here. With better representation from ethnic minority groups, we might have found that the experiences they reported might have been even worse compared with men in the white ethnic group.

A survey such as this may also suffer from some survivor bias (ie, only those who survive the 18 months past treatment will receive and be able to answer the survey). However, this survey was only sent to men with non-metastatic disease who underwent or who were candidates for radical treatment (ie, treatment with curative intent). These patients are very likely to survive beyond the 18-month cut-off, so this should not have had a large impact on this study.

**Recommendations**

Improved patient experience is evidently dependent on a suitable level of appropriately trained staffing, but high staff workloads and increased time pressures make it more difficult to give patients all the time they might need, and this may differ between hospitals. Both physical and staffing resources are currently at a premium<sup>50–52</sup> and these capacity issues may not be helping in supporting better patient centred-care.<sup>53</sup>

Increasing the number of Clinical Nurse Specialists available is particularly important so that they have enough time to spend with each patient. They play a pivotal role in helping patients to navigate their diagnosis and treatment,<sup>47 53 54</sup> and their involvement in conveying information and giving time to answer questions has been shown to have an important contribution to overall



satisfaction with care.<sup>6 47</sup> They are not always available, however: a recent organisational survey found 83% of NHS hospitals across England and Wales report having at least one CNS in all prostate cancer clinics at present.<sup>15 33</sup>

An increase in staffing capacity may be one option to address these inequalities in patient experience, but greater support for advanced communication skills training in addition to attaining core competencies would help to support more nuanced elements of shared decision-making so that patients can understand the practicalities, benefits and side effects of different treatment options and make informed choices. This includes helping physicians understand what constitutes shared decision-making, and improving their relational communication skills, defined as communication that focuses on the expression and interpretation of messages within close relationships.<sup>55 56</sup> The findings here also argue for increased family member involvement, where appropriate, for older patients<sup>57 58</sup> as well as language interpretation services and information booklets in multiple languages.

Effective care administration and coordination<sup>7 37</sup> is also key. As many treatment options are available (eg, active surveillance, focal and radical treatments) the options can be confusing and so, as well as affording patients the appropriate time to make a decision, giving them digestible information (such as videos for consenting, eg, that they can review in their own time) is important. Research has shown that patients depend on informal sources of information to guide their care choices, especially in the absence of valid comparative information.<sup>59</sup>

Patients may have to see several different healthcare professionals, and good coordination can simplify the patients' journey.<sup>60–62</sup> In joint prostate cancer clinics, patients are seen by a urologist, oncologist and clinical nurse specialist in the same appointment, discussing with specialists both prostatectomy and radiotherapy options, when these are legitimate choices for the particular patient, and before the patient's decision about which treatment to choose. These joint clinics can be challenging to facilitate, however, due to the degree of organisation needed to include all relevant specialists and other staff. For example, a recent survey of NHS hospitals in England and Wales found just 43% of hospitals have access to these.<sup>33</sup>

Further work is planned to explore the patterns of differences in experience between providers of prostate cancer services between hospitals and to analyse whether characteristics of hospitals themselves (eg, size, types of treatments offered, whether they are a specialist Multi-Disciplinary Team centre) might explain some of the differences and so further point to ways in which they might be addressed.

A critical evaluation of the questions included in patient experience questionnaires is welcome as the questions that we adopted from an existing national survey used in England did not always appear to be sufficiently discriminatory—extensive validation and testing of

these instruments is important so that the evidence they produce is as informative as possible.<sup>63</sup> The very high levels of positive responses we found may not reflect some of the important issues men face following diagnosis and with their experience of care (Box 1). Additional questions might need to be included that would help to get a better understanding of the variation in the responses between hospitals, for instance by collecting more information about the patients themselves, for example, their first language, years living in the country, perception of previous healthcare experiences (prediagnosis).

Beyond the type of survey reported here, more research using focus groups and/or individual interviews, or ethnographic methods, for example, shadowing patients through their cancer journey, would also help to get a more comprehensive understanding of the patient experience. This could build on the other work that has been carried out in the English NHS in patients diagnosed with prostate cancer.<sup>4 9 41 42 64 65</sup>

## CONCLUSION

This study has highlighted some aspects of poorer experience of care provided by the NHS in England and Wales for older patients with prostate cancer and those in ethnic minority groups which are likely to pertain across many cancers. These discrepancies highlight the need for more focus on initiatives to improve the experience of certain patient groups. In the UK, this is now a recognised priority in the national cancer strategy.<sup>8 27</sup> Our findings argue for further validation and testing of discriminatory instruments to help the cancer care community reach these goals.

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