



Experiences of the NHS prostate cancer pathway in Birmingham and Solihull

July 2023



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Executive Summary

Objectives

Healthwatch Birmingham and Healthwatch Solihull sought to understand people's experiences of using NHS prostate cancer services in Birmingham and Solihull by listening to their views of using screening services, care and treatment, and support services. We also sought to identify and understand barriers or challenges faced when using these services.

Methodology

A questionnaire was sent out to people diagnosed and/or treated for prostate cancer in the past five years. Questionnaires were shared through community support groups for cancer/prostate cancer, third sector organisations, the NHS, and social media. To further explore issues study participants shared with us, qualitative interviews were then held with some participants. We are aware that Black people are more affected by prostate cancer, with 1 in 4 Black people affected by prostate cancer compared to 1 in 10 white people and 1 in 44 Asian people. By attending events run by community and third sector organisations, we aimed to ensure that people from varied backgrounds were represented in the study. However, only three of our participants are from a black background and one from an Asian background. The findings of this study are therefore based mainly on the experiences of white people. We acknowledge that this represents a gap in our data and that consideration must be given to service users from a range of ethnic backgrounds when implementing any changes.

In total, 81 people completed the survey online and 12 people were interviewed.

Key findings

The feedback we heard shows that overall, a majority of the participants who have accessed prostate cancer services in Birmingham and Solihull have a positive experience along the prostate cancer pathway. However, variability exists and increases within the post-treatment support pathway.

Within the diagnostic pathway, participants were satisfied with the:

- Information they received about prostate cancer services and what to expect following referral (62.5%).
- Way the service communicated with them (61.6%), and support that was offered to them (58.3%).
- Interaction and support from healthcare professionals, with 72% indicating they had a named Cancer Nurse Specialist.
- Speed of diagnosis, support, and information.

However, people expressed dissatisfaction with the screening protocols, noting the difficulties in getting a prostate check or a Protein-Specific Antigen (PSA) test, a blood test to help detect cancer¹. It is notable that screening/testing for prostate cancer is not offered routinely, as is the case for female related cancers such as breast or cervical cancer. Education on early testing and screening is an area which participants argued needs to improve. There is a need to ensure that communication and awareness comes through primary care rather than overly relying on prostate cancer charities. Education is crucial to addressing inequality issues within prostate cancer. Studies have found that lack of education prevents black people from better understanding the disease and its side effects, leading to a misconception about screening procedures and mortality rates².

There is also dissatisfaction with the role of the GP in prostate cancer care. Although most received information, participants expressed concern with the content not addressing the various needs they have. Others noted the information they received was ambiguous, it was often not received in a timely fashion to enable decision making and the mode of delivery was inappropriate. At times compassion was lacking. Delays in getting a diagnosis was another key concern alongside the lack of support, information and communication while waiting for the diagnosis. High quality information needs to be a priority in prostate cancer care, in order to reduce uncertainty, anxiety and distress for people.

Participants received a range of treatment with the majority having surgery, radiotherapy and hormone treatment. Within the care and treatment pathway, a majority (73.9%) said the care and treatment they received was good or very good. Sixty-five percent of the participants said they were given enough information on treatment options, side effects and outcomes of each treatment. People's sources of information were varied, with most receiving information from healthcare professionals. However, there is also a reliance on information from the internet, support groups and cancer charities. Although less than half (47.8%) of the participants said healthcare professionals involved them in making treatment choices and in care planning, 69.6% said they were assisted in reaching an informed and balanced decision about treatment.

¹ [Assessment | Diagnosis | Prostate cancer | CKS | NICE](#)

² [Black African and black Caribbean men's understanding and experiences of prostate cancer post-treatment in England: a qualitative study \(rcni.com\); Black men's experiences of support following treatment for prostate cancer in England: A qualitative study - ScienceDirect](#)

Key concerns with the treatment pathway were:

- Lack of information about treatment options and content of information leaving some people unprepared for the post treatment effects.
- Timing of information making it difficult for some people to make informed decisions.
- Slow pace of treatment, which meant that at the time of treatment for some people the stage of the cancer had changed, which can potentially impact outcomes.
- Lack of post treatment support, especially after discharge.
- Delays in follow-up appointments.
- Lack of information about side effects following treatment.
- Lack of parity with other cancer services.

The support pathway is where we saw the most variable care, with a majority not offered or referred to support services for post treatment side effects. Symptoms after prostate cancer were common amongst the participants, with the greatest impacts on sexual dysfunction (92%), urinary incontinence (77%), fatigue (69%), psychological (64%) and social (64%) wellbeing. Other impact relates to bowel effects (50%) and hormonal issues (45%). However, more participants (68%) told us they were not offered interventions for these side effects. A majority were not offered access to a psychosexual clinic (88%), incontinence clinic (70%), specialist counselling (75%) and support with diet and lifestyle (80%).

Our study shows the importance of healthcare professionals identifying side effects when following up with patients to ensure that support meets people's needs. NICE¹ notes that a Holistic Needs Assessment (HNA) is crucial to providing good supportive care, as it enables an understanding of the physical, practical, emotional and spiritual needs which should inform care and support planning. However, only 8% of participants told us they had an HNA.

Improvements people want to prostate cancer services

- Increase education and early testing.
- Support people waiting for diagnosis and/or treatment.
- Improve access to appointments and reduce waiting times.
- Better information on treatment options.
- Improve psychological support and information/post treatment support.
- Improve continuity and coordination of care, including NHS and private providers.
- Improve communication, empathy, and compassion.
- Better information about treatments.
- Involve more health care professionals in support groups.

¹ [Assessment | Diagnosis | Prostate cancer | CKS | NICE](#)

Next steps

We have shared this report and its findings with NHS Birmingham and Solihull ICB (NHS BSOL) and University Hospitals Birmingham NHS Foundation Trust. The report, including the response from the commissioner and provider will be shared on our website and shared with participants who shared their contact details. It will also be shared with relevant stakeholders.

Six months following the publication of this report Healthwatch Birmingham and Healthwatch Solihull will publish a follow-up report highlighting evidence of actions that have been committed to by the commissioner and provider of prostate cancer services across Birmingham and Solihull. We will require them to provide evidence to demonstrate that those changes have been made and an indication of targets met and how these have been achieved.

Acknowledgements

We would like to thank everyone who told us about their experiences. We are also grateful to all the organisations that helped us access people that use local prostate cancer services. We would particularly like to thank Aidan Adkins, Chair and Trustee of Tackle Prostate Cancer, NHS Birmingham and Solihull ICB (NHS BSOL) and MacMillan Cancer support workers at University Hospitals Birmingham NHS Foundation Trust (UHB) for their support.



Introduction

Although some people had shared positive experiences of services for prostate cancer with Healthwatch Birmingham and Healthwatch Solihull other feedback highlighted concerns including access to services (e.g. urology and oncology), delays in getting appointments, lack of information and support for the social, physical and psychological needs of people living with and beyond prostate cancer.

The purpose of this study is to report the experiences of people diagnosed with prostate cancer who have used services in Birmingham and Solihull. These experiences will support commissioners (NHS BSOL) and/or providers (UHB) to improve the provision of services for people diagnosed with prostate cancer in Birmingham and Solihull.

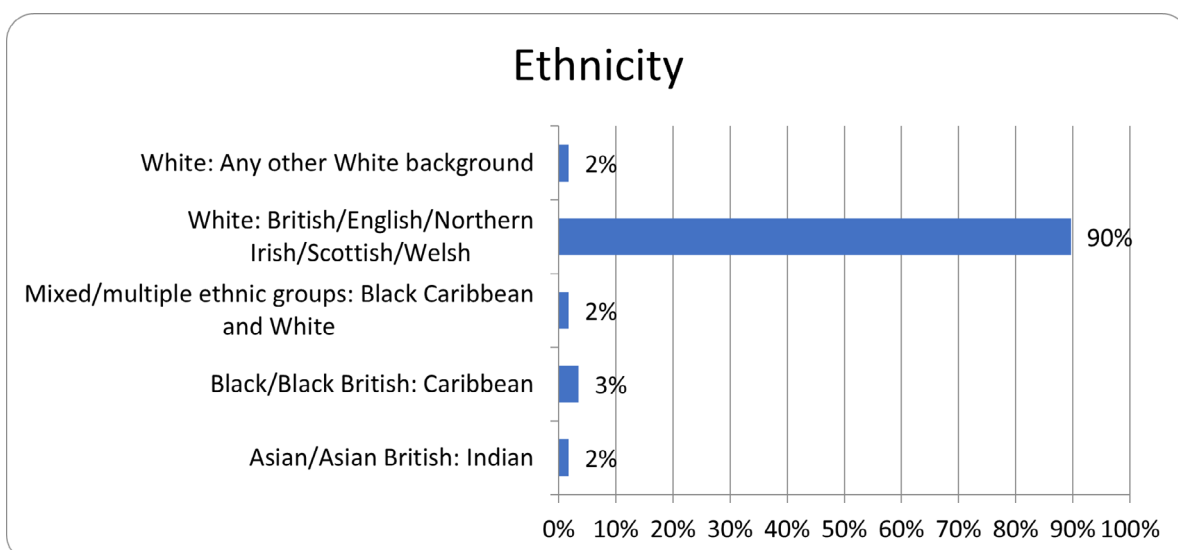
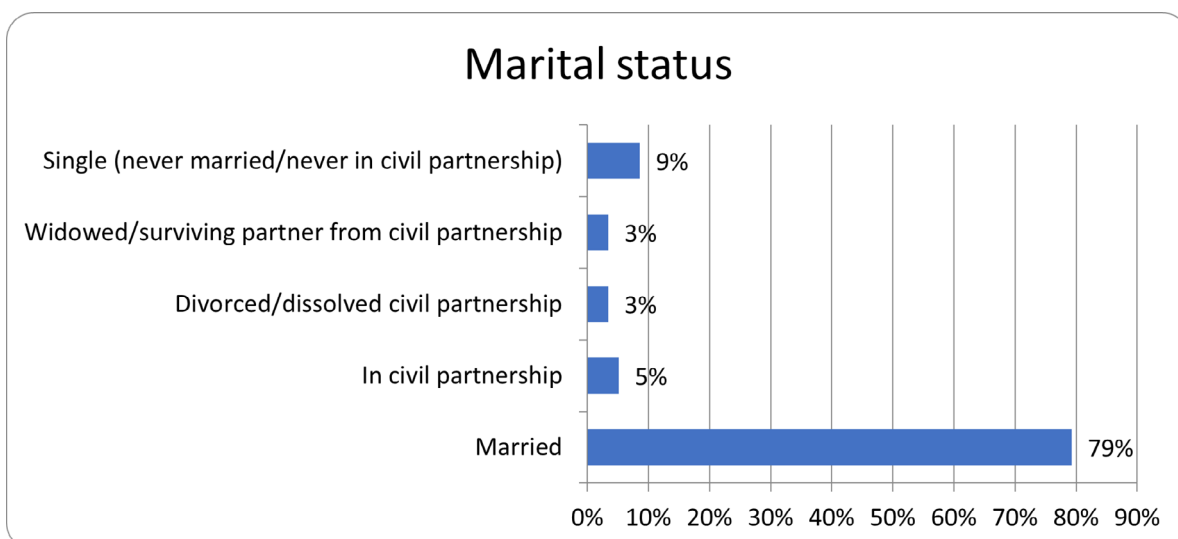
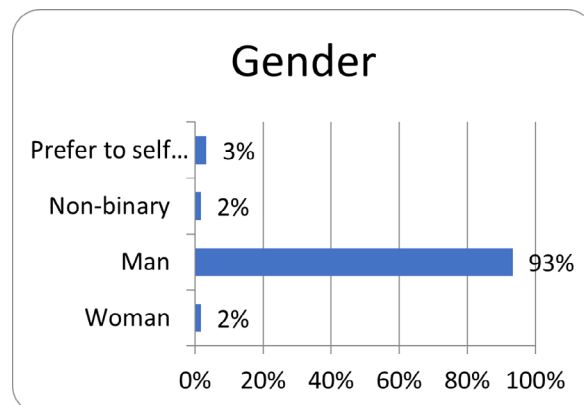
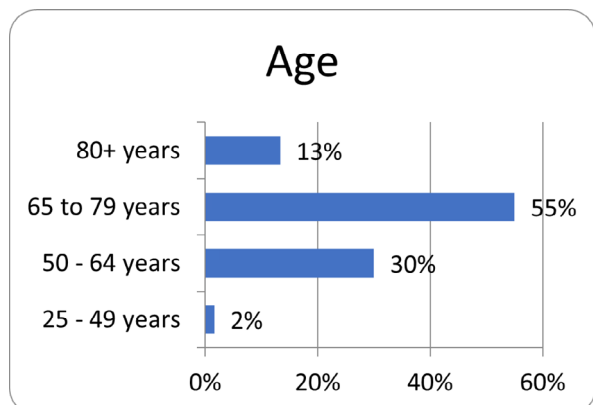
Background

Prostate cancer is one of the most commonly diagnosed cancers but is very treatable if identified early. This makes it important that symptoms are recognised, and treatment sought before the cancer spreads. However, the type of treatment people receive can lead to physical concerns that impact on the quality of life. In addition, the ability to treat prostate cancer successfully and advances in treatment options means that more people diagnosed are living with or beyond prostate cancer. Consequently, some are living with physical consequences that affect urinary, sexual, bowel and hormone functioning. There is therefore a challenge for health and social care services to provide services to support people living with or beyond prostate cancer (Nelson K. et al, 2019; NHSE, 2022; Obrey A. et al, 2023).

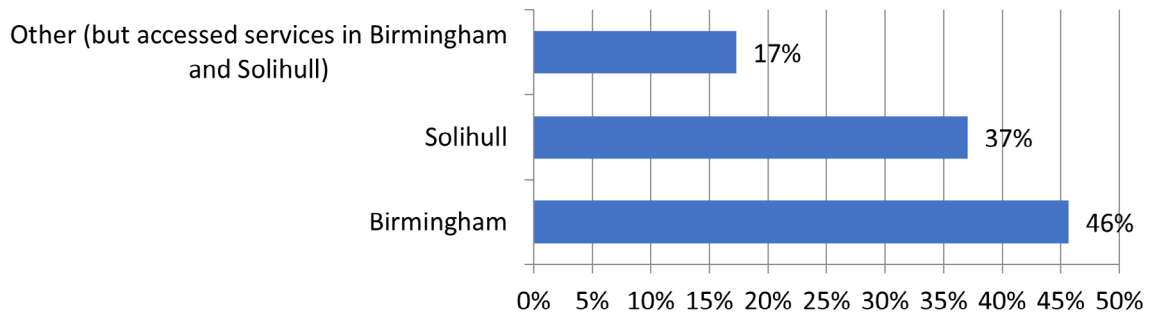
The National Institute for Health and Care Excellence (NICE) (2014; 2019;2021) has highlighted the following areas as important for ensuring quality provision of healthcare services for prostate cancer:

- Information and decision support (e.g., access to clinical nurse specialist, patient decision aids; discuss treatment options in an unbiased manner including risks and benefits, personalised care plan)
- Assessment and diagnosis (e.g., offer people with a raised PSA a biopsy only after multiple risk factors are taken into account; consider whether an MRI to determine if a biopsy is needed)
- Monitoring of localised and locally advanced prostate cancer (active surveillance for low-risk prostate cancer, timely referral for patients with disease progression following therapy, use state of the art technology)
- Managing adverse effects of treatment and offering after care for side effects of prostate cancer and its treatment (e.g., access to erectile dysfunction services, psychosexual counselling, urinary incontinence support, radiation-induced enteropathy).
- Metastatic prostate cancer – offer people tailored information and access to specialist urology and palliative teams to address specific needs, regular assessment of needs.

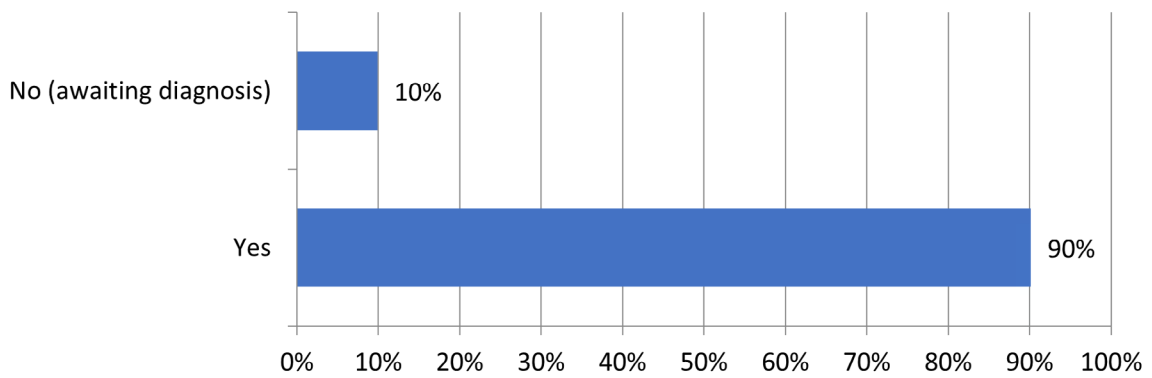
Information about participants



Local Authority



Prostate cancer diagnosis

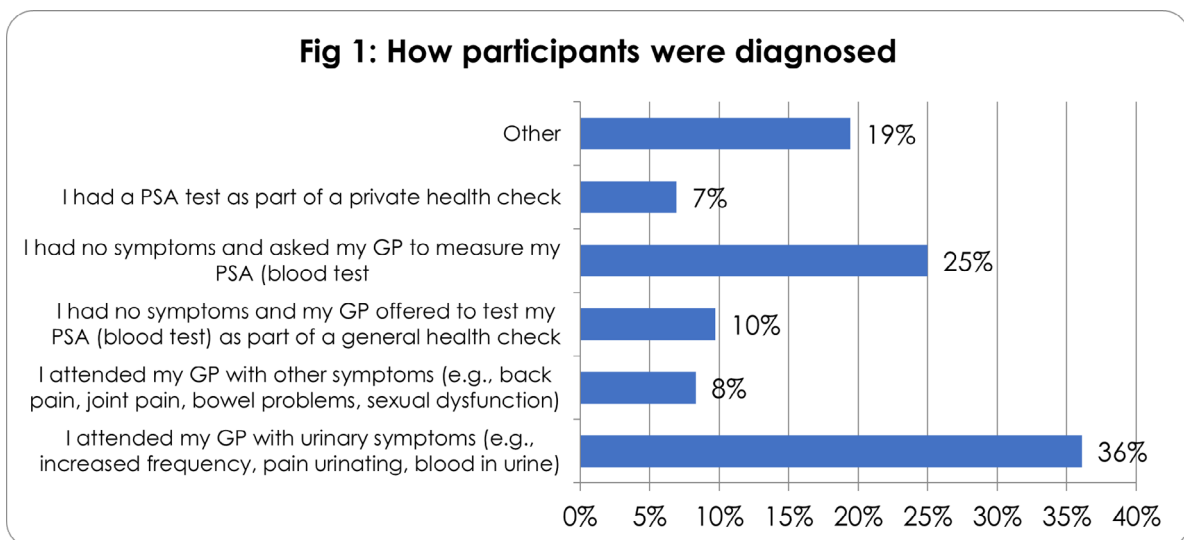


Findings

Diagnosis pathway

Although some people had shared positive experiences of services for prostate cancer with Healthwatch Birmingham and Healthwatch Solihull other feedback highlighted concerns including access to services (e.g. urology and oncology), delays in getting appointments, lack of information and support for the social, physical and psychological needs of people living with and beyond prostate cancer.

In the early stages, prostate cancer may not cause any symptoms. People begin to experience symptoms when the cancer has grown and starts to cause problems with urination, there is blood in urine and/or semen and they experience pain in their bones¹. In our study, 42% of the participants had no symptoms before they were diagnosed. They had either asked the GP to measure their PSA or were offered a PSA test as part of a general health check within the NHS or privately. In addition, those participants (19%) that indicated 'other' (see Figure 1) said they had no symptoms but went for voluntary screening with a cancer charity. Some were being treated for another condition when they were diagnosed.



On the other hand, 44% of the participants were diagnosed after attending their GP with symptoms. Some (36%) participants experienced urinary symptoms which prompted them to contact their GP, while 8% of the participants had other symptoms (e.g. back pain, joint pain, and bowel problems) that prompted them to seek help.

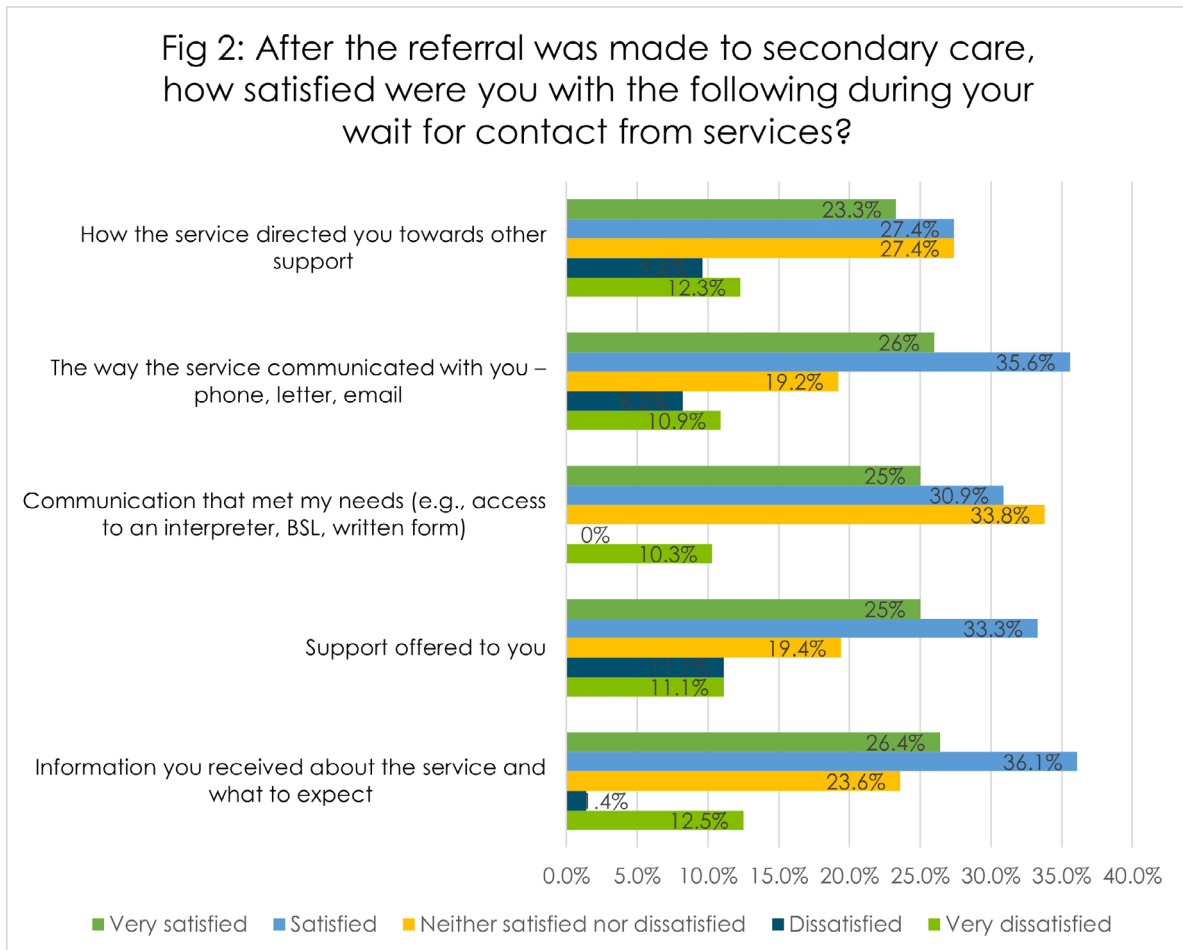
According to Cancer Research UK², early diagnosis can improve survival rates for prostate cancer. Almost 100% of those diagnosed at stage 1 and 2 (localised) will survive their cancer for five years or more post diagnosis. Ninety-five percent of those diagnosed at stage 3 (advanced localised) will survive five years or more post diagnosis³, whereas for those at stage 4 at the time of diagnosis 50% will survive five years or more. Our study shows that three-fifths of the participants had 'localised (stage 1 and 2)' prostate cancer at the time of diagnosis, 22.9% had 'locally advanced (stage 3)' and 17.1% had stage 4 prostate cancer at the time of diagnosis. That more people are diagnosed at an early stage in their cancer potentially improves outcomes.

¹ Prostate cancer - Symptoms - NHS (www.nhs.uk); Symptoms of prostate cancer | Cancer Research UK

² Survival of prostate cancer | Cancer Research UK

³ Survival rate is also impacted by the grade of the cancer, commonly known as the Gleason score (how abnormal the cells look under a microscope). The PSA level also affects survival from prostate cancer. A high PSA level means the cancer grows more quickly (Cancer Research UK).

A majority (76.4%) of the participants were diagnosed between the ages of 60–79, 19.4% between the ages of 40–59, and 4.3% at 80+ years. Of the three Black people that took part in our study, two were diagnosed between the ages of 40–59 and one between 60–79 years. Two were at stage 1 and 2 when they were diagnosed and one at stage 4. This is similar to national data that notes that prostate cancer is most common in older people between the ages of 65 and 79 years. Fifty percent of the cases of prostate cancer in the UK are in people aged 70 years or older and the incidence of the disease is highest among those aged 90 years and over. Ethnicity and family history also increases the risk of prostate cancer with 1 in 4 Black men likely to be diagnosed, compared to 1 in 10 white men and 1 in 44 Asian men¹.



We asked participants about their experience of waiting following referral to secondary care. On average, 57.8% of the participants expressed satisfaction across the five issues in Figure 2. However, 17.5% of the participants said they were dissatisfied across these five issues, whereas 24.7% said they were neither satisfied nor dissatisfied.

The top three issues that participants expressed satisfaction with were: information they received about prostate cancer services and what to expect following referral (62.5%); way the service communicated with them (61.6%); and support that was offered to them (58.3%).

I was unclear about what it meant to have Prostate Cancer, but the details unfolded slowly, and I was supported reasonably well.

Referred to a hospital nurse, consultant, and Community nurse between the three I have been looked after very well.

I had a mixed healthcare provision while I was trying to sort out the private healthcare offered through my employer. Everything done through the NHS was very efficient and communicated well whether by doctors or specialist nurses.

Some of the participants (17.5%) who expressed dissatisfaction with the issues in Figure 2 noted concerns around:

- What was communicated.

The communication was about what was going to be done by the cancer and to the cancer. There was nothing about what I could do to help myself.

- The role of the GP.

The GP service was more or less non-existent, but once I was in the 'hands' of the Birmingham-Solihull Hospital system I was treated superbly.

Initial appointment at the doctor was not very helpful- no examination and only given phone number to arrange appointment for the PSA test.

- Delays in communication.

I didn't feel that I needed support. However, communication was varied (sometimes letter, sometimes text) and throughout the process letters have been very slow to arrive (e.g. at least 2 weeks) but also texts have been very ambiguous.

- Delays in diagnosis.

First appointment with GP Blood test required. SHP do their own blood tests. This took 2 weeks to get a test. How can this be an acceptable service? Increased PSA another GP appointment required Rectal examination, referred to consultant. 2weeks to get a PHONE appointment. didn't phone at the time specified. Phoned more than 1 hour earlier which was very inconvenient. Suggested I go on a 44mile round trip to have a blood test, why not at a hospital in the town I live! 2 weeks to get a scan appointment no sign of a biopsy yet. Told results from scan will take 3 weeks. Absolutely appalling service.

Some participants' dissatisfaction arose from the failure of the service to provide support, information, and adequate communication.

A letter arrived detailing an appointment with a prostate oncologist, but other than this there was no communication, no offer of support, no communication about what might happen. Had I not researched things myself, I would have been completely in the dark, sitting for two weeks knowing nothing and fearing the worst. After I had an appointment with the oncologist, life was more certain, as he was extremely professional, explained likely outcomes, what probable treatments I would undergo, and set the process of scans in train.

When we asked participants who delivered their diagnosis, a majority indicated that their diagnosis came from a consultant (52.8%) or from a Cancer Nurse Specialist [CNS] (29.2%). Most of the 12.5% participants who indicated 'other,' had their diagnosis delivered by a senior nurse, urology specialist nurse or a GP. One person indicated they received their diagnosis from a booking clerk and another from a registrar in training. Overall, there is good practice within prostate cancer services as a majority of service users are being given their diagnosis by clinical staff. According to NICE there is evidence they are likely to have a positive experience as they can discuss any concerns they may have, including signposting to support services¹.

At least 72.7% of the participants indicated they had a named clinical nurse specialist in charge of their care. Only 16.7% said they had no named CNS. Overall, most people had support from diagnosis through to recovery 'yes I was given the name of a clinical nurse specialist and he proved very helpful and always available for a chat before and after the operation.' Others felt that their CNS was not forthcoming with information and had limited time. 'He was very busy, and I feel that he had only a limited time that he could spend on each patient. I felt that there was not enough time available to fully address all of my concerns.' Those that did not have a named CNS indicated they had a number of a team but not a specific named individual.

¹ [prostate-cancer-qs-briefing-paper2 \(nice.org.uk\)](https://www.nice.org.uk/prostate-cancer-qs-briefing-paper2)

Positive experience of diagnosis

- Speed of diagnosis, support, and information.

The RDE although maligned by most people, was I thought fairly simple and not too uncomfortable. The biopsy was less pleasant and since having it I have been concerned about its effects. The speed of the diagnosis process was pretty good and the attention to me as a patient was also good. The most outstanding support I received was from the Prostate Specialist Nurse, who provided lots of information and supportive interaction. The criticism I would make of the whole process is that the information pamphlets were very poor, photocopied badly, disorganised and as a result hard to understand. The information contained was good, but it was hard work getting to a reasonable understanding.

- Support and treatment options discussed.

The formal diagnosis of prostate cancer was delivered by a specialist nurse at the QE and was done well. Further emotional and practical support was available, and I was encouraged to use it, but I don't feel the need for it and haven't taken it up. Treatment options were discussed at the diagnosis appointment, but they are dependent on the results of the scans to see if it has spread.

- Diagnosis explanation, support from CNS and signposting to support services.

Diagnosis well explained and offer of help from all quarters. Very satisfied with help I'm currently having active surveillance and have 3 monthly blood tests and telephone calls with the specialist nurse at QEH. It was very upsetting getting the cancer diagnosis but fortunately my partner is a doctor, and I got a lot of support from him. My specialist nurse also gave me details of a local support network.

- Good communication and compassionate staff.

Wonderful sympathetic professional communication – face-to-face and by phone.

Negative experience of diagnosis

Although overall a majority expressed satisfaction with the diagnostic pathway, the following concerns were expressed.

- Difficulties getting a prostate check or a PSA test.

I had requested a PSA in my early 50s at the GP practice, but they said I was too young to have one!!

Initially I was told that I could not be tested unless I had symptoms. As my father had prostate cancer when he passed away and my younger brother has an enlarged prostate I decided to get tested and said that I had symptoms even though I didn't [just to get a test].

My request for a PSA test was turned down during a telephone consultation. I was told they were unreliable. 18 months- two years later a different GP gave me a PSA test and then a few days later phoned me to say I was being fast tracked for cancer treatment. It then took another 9 months before I had a radical prostatectomy.

The GP was very reluctant to give me a PSA test but agreed after I told her my family history of Prostate cancer.

Doctor seemed a little reticent, but a friend of my age had been diagnosed and had had surgery and advised me to check. Good job I did.

I had to persuade the nurse to add the PSA test to my yearly check-up. If she had not been prepared to stick her neck out for me, I would probably be dead.

- Communicating diagnosis and test results.

Some participants expressed concern over how their diagnosis was communicated to them. They argued that being told they had prostate cancer over the phone was unacceptable and left them unable to get the information needed to make decisions. Others spoke about lack of communication regarding test results and being booked for a cancer x-ray before being told the diagnosis. Another participant spoke about his needs being ignored and diagnosis being communicated against his wishes.

Being told you have cancer over the phone it totally unacceptable!

Diagnosis was done via a phone call, and I could have done with considerably more information as to how to decide what treatment to opt for. I've subsequently (after the operation) received far more information which would have been useful at the time.

I had a biopsy and a few days later, 2 days before I was seeing the nurse for the results a hospital booking clerk contacted me to book for cancer X-rays and bone X-ray.

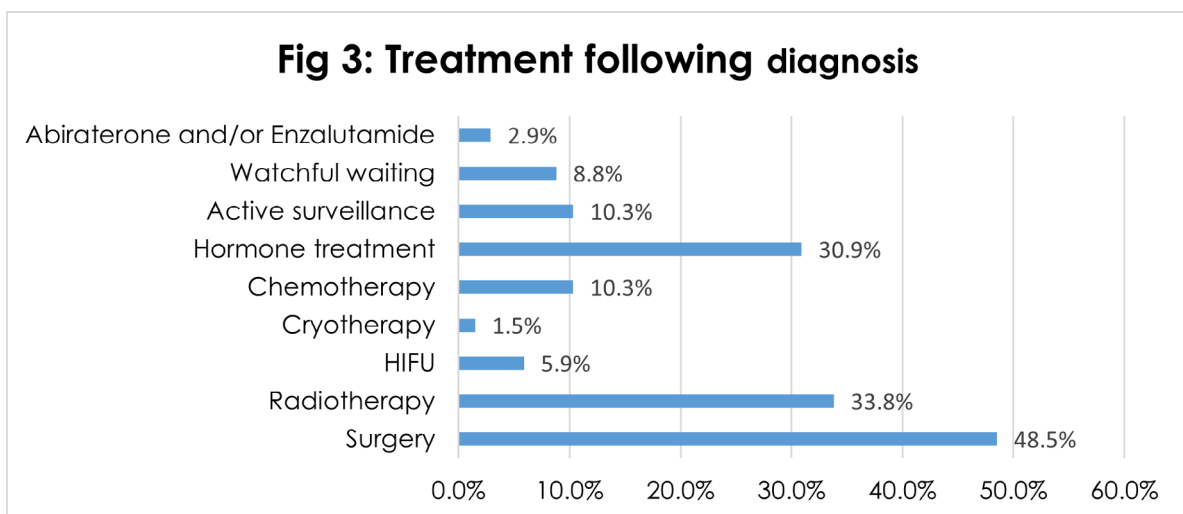
Wasn't given any forewarning, was told I need biopsy, no explanation regarding the outcome of my MRI! No warning!

I saw a senior nurse at good hope hospital, and I asked her not to tell me the severity or whether it had spread just tell me the treatment. A few days later I attended at heartlands for an initial injection when the senior nurse blurted out it is 9 out of 10 severity and that they thought swollen lymph nodes suggested spreading in fact it had not spread.

The doctor and nurse were kind, but the process was about information sharing about the cancer, treatment and support. It didn't take into account the fact that after you hear the word cancer, you can't really hear anything else. It all becomes blah, blah, blah.

Care and treatment pathway

The stage of the disease, age and the presence of comorbidity determines the treatment options available to people with prostate cancer. Most people with prostate cancer do not require treatment. When they do, treatment is aimed at curing the disease or controlling it to minimise its impact on everyday life and prolong life¹. A majority (48.5%) of participants had surgery, with most having open prostatectomy (26.5%)² followed by robotic prostatectomy (17.6%)³. At least 33.8% had radiotherapy, with most having had external beam radiotherapy (26.5%) and 5.8% having low-dose and high-dose brachytherapy. Thirty-one percent of the participants had hormone treatment, 19.1% were on active surveillance or watchful waiting and 10.3% underwent chemotherapy (see figure 3).



¹ Prostate cancer - Treatment - NHS (www.nhs.uk)

² Open prostatectomy - Operation performed through a cut in the abdomen above the pubic bone area (retropubic prostatectomy) or a cut in the area between the testicles and back passage (perineal prostatectomy)

³ Operation performed with the assistance of a surgical robot (Da Vinci prostatectomy)

Overall, 73.9% of the participants felt that the care they received was good or very good, 15.4% felt that it was poor or very poor and 10.8% found care neither poor nor good. Most positive experiences were around the actual treatment, which most participants found very good. Key concerns for participants who felt that care was poor or very poor are:

- Slow pace of treatment

The decision-making process has been fine. It would be helpful if the treatment process was faster. There are a large number of steps with various scans, results, appointments to discuss results and way forward etc and each step takes weeks or months leading to a prolonged process before treatment commences. I hope that the scans and scan results that I am still awaiting will show that the cancer hasn't spread. If it has it may be partly due to the long waits after initial suspected cancer diagnosis without treatment. As the potential for spread means that hormone therapy will be part of my treatment, I did ask at the diagnosis appointment if this could be commenced immediately but was told that it had to wait until the further body scans were completed, which is going to mean a delay of at least 6 weeks in commencing treatment to reduce the diagnosed cancer due to the long wait for scans'. Another participant said, 'cancer was stage 1 at time of diagnosis but was stage three when I was operated on.

- Lack of post treatment support

Treatment and hospital care was excellent. But once at home there was no care and no route for advice. It would have been comforting to have contact details of a medical team once discharged from hospital.

- Delays in follow-up appointments

I waited 16 weeks for a post-surgery follow up appointment and that was only after contacting Solihull Hospital to complain. At the time they said I was on a waiting list. I have still not had a written confirmation of my prognosis from my post-surgery appointment over a month ago.

- Lack of information about side effects following treatment

The problem is that no one has told me why I am in such a mess on the continence front which is stopping me making an informed decision about what to do next. I have been referred to another surgeon to consider sphincter replacement. I am finally due to see him in a couple of weeks.

- Lack of parity with other cancer services

Ladies with gyne issues etc are treated very differently to us blokes - speedy service, helpful staff. Men's urology is poor and very different to ladies' service for similar issues. Not equality at all!

Information, involvement and treatment decision support

NICE recommends that people with prostate cancer should be offered information tailored to their needs and should be supported by written and/or visual media. People with prostate cancer should be offered advice on how to get information and support from websites, local and national cancer information services and cancer support groups. Information resources recommended should be clear, reliable and up to date. In addition, services should engage with patients to identify the highest quality information resources¹.

On average, over three-fifths (65%) of the participants agreed that they were given enough information on treatment options, side effects and outcomes of each treatment option (see Figure 4). Fifty-four percent said information was received at a time where it could affect decisions.

¹ Recommendations | Prostate cancer: diagnosis and management | Guidance | NICE

We were given written information from hospital and researched widely on internet.

I was told I couldn't have surgery as the cancer was breaking out of the prostate, so chemo and radiotherapy was the only options...and it was to help but not cure as the cancer was terminal and was told 3-5 years then 5-7 years.

I was given options, but advised a radical prostatectomy would be the best option, I chose not to have it due to possible life changes, we found Hifu ourselves.

I have not yet received treatment; I am still in the process of determining the extent of cancer and the appropriate treatment. Nevertheless, I have been given information about the likely treatment pathways dependent on the outcomes of whole-body scans.

When I was finally diagnosed with PC my clinical nurse explained the different treatments & side effects & all the hospital visits etc that goes with it

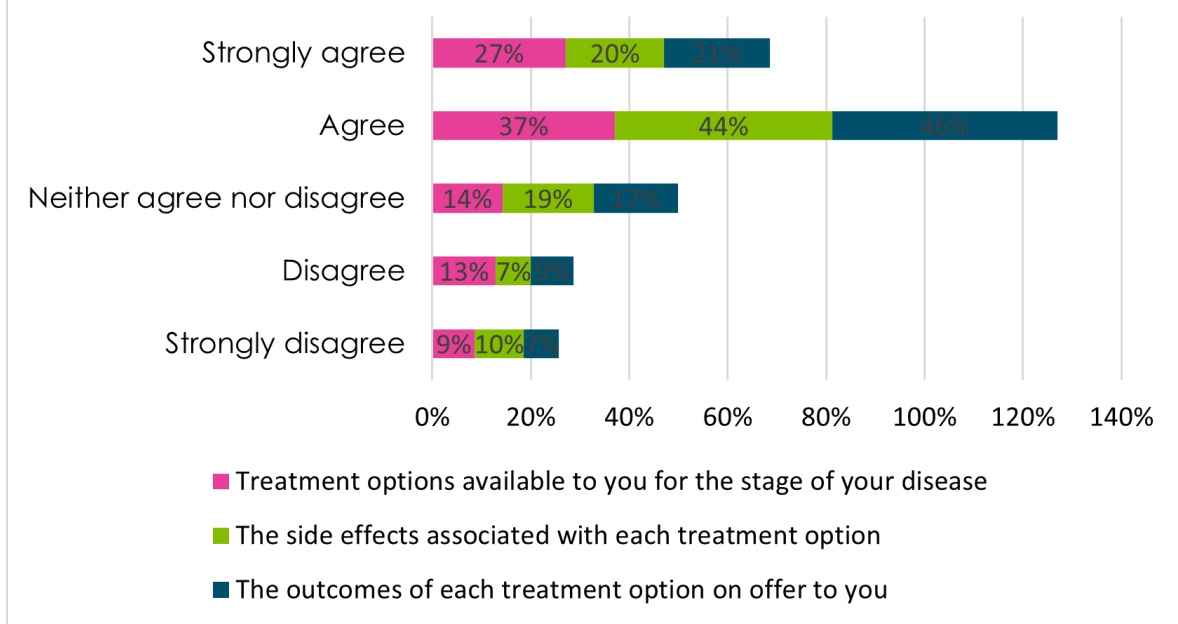
I was given information suffice to understand the options and the likely side effects of the hormone therapy.

Consultant surgeon was very thorough and took me through various stages explaining in detail using plastic models as to what was happens in a variety of scenarios.

I was given suggestions on where I could do my own research. I also got a lot of support and suggestions from my GP, and also friends that had experience. Through my web searches I found the local Support group which I started to attend.

Although they are obviously unable to recommend which direction to go, my wife and I were supplied with comprehensive information which made the decision quite easy.

Fig 4: Were you given enough information before treatment?



On average, 18% of the participants told us they were not given enough information regarding treatment options, side effects and outcomes of each treatment.

There were particular issues around:

- Lack of information about treatment options

Although they are obviously unable to recommend which direction to go, my wife and I were supplied with comprehensive information which made the decision quite easy.

I would have liked more information and a chance to discuss options.

I only had booklets sent to me about what to expect, when undergoing treatment. I had to constantly chase for information. I appreciate that everyone is busy, but it added to the stress.

Only given two options available Radiotherapy following, and accompanied by hormone treatment, or a radical prostatectomy which would have life changing consequences. I found YouTube gave me a far better understanding of where I was, both pre and post op.

- Information received leaving some unprepared for post treatment effects

I wasn't prepared for the post operation discomforts & felt abandoned to a certain extent, but I understand the pressures the NHS are under.

I did not realise that incontinence was so likely' whilst another said 'no warning, no information regarding pre-treatment & absolutely no information regarding post treatment. No calls to see how I'm progressing.

- The timing the information is shared - making it difficult for some people to make informed decisions.

CSN told me of the options on a Thursday & demanded my option choice on the following Monday due to it needing radical treatment. Was sending a booklet out in the post for me to read further information regarding options. This booklet arrived on Monday at 12.30pm I was called at 2pm for my decision. The aggressive CSN demanded my choice as it was radical treatment!

I expected that the conversation with the consultant would discuss the options available, but it was more a this is what happens with a robotic prostatectomy. He did discuss side effects of the robotic prostatectomy but no others. It would have been nice to be able to have a discussion soon after diagnosis that covered all options and been given both the Prostate Cancer Organisation's booklets and the Tackle Prostrate Cancer booklets, I've only been given these recently.

They gave me all the choices but its time limited. Gave me background but not enough in that interview to really go into the detail that I need.

On the other hand, 17% of the participants neither agreed nor disagreed, noting that although they received some information, this was inadequate. Others felt that it was difficult to know if they had enough information and felt that they had more information from friends going through a similar experience and support groups than from clinicians.

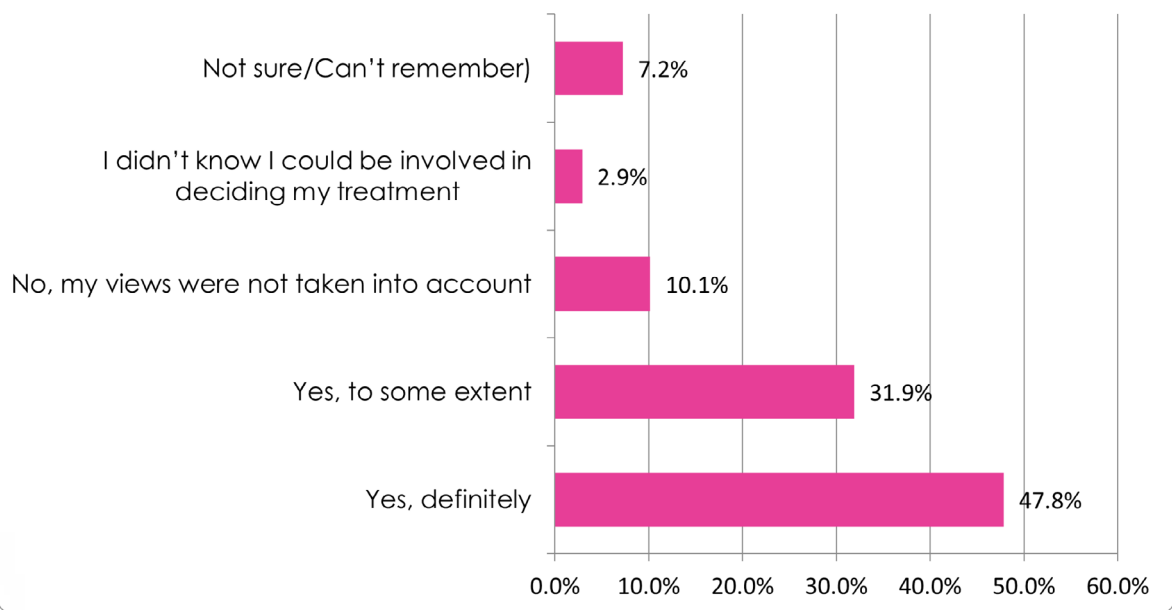
Support was limited and only offered after requesting it. Please remember, patients don't know what they don't know. After being diagnosed I had to wait 7 months for a radical prostatectomy.

Even though it was semi expected it was a surprise. Although the Urology nurse itemised the possible treatment options, I felt that I was left with having to make a decision based upon very little information. As I thought that I would prefer removal of the prostate I asked to talk to a consultant about the procedure, this was booked for 7 weeks later. Subsequently the appointment was moved so that it was 8 weeks after diagnosis. At this point I asked if I could see another consultant and the timescale was shortened by 2 weeks. Throughout this waiting time I received no support.

Another key recommendation from NICE guidance is that information about prostate cancer, diagnosis and treatment is shared by a healthcare professional (e.g. consultant or CNS). A majority of the participants told us their main source of information about prostate cancer and treatment was a Cancer Specialist Nurse (46.9%), the internet (46.9%), urologist (43.8%), oncologist (35.9%), support groups (26.6%), cancer charities (21.9%), GPs and nurses (15.6% respectively) and friends and family (12.5%). Participants also indicated that they received written and/or verbal information from an oncologist (70.5%), urologist (78%) and cancer specialist nurse (88.7%). Overall, people’s sources of information are varied, but a majority get information from a healthcare professional.

The cancer nurse gave me a very large pack from the prostate UK charity which was very helpful has also been fairly extensive. And my oncologist in the early stages answered every question I had.

Fig 5: Did healthcare professionals actively involve you in making treatment choices and in care planning?



People with prostate cancer have the right to be involved in discussions and make informed decisions about their care. This means that different choices available to patients are discussed, treatment options are fully explored, including risks and benefits, and a decision is jointly made by the patient and professional¹. 47.8% of the participants told us that healthcare professionals actively involved them in making treatment choices and in care planning (see Figure. 5).

So far, I have been able to provide input and expect this to continue.

¹ Making decisions about your care | NICE and the public | NICE Communities | About | NICE

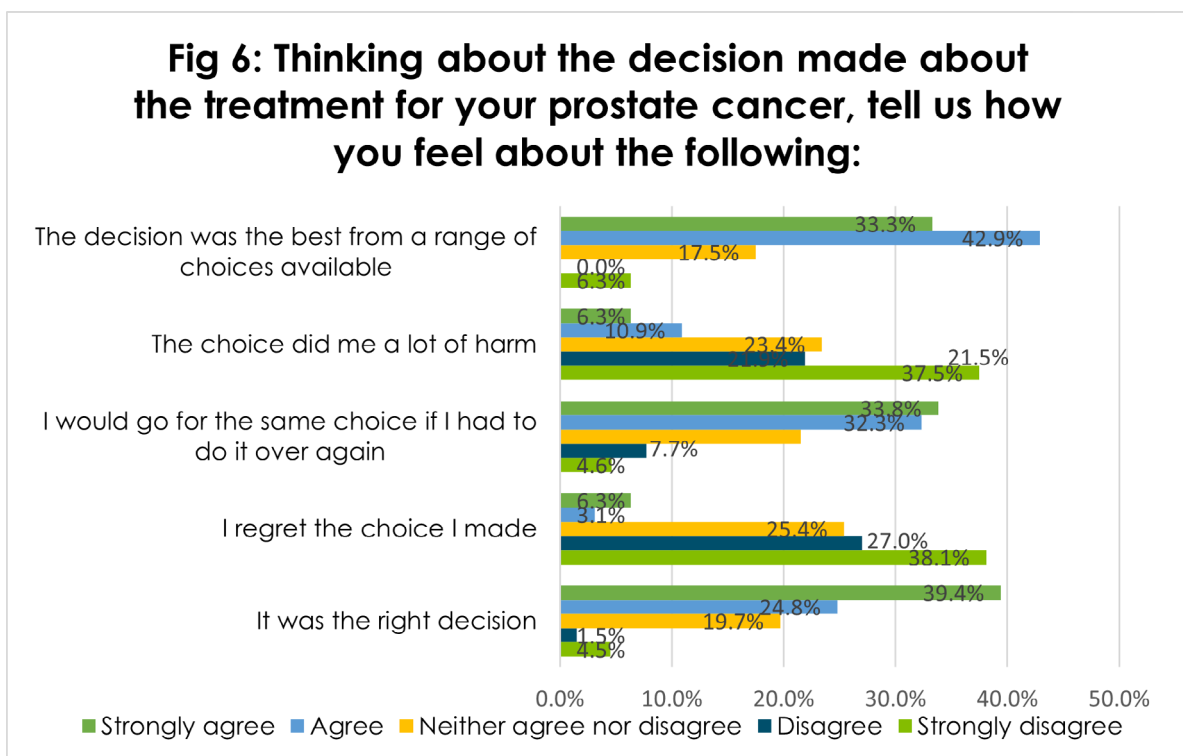
Over 31% (31.9%) of the participants said they were involved to some extent.

Not really involved – I was told the view from the MDT and more or less told that was what would happen next. I had this appointment in the NHS and did ask about nerve sparing procedures to preserve continence and sexual functionality. This couldn't be provided, so it was suggested I found somewhere else to go – which I did but on a private basis. It did feel as though I had to take control of my care if I was to get the treatment I wanted.

Only 10.1% said their views were not taken into account and 2.9% did not know that they could be involved in deciding their treatment.

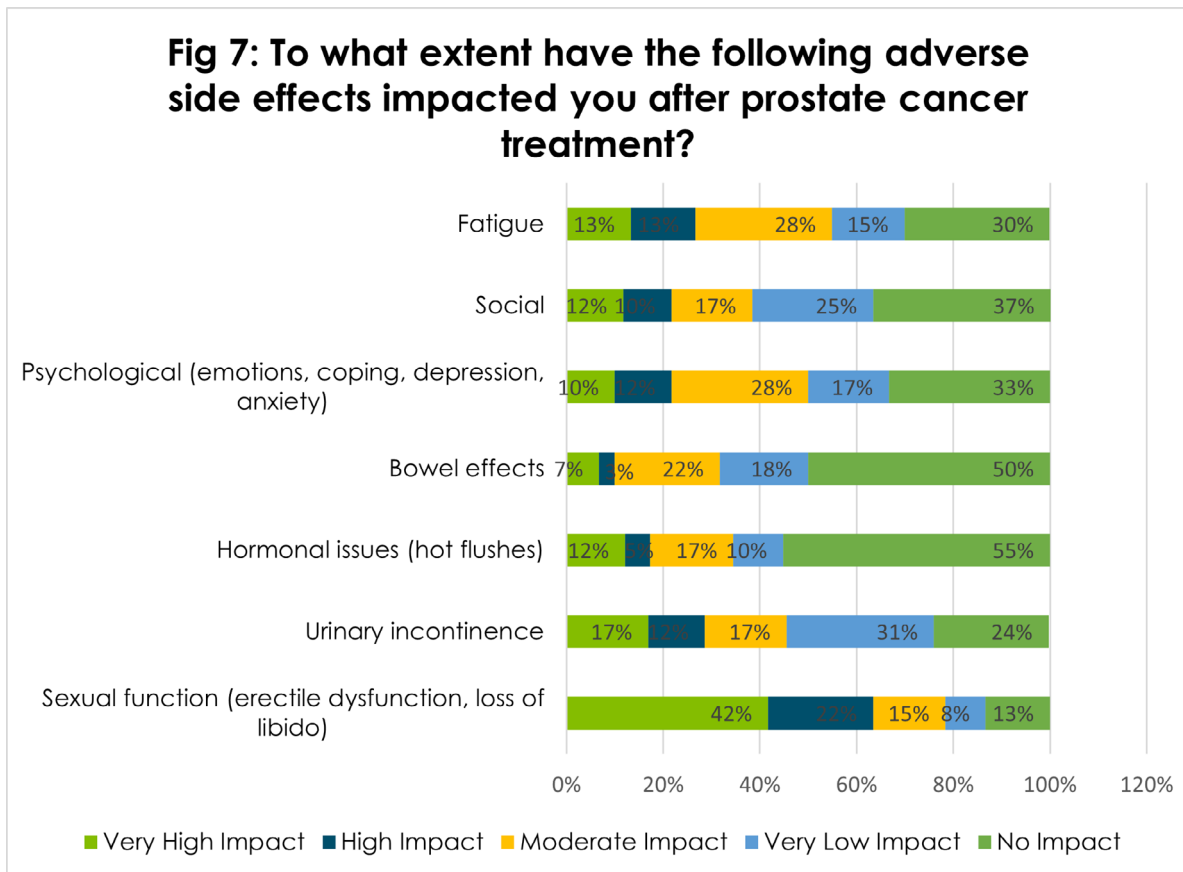
I initially wanted surgery but for consultant abusively called me TOO FAT & not explaining was wrong!

When we asked participants if healthcare professionals assisted them in reaching an informed and balanced decision about their treatment, 69.6% agreed, 23.2% disagreed and 7.2% did not know/remember. A majority (76.2%) said their decision was the best from the range of choices available, 66.1% that they would make the same choice again, and 64.2% believed their choice of treatment was the right one. Most (59.4%) of the participants did not believe that the choice of treatment did them a lot of harm, whereas 17.2% indicated that the treatment did them a lot of harm (see Figure 6).



Impact of treatment

People can experience side effects following treatment for prostate cancer. Effects can be physical, psychological, or social and can have a profound effect on quality of life and their partners or spouses. Figure 7 shows that participants in our study have experienced varied side effects ranging from fatigue, social, psychological, and hormonal through to urinary and sexual dysfunction. Areas of greatest impact were sexual dysfunction (92%), urinary incontinence (77%), fatigue (69%), psychological (64%) and social (64%). Other impact relates to bowel effects (50%) and hormonal issues (45%).



Support pathway

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When we asked participants whether they received early support for the side effects they experienced following prostate cancer treatment 48% said yes, 37% said no, 8% said they did not know while 7% did not remember.

Support to address side effects, such as pelvic exercises, physiotherapy and injections helped participants.

I received guidance on pelvic floor exercises together with mechanical and pharmaceutical products to treat erectile dysfunction.

In terms of Incontinence, I was completely dry within two weeks of the post operation catheter's removal and have remained so ever since. It was, I believe, due to my specialist assessing my pelvic floor muscle competence and suggested the correct exercises to prepare for post operation continence difficulties.

68% of participants were not offered specific interventions for side effects (see Table 1). A majority were not offered access to a psychosexual clinic (88%), incontinence clinic (70%), specialist counselling (75%) and support with diet and lifestyle (80%).

Table 1: Were you offered any of the following interventions for the side-effects you experienced after treatment?

	Not offered	Offered but not wanted	Offered but not used	Offered, tried but not helpful	Offered, used and helped
Medication or devices for sexual function	54%	7%	5%	21%	13%
Specialist counselling	75%	8%	8%	2%	7%
Support with diet and lifestyle changes	80%	5%	10%	2%	3%
Local support groups	43%	10%	3%	5%	38%
Incontinence clinic	70%	5%	9%	4%	12%
Psychosexual clinic	88%	5%	7%	0%	0%

More participants (56%) were signposted to local support groups than those that were not (43%). Three-quarters of those signposted to local support groups used the support and found that it helped. Interestingly, for the 12% of the participants that were offered access to a psychosexual clinic, none went on to use the intervention. Previous studies¹ have suggested that greater attention should be paid to symptoms and problems people may be reluctant to discuss due to the perceived stigma associated with them.

Other participants who were not offered support post treatment felt this might be because they received private treatment.

I had private consultation, sold as total prostatectomy as opposed to radical. Only remove the prostate, every effort made to maintain normal functions in terms of continence and libido. I had the operation the following week. As a result, I found myself outside of the NHS team, hence no support or postoperative advise available.

The support has been mixed - but that is due to the mix of NHS and private healthcare, so I have no complaints other than how to bring the two elements together to give a comprehensive service to all. I have great medical/surgical support through the consultant, but I had my procedure in Hertfordshire. So, my local cancer support team do not know I exist, and my GP hasn't referred me to anyone. I am maintaining contact with the NHS nursing team in Hertfordshire and will be asking them to refer me to a more local service.

¹ Kalakoue et al (2021) Supportive care needs of men with prostate cancer after hospital discharge: multi-stakeholder perspectives - PubMed (nih.gov)

Nothing offered. Perhaps my fault due to the route I took. i.e., private surgery. My GP never asked how I was progressing, and I never felt the environment was right to raise it. We would talk about PSA rising but never anything else. I think had I had surgery via NHS then I would have had follow-up clinics etc. and been part of a multi-disciplinary team that would have been beneficial to my recovery.

When participants rated the support, they received to manage any side-effects following treatment a majority (44.1%) said care and support was neither poor nor good. 35.6% of the participants said care and support was good or very good, while 20.4% found it poor or very poor. The main issues around support following treatment are:

- Lack of follow up post treatment.

I have been unable to have an erection and therefore sex since the op to remove my prostate. I had some initial equipment and advice but there was no follow-up support when this did not work for me.

I was offered to be referred to Erectile Dysfunction Clinic by doctor at the beginning of COVID, once things got back to normal, but nothing ever materialised.

In terms of dealing with immediate impacts of sickness, etc. while undergoing chemo and radiotherapy, the staff were excellent. But as indicated previously, not much help in the longer term, coming to terms with fatigue and my knee problems.

Rehabilitation not even discussed. I was given a vacuum pump for penile rehabilitation but only because I requested one. No other rehabilitation offered.

- Delay in receiving post-treatment support.

I had had ED issues since the procedure. I am now 4 months post-surgery and have had no support for this.

'Early' intervention may have been beneficial if it had been offered. I was not offered penile rehabilitation pump until 16 weeks after surgery, and then there was little advice given about using the pump. I could not find sufficient guidance on frequency, intensity and duration of each session included in the instructions supplied with the equipment. NHS staff are themselves under pressure and it was difficult or impossible to discuss matters to the extent which I would have liked. I feel that I may have caused some damage to penile tissue, and I have stopped using the pump. I have recently found that I could have had professional guidance in using the pump, but this is something I was never offered and had not been aware of.

I am on a waiting list for erectile dysfunction (6months plus)

First appointment at the Incontinence Clinic is 4 months after the operation so it will be used and hopefully will help but should be sooner.

- Availability of support.

Apart from the sexual function advice and bi-monthly assistance of incontinence pads from the incontinence nurse there appears to be nothing available. The overall impression was very much that "you are on your own". One memory that stays with me since being discharged after my prostatectomy was being handed a few incontinence pads and being told to use children's nappies when the few pads were used up. It was for me, or rather my wife, to stop at supermarket on the way home and purchase packets of children's nappies. I also managed to find out for myself where to obtain a limited supply of incontinence pads from the community incontinence nurse and have spent, over the years, several thousand pounds to supplement the limited supply.

There was no support for pelvic floor exercises. My GP did arrange an appointment for penile rehabilitation but when the procedure was explained to me by a very pleasant and helpful nurse, I found the whole thing very depressing and politely declined. Any other information I found was by searching the internet, trawling support groups for information and becoming a member of a prostate support group run by volunteers. Indeed, I did notice while trawling for information or support that there appeared to be nothing offered by the QEHB. The only time I have anything to do with cancer support is when a QEHB nurse visits my GPs surgery to take a blood sample for my annual PSA test the results of which I phone up my GPs receptionist a few days later and I am given the result. But of course, I have no one to explain or interpret the results to me.

Holistic Needs Assessment

Good supportive care includes interventions such as Holistic Needs Assessments (HNA). This questionnaire covers physical, practical, emotional and spiritual needs, which informs care and support planning enabling early intervention, diagnosis and identification of treatment side effects ¹. Only 8% of our participants told us they had a HNA, while 57% said they did not, 29% do not know and 6% do not remember. We asked participants how well the HNA took account of their needs and concerns. Ten percent of the participants said that the findings from the HNA were fully or partially incorporated into their care plan whilst 18% felt it did not.

Some participants indicated that they did receive an HNA form but chose not to complete it or completed it but did not progress it.

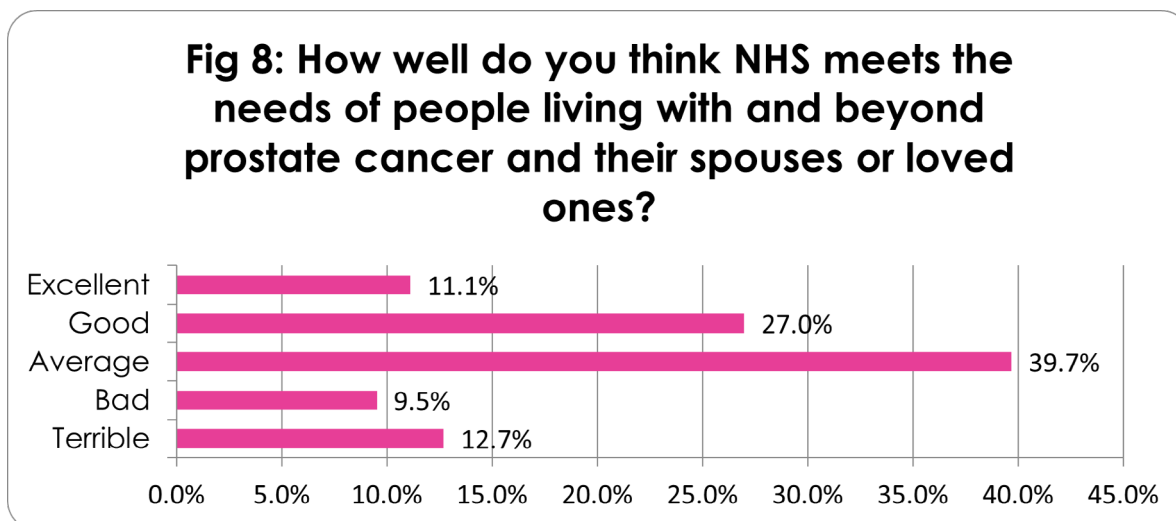
A brief assessment was carried out at my diagnosis appointment and a detailed questionnaire form provided to fill in and return after further consideration. However, at this point, I don't feel I have further Holistic needs.

I did receive a questionnaire pre-treatment, but it was my choice not to complete it.

From the questionnaire it appeared fairly comprehensive, but I haven't taken it up as I currently don't feel the need. I may pursue it further after treatment depending on side effects.

¹ [03-support-pathway-jan-2018-final.pdf \(prostatecanceruk.org\)](https://www.prostatecanceruk.org/03-support-pathway-jan-2018-final.pdf)

Improvements people would like to see to prostate cancer services



One in five people replied 'Bad' or 'Terrible' when asked how well they thought the NHS met their needs (see figure 8). Almost 40% replied 'average'. On the other hand, 38.1% of the participants indicated that the NHS is effectively meeting the needs of people living with and beyond prostate cancer.

Participants told us the following would improve their experience:

Increase education and early testing

Not enough testing / education for early testing...I was lucky in being offered and took part in a test as part of some medical research they were undertaking.

More education of men to this problem...continue to employ surgeons with small fingers!

Like everywhere it needs better promotion within primary care. It feels as though all the communication and awareness is being done through Prostate Cancer UK. Even in the GP surgery only their publications are on the information racks. I appreciate there is no reliable screening service - but nothing comes from the GP surgery to highlight prostate cancer and to signpost to the PCUK survey or to suggest taking a PSA test may be a first step for any men over 50. Women's cancers, breast and cervical have comprehensive programmes in place - but for men there is nothing even though prostate cancer diagnoses are similar at national level to breast cancer. It feels as though once you get a diagnosis help is there - but getting the diagnosis is the difficult part. Often found by accident - like myself.

Support people waiting for diagnosis and/or treatment

I can't really comment on this as post diagnosis, I've had no interaction with the NHS.

What you almost need is a flowchart of what happens next, this is what you have likely got but these are the broad outcomes, these are the services - whatever comes.

Improve access to appointments and reduce waiting times

I now have a yearly PSA test to make sure it hasn't returned but it's like pulling teeth trying to get them & I have to ask for them in the 1st place doesn't seem to be on the surgery radar & have to phone for the result with no explanation of the result.

Make the diagnosis and scans etc. process quicker! I suspect that I will find that some potential treatment options are not available through the NHS in Birmingham, but I am not at that point yet.

Primary care needs to run protected clinics allowing men to book into - not having to phone every day at 8am trying to secure an "emergency" slot which it doesn't need. Booking an appointment 2 or 3 months in advance would be more than fine - but nothing exists.

Have a drop-in clinic at Sol hosp or a regular gp clinic - we men seem to be ignored in this area!!!!

Make the urology department more accessible.

Reduce treatment times, reduce waiting times between each test carried out (MRI, CT, etc.). Vastly improve administration.

Improve waiting times- it's very stressful waiting for results of scans / biopsies.

Better information on treatment options

They don't always offer alternatives; they were a bit too quick just to remove the prostate.

How is it an option if they know I can't do two of them. They even sent me to meet a consultant about surgery when they knew it was not an option. Wasted his and my time.

Improve psychological support and information/post treatment support

Medically everything was fine, but counselling in the early stages and explanations and advice latterly, were missing.

I have had good treatment from staff who looked after me. The consultant treated me with no concern about how I was feeling, no reassuring me. No feedback of me about how things were affecting me.

Ensure that rehabilitation support includes full explanation on use of vacuum pump.

More assistance after the op in dealing with the affects.

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Ensure that rehabilitation support includes full explanation on use of vacuum pump.

More assistance after the op in dealing with the affects.

Improve continuity and coordination of care, including NHS and private providers

There appears to be no continuity in services which seem to be patchy, unreliable, and ad hoc. What is needed, I feel, is an acknowledgement that prostate cancer is an ongoing condition and is not something that is finished or goes away after the prostate is taken out. The problems encountered by patients appear eminently predictable. Aftercare and monitoring therefore needs a coordinated and supervised approach that has been thoroughly thought through so that solutions are readily available to problems encountered by patients.

It has to be far better organised and coordinated. The number of different bodies that try to help but fall by the wayside because of lack of coordinated planning is a sin. I see many very well-intentioned groups presenting at the Solihull PC Support group and elsewhere who are never heard of again, and so many that it is almost impossible to focus on them long enough to gain benefit from them. My profession is that of senior management. I had to apply significant management skills to all our projects, or they would fail. The NHS and ancillary parties need to be brought together. If they were the impact would be so, so much greater, and probably resource costs would reduce accordingly. Frustrates me continually.

Went privately for treatment using company insurance. Everything within the NHS was efficient before I went private. It's the handover from private to NHS that's been a problem. When I have questions, the GP keeps sending me back to the private consultant. Now that I have had the surgery am not plugged into the Birmingham services, no follow-up from GP or CNS. No one to ask for advise until I joined a support group. Otherwise, I have been paying for counselling privately.

Improve communication, empathy and compassion

The immediate diagnosis and pre-treatment period were lacking empathy, information, and explanation, at what is probably the worst time of one's life, having just been given a terminal cancer diagnosis. I feel that getting better communications and support in those early days would be of immense benefit to those diagnosed with advanced prostate cancer.

I had a phone call from the QE telling me that I had high Cancer of the prostate. When was in shock I had no consultation, so I was left in limbo land, with no one to talk face to face. It was very frightening.

Better information about treatments

Some of the information you receive is hard to understand & a lot to take in, sometimes in a short time.

Try to have as many face to face appointments as possible and let the patient feel they are part of the decision-making process. This really requires access to information from all disciplines within the treatment process. Difficult to establish doctor, patient, rapport over the telephone.

Maybe print the information on the services available that way if a nurse forgets to say something the information is still to hand.

Don't overwhelm people with so much information, remember not all people are literate or confident to understand this information. Show people pictures.

The surgeons need to be forthcoming with people about the possible outcomes, so I understand when am fine one minute and come out of surgery and am incontinent.

Involve more health care professionals in support groups

Could do better, support groups help fill the gaps, but support groups need more involvement from health care professionals.

Accessibility to specialist people at these support group meetings. This has been reduced since Covid. There is a need to take these groups more seriously. Make the groups higher quality by supporting them. They were a life saver for me.

have local cancer charities working closely with the oncology department to give support and advice. I was only aware of the service at Sutton Cancer centre in Lind ridge road as our best Friend was on the board and suggested I go down and see them for support which was really helpful.



Conclusion

The experiences we heard throughout this research show that a majority of the participants who have accessed prostate cancer services in Birmingham and Solihull have a positive experience. However, there is some variability that exists and this increases within the post-treatment support pathway.

Some participants are dissatisfied with follow-up, availability of support and delays in receiving post-treatment support. Our study shows that many of our participants experienced varied side effects that have impacted their quality of life and thus there is a significant number of people who require post treatment support. Areas of greatest impact were sexual function (92%), urinary incontinence (77%), fatigue (69%), psychological (64%) and social (64%) wellbeing. However, a majority of the participants told us they were not offered interventions for the side-effects they experienced following treatment. Overall, 68% were not offered interventions for side-effects they experienced. This suggests there are unmet supportive care needs for people with prostate cancer to help them manage their side effects following treatment.

Participants expressed satisfaction with hospital care and the role of clinical staff (e.g., Cancer Nurse Specialist, Oncologist, urologist etc) in their care. On the other hand, they were dissatisfied with the role GPs play in prostate cancer care.

Participants receive information from a wide range of sources including from cancer specialist nurses, oncologists, urologists, GPs, friends, family, charities and support groups. Participants expressed concern with the content and timing of the information they received from healthcare professionals and its communication. They felt that the information provided does not cover all aspects of prostate care from screening, diagnosis, treatment outcomes, follow-up processes and side effects. In addition, information is not shared in a timely manner that enables decisions to be made. There is a need to provide information covering the various aspects of the pathway, starting from screening to post-treatment. The information should be shared in a timely fashion and varied modes of delivery (verbal and written) to enable people to revisit the information.

The findings indicate the importance of the following:

- Increasing testing and education for early testing. Increasing awareness of prostate cancer and early testing is especially important for black men who experience higher rates of prostate cancer. Studies have found that lack of education prevents black men from better understanding the disease and its side effects. This consequently leads to misconceptions about screening procedures and mortality rates¹.
- Better information about treatment options. NICE recommends that men are told about treatment options and their risks and benefits in an objective and unbiased manner so that they can make an informed decision².
- Improving access to appointments and services and reducing waiting times for treatment. Slow pace of treatment, which meant that at the time of treatment for some people the stage of the cancer had changed, which can potentially impact outcomes.

¹ [Black African and black Caribbean men's understanding and experiences of prostate cancer post-treatment in England: a qualitative study \(rcni.com\)](#); [Black men's experiences of support following treatment for prostate cancer in England: A qualitative study - ScienceDirect](#)

² [prostate-cancer-qs-briefing-paper2 \(nice.org.uk\)](#)

- Giving people information while waiting for a diagnosis, including information about the tests and what they mean, possible treatments including active surveillance, side effects of treatment and post-treatment support services available.
- Recognising that each treatment pathway should be tailored to the patient's individual needs. Each person must have the opportunity to make informed choice about their treatment pathway having been given detailed information about the treatments available for the stage of their disease, side effects associated with each of these treatments and possible outcomes treatments.
- People should have their needs assessed through a Holistic Needs Assessment (HNA) and ensure findings inform care plans and support offered. Prostate Cancer UK notes that carrying out an HNA is associated with improved quality of life and patient experience outcomes highlighting that an HNA supports patient centred and collaborative care as well as enabling early intervention.
- Improving the availability and accessibility of services supporting people experiencing side effects from cancer and treatment (psychological, incontinence, ED etc.)
- More access to cancer nurse specialists enabling people to engage with CNS' from the pre-diagnosis/diagnosis phase, thus ensuring people are offered advice on tests and subsequent treatment.
- Better coordination of care across the NHS and also between the NHS and other health/ social care services, including private healthcare. This will improve the provision of care and the provision of supportive care needs.

About us

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham and Healthwatch Solihull listen to and gather public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Lines, our online Feedback Centres, and through our community engagement activity led by staff and volunteers.

You can read more about the work of Healthwatch Birmingham here:

<https://healthwatchbirmingham.co.uk/about-us/>

You can read more about the work of Healthwatch Solihull here:

<https://healthwatchsolihull.org.uk/>

healthwatch

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