Prostate Cancer Project report

Healthwatch in Greater Manchester

March 2026

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Introduction to Healthwatch Bury

This report has been produced by Healthwatch Bury in collaboration with the GM Healthwatch network. The Healthwatch network consists of 152 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London. We are all independent organisations who aim to help people get the best out of their local health and social care services, whether it's improving them today or helping to shape them for tomorrow.

Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience. We are the only body looking solely at people's experience across all health and social care in Bury. As a statutory watchdog, our role is to ensure that local decision makers put the experiences of people at the heart of their care so that those who buy (commissioners) and provide our services (NHS Trusts, GPs, the voluntary sector and independent providers) can benefit from what Bury people tell us. Our reports on various elements of health and social care in Bury can be found on our website at the following link: healthwatchbury.co.uk or by contacting us directly using the details on the back cover.

Executive Summary

Healthwatch in Greater Manchester, led by Healthwatch Bury, launched a research project in September 2025 to understand the experiences, needs, and barriers faced by men affected by prostate cancer across the region. The project was developed in response to growing concern about men's health inequalities, delays in diagnosis, and low awareness of prostate cancer risks. Healthwatch England has also highlighted this issue at a national level, reinforcing the importance of local research into early detection and support.

The aim of the project was to gather insights from men across all 10 Greater Manchester localities to help improve information, testing pathways, aftercare, and overall support. The findings will inform local NHS services, commissioners, voluntary organisations, and Prostate Cancer UK.

To collect this insight, Healthwatch Bury designed and launched a lived experience survey. The survey was shared widely across Greater Manchester through Healthwatch teams and networks, GP practices, primary care teams, cancer networks, community groups, sports clubs, and public events. It remained open until middle of February to ensure strong and diverse participation. By the close of the survey period, 146 men had taken part of the survey, providing valuable feedback on their awareness of symptoms, their experience of PSA testing, GP conversations, diagnosis pathways, and the emotional and practical impact of prostate cancer.

Alongside the survey, several one-to-one interviews were conducted with men who volunteered to talk in more depth about their experiences. These interviews provided detailed insight into issues such as delays in seeking help, fear or stigma around prostate cancer, confusion about testing, and differences in how GPs approach conversations about risk. Monthly focus groups also took place with 11 people attending, these sessions offered rich personal reflections that added depth to the findings.

Together, the survey, interviews, and focus groups have helped build a clear picture of the challenges men face. Key themes include low awareness of symptoms, uncertainty about when to seek help, concerns about waiting times, and the need for clearer communication from health professionals. Some high-risk groups, including Black men, men with a family history of prostate cancer, and socially isolated individuals, may require more targeted messages and support.

The findings from this project will form the basis of recommendations aimed at improving early diagnosis, GP engagement, culturally inclusive information, and accessible support for men across Greater Manchester. This report sets the tone for exploring these insights in greater detail and shaping future work to ensure services are responsive, equitable, and designed around the needs of local men.

Key findings

- **Men’s diagnosis journeys vary widely and often depend on chance**

Many men reached diagnosis through **routine or incidental PSA blood tests,** which measure prostate-specific antigen and can indicate potential prostate problems, or by persistently requesting help, rather than through a clear and proactive clinical pathway. Delays, mixed messages, and missed opportunities were common.

- **Awareness of symptoms and risks is low, even among high-risk groups**

Over half (53%) had no symptoms before diagnosis, and many were unsure when to seek help or request a PSA test. Men with family history or from higher-risk ethnic groups reported inconsistent conversations about risk with their GP.

- **Care is rated highly, but treatment and side effects of treatments have major life impacts**

Although **88%** described their care as **Excellent or Good**, men commonly experienced significant impacts on daily life, including urinary problems, fatigue, emotional changes, and sexual dysfunction, often feeling unprepared for these long-term effects.

- **Communication and follow up support by local health care professionals are inconsistent and leave gaps in care**

Experiences ranged from clear, supportive communication to confusion, conflicting information, and limited guidance after treatment. **Nearly half (49%)** reported receiving **no follow-up support**, leaving some feeling isolated and unsure who to contact.

- **Peer and community support are highly valued but not routinely promoted**

Support groups, charities, and peer networks were described as essential for reassurance and emotional wellbeing but many men found them only by chance

Our recommendations:

Based on findings from the survey, focus groups and interviews, Healthwatch recommends the following actions to local NHS services, commissioners and voluntary organisations. These recommendations are structured around the key stages of a man's journey with prostate cancer.

Awareness of Symptoms and Risk

1. Improve access to PSA testing and reduce barriers to early diagnosis

With 53% of people diagnosed with prostate cancer reporting no symptoms, earlier detection is critical. PSA testing should be offered more proactively to high-risk groups, rather than relying on patients to request it. Variation in PSA testing rates between GP practices across Greater Manchester should be reviewed and addressed. Public awareness messages must clearly highlight that prostate cancer is often asymptomatic in its early stages.

System leadership: GM ICB (Cancer and Early Diagnosis leads)
Delivery: PCNs and GP practices
Support: Public health teams, VCSE and community outreach partners

2. Provide dedicated support for partners and carers

Partners and carers are significantly affected by diagnosis and treatment but are rarely offered support in their own right. A short, accessible guide for partners should be provided at diagnosis, covering emotional wellbeing, sexual health, continence, and available services. Inclusive support groups that welcome partners should be clearly promoted.

System leadership: Acute trusts
Delivery: Clinical teams and patient experience services
Support: Macmillan, Prostate Cancer UK, local carer organisations

GP Conversations and PSA Testing

3. Standard PSA conversations and proactive testing in primary care

A consistent, Greater Manchester–wide approach should be adopted for discussing PSA testing with men aged 50 and over, and with younger men at higher risk, including those with a family history of prostate cancer. These conversations should be supported by a plain-English, one-page explainer that clearly sets out what the PSA test is, what the possible results mean, and what happens next. This should be available both in print and digitally (for example, via a QR code).

PSA testing should be offered proactively to high-risk groups, rather than relying on individuals to ask for a test. The pathway must also include a clear and agreed timeline for receiving results and follow-up, aligned with other cancer pathways, so that patients are not left chasing GP practices or hospitals for updates.

System leadership: GM Integrated Care Board (ICB)

Delivery: Primary Care Networks (PCNs) and GP practices
Support: GM Cancer Programme / Cancer Alliance

4. Targeted outreach for underrepresented communities

Develop targeted outreach and research for underrepresented groups
Current engagement has not adequately reached Black men and other minority ethnic communities, despite their higher risk of prostate cancer. Commissioners and community organisations should work together to develop culturally appropriate outreach, including partnering with trusted organisations such as the Black Health Association and community leaders to conduct targeted listening exercises or culturally adapted versions of the survey. This will ensure future service design is equitable and responsive across Greater Manches

System leadership: GM ICB (Health Inequalities leads)
Delivery: Local authorities and public health teams
Support: Community organisations and VCSE partners

Diagnosis Pathways

5. Ensure consistency between written information and verbal advice

Men reported receiving contradictory or confusing messages from different clinicians and written materials. All patient-facing information should align with current clinical guidance and be consistent across providers, particularly in relation to hormone therapy, radiotherapy side effects, sexual function, continence, and points of contact for support.

System leadership: Acute trusts delivering prostate cancer services
Delivery: Clinical teams and Clinical Nurse Specialists (CNSs)
Support: GM Cancer Programme; national charities such as Macmillan and Prostate Cancer UK

6. Strengthen follow up care after treatment

All men completing treatment should leave hospital with a clear, structured follow-up plan. This should include a named contact, a proactive check-in (e.g. a call within the first month after treatment), and clear signposting to physical, emotional, and psychological support. Men should not feel abandoned or unsupported at the point of discharge.

System leadership: Acute trusts and multidisciplinary teams
Delivery: CNS-led follow-up and discharge planning
Support: GM ICB (commissioning expectations); primary care for shared care where appropriate

Emotional and Practical Impact

7. Expand holistic and psychosexual support as part of routine care

Psychosexual side effects, anxiety, depression, and emotional distress were among the most frequently reported challenges, yet support was often unavailable or accessed only through self advocacy. Counselling, psychosexual services, and mental health support should be routinely offered within the prostate cancer pathway, rather than treated as optional add ons.

System leadership: GM ICB
Delivery: Acute trusts, mental health and psychosexual services
Support: Macmillan, Maggie's Centres, and VCSE counselling providers

8. Proactively connect men with peer support and community groups

Peer support groups were consistently described as highly valuable, yet many men found them only by chance. All men should be routinely signposted to local and national support organisations at the point of diagnosis, including local prostate cancer support groups, Macmillan, Maggie's Centres, Prostate Cancer UK, and physical activity programmes such as CanMove.

System leadership: Clinical services
Delivery: Cancer nurses and diagnosing clinicians
Support: Local peer support groups and VCSE partners

9. Reduce practical barriers to attending appointments

Practical issues such as parking, transport, distance, timing of appointments, and access to toilets were frequently cited as barriers—particularly for men undergoing long courses of treatment or experiencing urinary symptoms. Appointment communications should include clear travel and parking information, and local or satellite sites should be used where possible.
System leadership: Acute trusts
Delivery: Outpatient and scheduling services
Support: GM ICB (estate and service planning); local authorities and transport services

10. Identify, share and scale effective practice across GM

Examples of excellent care already exist across GM, including specialist services, CNS support, peer groups, and joined up working between GPs and hospitals. These examples should be systematically identified, documented, and shared so that good practice becomes the GM standard rather than the exception.

System leadership: GM Cancer Programme / GM ICB
Delivery: Acute trusts, PCNs, VCSE partners
Support: System learning and improvement networks

These recommendations emphasise the need for a coordinated, system wide approach to prostate cancer care in Greater Manchester. Clear leadership from the GM ICB, combined with strong delivery by providers, primary care, and VCSE partners, is essential to reduce variation, improve patient experience, and ensure that no man feels unsupported at any stage of their prostate cancer journey.

Background

This report explores the experiences of men across Greater Manchester who have been affected by prostate cancer, including diagnosis, testing, or concerns about their risk. It focuses on how men seek help, their interactions with GP and hospital services, and the barriers that may delay diagnosis or affect the support they receive. Prostate cancer is one of the most common cancers in men, yet awareness of symptoms and risk factors remains low, particularly among higher-risk groups such as Black men, older men, and those with a family history. Early diagnosis is vital for better outcomes, making it important to understand where current pathways fall short.

Greater Manchester has a diverse population with significant variation in age, ethnicity, income, and health needs. Some areas, including Bury, have ageing populations and higher levels of long-term conditions, which may increase contact with health services but can also make early prostate cancer symptoms harder to recognise. The region is also home to minority ethnic communities who may face higher risk and additional barriers to accessing information and care.

National research highlights issues such as delayed testing, inconsistent advice about PSA tests, low awareness of symptoms, and emotional barriers including fear and stigma. Local engagement supports these findings, with men reporting confusion about testing, mixed messages from professionals, and uncertainty about follow-up care. This report brings together local evidence to identify key gaps and outline improvements needed to support earlier diagnosis, reduce inequalities, and improve care for men affected by prostate cancer across Greater Manchester.

Further context:

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 | BMJ Open

Data and Evidence | Prostate Cancer UK

Prostate Progress project to support research through combination of clinical data with patient-reported outcomes – HTN Health Tech News

Patient-Reported Outcome Measures Help Patients with Cancer | Oncology | JAMA Network Open | JAMA Network

How we're using data to transform prostate cancer research - NHS England Digital

Methodology

This project used a mixed-methods approach to understand the experiences, needs, and barriers faced by men affected by prostate cancer across Greater Manchester. Using a mix of surveys, group discussions, interviews, community visits, and background research helped us gather both broad views and more personal stories.

- **Greater Manchester wide online survey**

The survey was open to men in all ten Greater Manchester boroughs and remained live until mid-February. It was widely promoted through Healthwatch teams, NHS partners, GP practices, community groups, sports clubs, cancer events, and social media. A total of 146 men completed the survey, offering both quantitative responses and rich qualitative comments.

- **Monthly focus groups (September–December)**

Four focus groups were held from September to December, involving 11 participants in total. Sessions were delivered both online and in accessible community locations.

Participants included men with a diagnosis of prostate cancer, men undergoing tests, and those at increased risk. A semi-structured discussion guide supported open conversation about experiences with symptoms, GP appointments, testing, treatment, and emotional wellbeing.

- **One-to-one telephone or MS Teams interviews**

To capture in-depth personal stories, six one-to-one interviews were conducted by phone or Microsoft Teams. Additionally, one participant shared a detailed written account via email. Men were recruited through the survey and community outreach. Interviews were essential for exploring sensitive experiences that participants may not feel comfortable discussing in a group setting. These accounts added significant depth and nuance to the findings.

- **Community engagement activities**

In addition to structured data collection, the team attended a local cancer wellbeing event and visited the Bolton Prostate Cancer Support Group. These visits helped build trust, raise awareness of the project, and gather informal insights from men who may not participate in online surveys or formal interviews. This also supported engagement with harder-to-reach communities.

- **Background research**

We also reviewed existing evidence, including NHS and GM cancer pathway information, research from national charities, previous patient experience surveys, and academic studies. This helped us understand the wider context, identify gaps in knowledge, and ensure our findings were interpreted correctly

Survey findings

The survey gathered responses from 146 men across Greater Manchester who had experience of prostate cancer, diagnosis, or concerns about their risk. The findings provide insight into awareness, diagnosis pathways, treatment experiences, and access to follow up support, based solely on respondents' survey answers.

A key finding identified was variation in how men reached a prostate cancer diagnosis. Nearly one third (32%) of respondents said their diagnosis followed a routine or incidental PSA test, while others sought help due to symptoms or personal concern. Over half of respondents (53%) reported having no symptoms prior to diagnosis, highlighting that prostate cancer is often detected without clear warning signs. This lack of symptoms contributed to uncertainty about when to seek help or request testing.

Awareness of prostate cancer symptoms and risk factors was generally low. Many respondents reported being unsure about the purpose of PSA testing, what their results meant, or when testing should be requested. Men with a family history of prostate cancer reported inconsistent advice, with some feeling they had to repeatedly request testing before it was offered.

Overall, respondents reported positive experiences of clinical care. A large majority (88%) rated the care they received during treatment as "excellent" or "good", and 72% said they felt involved in decisions about their care. However, despite high satisfaction with treatment, many respondents reported being unprepared for the longer-term effects of diagnosis and treatment.

Commonly reported impacts included fatigue, urinary problems, emotional changes, and sexual dysfunction, all of which affected daily life and wellbeing. These effects were often described as ongoing rather than short-term.

The survey also highlighted gaps in follow-up support. Nearly half of respondents (49%) said they received no follow-up support after diagnosis or treatment. Where support was accessed, this varied widely and was not consistently offered or explained. Many respondents reported finding peer support groups and charities independently rather than through routine signposting.

Overview

146

responses to the survey

88%

said the care they received was 'Excellent' or 'Very Good'

Diagnosis journey

32%

said it was routine PSA test that led them to initial diagnosis.

'Company health check where i was offered PSA test due to my age'

Survey respondent

What led respondents to their initial diagnosis

Survey respondents reported a wide range of pathways that led to their initial prostate cancer diagnosis. The most common cause was a routine PSA test, mentioned by 32% of participants. For many, this involved standard health checks, Well Man clinics, workplace health assessments, or incidental findings during blood tests conducted for unrelated reasons. In several cases, PSA testing was introduced only because another clinician, such as a physiotherapist, nurse, or sports injuries specialist, raised concerns during examinations for unrelated health issues.

A further 28% of respondents said their diagnosis was prompted by symptoms that led them to visit their GP. These symptoms included urinary frequency, weak or intermittent flow, nighttime urination, urinary pain, blood in urine or semen, acute retention, and persistent or unexplained pain in areas such as the lower abdomen, groin, or bones. A small number of respondents described severe or acute episodes, such as collapse, uncontrolled bladder symptoms, or emergency hospital presentation, that ultimately led to PSA testing. Others described protracted journeys in which symptoms were repeatedly attributed to non-cancer causes before a PSA test was finally offered.

Family history played a significant role for 12% of respondents. Many had fathers, brothers, or close relatives diagnosed with prostate cancer, which prompted them, or their relatives, to request PSA tests. Several participants expressed concern that family history had *not* been proactively considered by their GP, requiring them to be persistently self-advocating to access testing.

Other individual circumstances also contributed to diagnosis. Some respondents were influenced by public awareness campaigns or media coverage, including high-profile cases that prompted them to seek testing. Others were encouraged to get tested after discussions with friends who had prostate cancer or similar symptoms. A number of respondents were diagnosed incidentally, such as during investigations for IBS, kidney issues, chest infections, UTIs, anaemia, or during scans for unrelated conditions.

Diagnosis journey

53%

Of the respondents had no symptoms prior to diagnosis

'Good but felt that info was scary - diagnosed during Covid pandemic which probably explains.'

Survey respondent

Across all responses, a recurring theme was the importance of chance encounters, persistent self-advocacy, or external prompts, rather than a straightforward clinical pathway, in achieving an initial diagnosis. While some respondents experienced timely and proactive testing, others described delays, initial GP resistance, or missed opportunities where symptoms or risk factors were not acted upon. This highlights the significant variation in how men arrive at diagnosis and the need to strengthen early-detection pathways, especially for those with symptoms or family history.

Symptoms experienced prior to diagnosis

When asked whether men had experienced any symptoms before their prostate cancer diagnosis, 47% of respondents reported yes, while 53% said no, highlighting that symptoms are not always present or recognised.

Among those who did experience symptoms, the most common were changes in urinary patterns, including increased frequency (especially at night), urgency, reduced flow, hesitation, dribbling, and difficulty fully emptying the bladder. Several respondents described needing to urinate every 30 minutes, feeling a constant urge to go, or being unable to pass urine at all. Others reported recurrent urinary tract infections, discomfort in the perineal or groin area, or generalised pains that were initially attributed to other conditions such as muscular issues or ageing.

A small number experienced more severe symptoms, including spinal cord compression, significant back pain, or bone pain related to metastatic disease. Some noted erectile dysfunction, reduced libido, tiredness, or unexplained weight loss. A few respondents mentioned that their only symptom was what they assumed to be a sports injury, later found to be linked to advanced cancer. These experiences underline the wide variation in symptoms and the importance of not dismissing subtle or seemingly unrelated changes.

Diagnosis journey

60%

said their diagnosis journey was supportive and informative

'Good but felt that info was scary - diagnosed during Covid pandemic which probably explains.'

Survey respondent

The diagnosis journey varied significantly among respondents.

While 60% described their experience as supportive and informative, others faced notable challenges.

Around 16% found the process stressful or difficult, and 11% reported confusion or a lack of information. 13% responded 'Other', further comments below:

Several respondents highlighted issues such as scary or overwhelming information, limited holistic support, and distress associated with emergencies or rapidly progressing cases. Some experienced delays or resistance at the GP stage, with a few needing to be assertive to access follow up tests, particularly those with a family history of prostate cancer. A recurring theme was the need to actively chase GPs or hospital teams for PSA results or referral updates, which caused significant anxiety and uncertainty.

Communication inconsistencies were also noted, including being given conflicting information between specialists or receiving significant news over the phone without adequate follow-up. A small number reported painful or distressing diagnostic procedures, inaccessible materials, or feeling dismissed by clinicians. Others described a mixture of positive and negative elements, with supportive oncologists and useful resources, but also difficulty navigating advice and making long-term treatment decisions.

Treatment Received

Respondents reported a wide range of treatments for prostate cancer. The most commonly received were **hormone therapy (49%)**, **radiotherapy (46%)**, and **surgery (23%)**, followed by **active surveillance (17%)** and **chemotherapy (10%)**. A small proportion (3%) had not yet received treatment.

In addition, **24%** of participants listed **other forms of care**. These responses highlighted the complexity of treatment pathways and included:

- **Brachytherapy** (multiple mentions, including high-dose/HDR)
- **Advanced hormonal therapies** (Abiraterone, ADT, ARPI, Prednisolone, Decepeptyl injections, Zometa)
- **Radiotherapy variants** (SABRE, Radium-223)
- **Participation in clinical trials**, including studies at The Christie and the Radicals Programme
- **Enhanced monitoring**, such as long-term PSA testing, MRI-led surveillance, and watchful waiting
- **Supportive treatments**, such as hormone tablets and muscle-relaxing medication

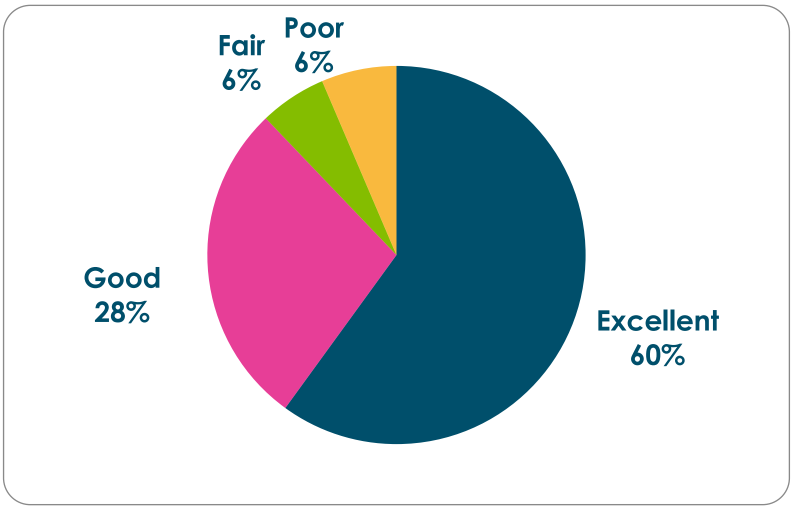
These findings illustrate that alongside standard treatment pathways, many respondents access **specialist, combination, or trial-based therapies**, reflecting the increasingly personalised nature of prostate cancer care.

Treatment and care

88%

said the care they had received was ‘Excellent’ or ‘Good’.

Quality of care received We asked the respondents to rate the care and support received from healthcare professionals during their treatment. **Overwhelmingly 88% said the care they had received was 'Excellent' or 'Good'.**



When asked if people felt involved in the decisions about their treatment, **72% answered 'Yes'**, **16% answered 'Partially'** and **12% said they didn't feel involved in the decisions about their care**.

Impact of diagnosis on daily life

Respondents reported a wide spectrum of experiences following their prostate cancer diagnosis, ranging from minimal disruption to profound and life altering change. The themes below reflect the most commonly reported impacts.

1. Mental Health and emotional wellbeing

- Many respondents described significant emotional effects, including anxiety, depression, worry about progression or recurrence.
- Emotional volatility linked to hormone therapy
- Feelings of loss, low self-worth, or emasculation
- Difficulty discussing the diagnosis with family or feeling unsupported
- A small number reported severe distress, including breakdowns or suicidal thoughts
- For some individuals, however, diagnosis prompted a more positive outlook, gratitude for early detection, or strengthened relationships.

Treatment and care

72%

of respondents said they were involved in the decisions about their care.

2. Physical symptoms and treatment side effects
A wide range of physical impacts were reported, including:

- Fatigue, disrupted sleep, and reduced stamina
- Pain, particularly back pain
- Bowel and bladder issues, including incontinence, urgency, and proctitis
- Hormone related changes, hot flushes, weight gain, muscle loss, low libido
- Sexual dysfunction, often described as one of the most difficult impacts
- Mobility challenges, reduced ability to walk long distances, and increased need to rest

Some reported minimal physical impact, especially earlier in their treatment journey.

3. Daily life and independence Experiences varied considerably. Many continued daily routines with little change. Others experienced restrictions in work, exercise, social activities, or independence. Some respondents became medically retired, disabled, or housebound due to severe fatigue or treatment effects. Ongoing monitoring (e.g., frequent PSA tests, scans, clinical reviews) was described as stressful but necessary.

For a smaller number, day-to-day life largely continued as normal.

4. Relationships, intimacy, and family life
Recurring themes included:

- Strain on intimate relationships due to loss of libido, erectile dysfunction, or emotional changes.
- Feelings of embarrassment linked to incontinence or sexual changes.
- Impact on communication within families, some felt well-supported, others felt isolated
- Several individuals noted that partners and relatives were more distressed than they were.

5. Work, retirement, and financial impact

- Respondents described needing extended time off work for treatment or recovery.
- Leaving work entirely due to ill health or side effects
- Selling businesses or reducing hours
- For some, retirement eased the impact, while for others it intensified feelings of loss or worry

Treatment and care

47%

had not experienced delays in getting their prescription approved.

‘Complete change in career to supporting prostate cancer patients and also educating clinicians on how to support patients.’ Survey respondent

- A few individuals described career changes motivated by their diagnosis.

6. Personal identity

A number of respondents reflected on:

- Reevaluating priorities, focusing more on family or meaningful activities
- Working to "carry on as normal" despite challenges
- Grieving the loss of aspects of identity tied to strength, independence, or sexuality
- Accepting the diagnosis, particularly among those whose cancer was stable or detected early

7. Positive or minimal impact

Notably, some respondents stated:

- "No effect" or "not much change"
- Feeling fortunate due to early detection or successful treatment
- Believing their life had returned largely to normal after treatment
- Being able to manage side effects effectively with support

Overall, the findings show that prostate cancer affects individuals in highly varied ways. While some experience minimal disruption, many describe significant challenges involving physical symptoms, mental health, sexual wellbeing, daily functioning, and relationships. Treatment side effects, particularly from hormone therapy, were frequently cited as more impactful than the diagnosis itself.

These insights highlight the importance of holistic, ongoing support that addresses not only clinical needs but also emotional, social, and quality of life considerations.

Treatment and care

72%

of respondents said they were involved in the decisions about their care.

Follow up care

51%

reported they had received a follow up support.

We asked respondents whether they had received any follow up support from Macmillan or other organisations after their diagnosis or treatment. 51% reported that they had received follow-up support, while 49% said they had not received any.

Among those who did receive support, experiences varied widely. Responses highlighted a mixture of clinical follow up, emotional support, practical assistance, and community based services. Key themes included:

1. Clinical and nursing follow up

Many respondents described regular check-ins or monitoring from clinical teams, including:

- Annual PSA reviews with urology nurses
- Biannual or annual oncology nurse appointments
- Regular face-to-face consultations at hospitals
- Telephone check-ins
- Monitoring at specialist centres such as The Christie, Salford Royal, Glan Clwyd Hospital, and Bolton Hospital

Some relied heavily on the advice and guidance of clinical nurse specialists, while others reported minimal or declining contact over time.

2. Support from Macmillan and other cancer organisations

Macmillan was frequently mentioned as a key source of follow up support, including:

- Emotional support and a listening ear
- Practical advice, benefits guidance, and help with applications (e.g., blue badge, PIP, attendance allowance)
- Access to nurses, helplines, printed information, and online communities
- Signposting to prostate cancer support groups and activity programmes

Several patients also mentioned excellent support from Maggie's Centres (Manchester, Neil Cliffe Centre), Prostate Cancer UK, local support groups (e.g., Bolton, Salford, Stockport, P.S.G.), CanMove programmes supporting exercise and rehabilitation.

Follow up care

Some respondents noted excellent and responsive support when needed; others said they had not sought further assistance.

3. Peer support and community groups

Peer networks played an important role, with respondents referencing:

- Local prostate cancer support groups
- Online communities
- Talking openly with others who had lived experience
- Group meetings hosted by charities or hospitals

These groups offered reassurance, shared experiences, and practical day to day coping strategies.

4. Practical and lifestyle support

Respondents also mentioned:

- Gym or exercise support through CanMove
- Advice on fatigue, anxiety, and exercise
- Help navigating the healthcare system
- Information on available services

A small number reported only receiving routine PSA testing and no additional support.

5. Gaps in follow up care

Several individuals reported:

- No follow-up at all after diagnosis
- Support limited to printed leaflets
- Feeling *"left on their own"* or *"out on a limb"*
- Discontinuity or administrative errors in support.
- Lack of access to local support groups, particularly for those who had radiotherapy rather than surgery

While just over half of respondents reported receiving follow-up support, the nature and quality of that support varied significantly. Many found valuable help through Macmillan, clinical teams, support groups, and specialist cancer services. Others, however, described limited or no follow-up, leading to feelings of isolation or uncertainty. This variation underscores the need for clearer, more consistent, and more proactive support pathways, particularly following treatment and during longer-term monitoring.

> 'Yes, they have been excellent I have been able to contact them if I have any concerns.' *Survey respondent*

Advice for someone newly diagnosed with prostate cancer

Respondents offered a wide range of advice for individuals newly diagnosed with prostate cancer. Although personal experiences varied, several strong and consistent themes emerged.

1. Seek information and understand your options. Many respondents emphasised the importance of becoming well-informed before making any decisions:

- Learn as much as you can about prostate cancer, treatment pathways, and side effects.
- Ask questions, there is *no such thing as a stupid question*.
- Explore all treatment options thoroughly, including potential long-term impacts on quality of life.

  Use trusted sources only, such as Prostate Cancer UK, Macmillan, The Christie, Tackle Prostate Cancer

2. Do not panic and stay positive. A recurring message was reassurance:

- *"Don't panic, prostate cancer is often very treatable."*
- Many encouraged staying hopeful and focusing on the fact that there are usually multiple treatment options available.
- Several respondents shared positive long-term outcomes to reassure newly diagnosed patients.

3. Ask for help and use support networks. Respondents strongly encouraged seeking emotional and practical support:

- Join a local or online prostate cancer support group.
- Speak to others who have been through similar treatment, they understand the journey better than anyone.

Advice for newly diagnosed

Seek information and understand your options

Ask for help and use support networks

- Make use of helplines, specialist nurses, Maggie's Centres, community groups, and Macmillan services.

4. Communicate with family, friends, and professionals Many men highlighted the importance of not facing the diagnosis alone:

- Talk openly with family and trusted friends.
- Share concerns early, don't bottle things up.
- Take someone with you to appointments.
- Be honest with clinical teams about symptoms, side effects, and worries.

5. Take an active role in your care Respondents stressed the value of self-advocacy:

- Take control of your care pathway, don't be afraid to challenge, clarify, or seek second opinions.
- Follow medical advice, but ensure you understand *why* it is being recommended.
- Stay engaged in appointments, monitoring, and follow up checks (e.g., regular PSA tests).
- For those choosing surgery, several recommended practising pelvic floor exercises well in advance.

6. Prioritise mental health and wellbeing Men emphasised the emotional toll of diagnosis:

- Seek mental health support early, through counselling, support groups, or charities.
- Acknowledge that coming to terms with the diagnosis can take time.
- Build coping strategies, stay active, and reach out when struggling.

7. Look after your physical health Respondents encouraged maintaining healthy routines:

- Keep active where possible and adopt healthier habits.
- Consider structured exercise programmes such as CanMove.
- Be attentive to symptoms and report changes promptly.

Advice for newly diagnosed

Prioritise mental health and wellbeing

Look after your physical health

8. Practical advice Some shared practical life advice:

- Plan ahead, consider wills, work adjustments, finances, and support benefits if needed.
- Ensure you understand what assistance (e.g., blue badge, allowances) is available.

9. Trust the medical team but stay informed Many men advised balancing confidence in clinical expertise with personal responsibility:

- Trust clinicians, they deal with prostate cancer every day.
- But do your research, ask questions, and ensure your decisions are truly informed.

A number of respondents ended their advice with encouragement:

> *"You are not alone."*
>
> *"Stay positive, there is light at the end of the tunnel."*
>
> *"Treatment has improved greatly; many people live long, healthy lives after diagnosis."*

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Advice for newly diagnosed

Trust the medical team but stay informed

Take an active role in your care

Suggested improvements

Respondents provided a wide range of suggestions on how prostate cancer care could be improved locally. While experiences varied, several strong and consistent themes emerged.

1. Improve access to PSA testing and introduce routine screening

The most frequent suggestion related to earlier, easier, and more proactive detection:

- Routine PSA screening for men over 40 or 50
- National screening programme similar to breast and bowel cancer
- Better access to PSA testing through GPs, without needing to "justify" the request
- Clearer communication about symptoms and risk factors
- More national and local awareness campaigns encouraging men to get tested

2. Improve communication and information sharing

Respondents expressed the need for improved communication at every stage of the pathway:

- Better communication between hospitals, GPs, and patients
- Timely sharing of test results, including making hospital results available on NHS and GP apps
- Clear, accessible information about treatment options and their side effects
- More guidance during the early diagnostic period, when several men felt "left on their own"
- Some felt communication dropped significantly after ringing the treatment bell or transitioning back to primary care.

3. Increase follow up support after treatment

A recurring theme was the need for more structured post treatment support:

- Face to face follow up appointments rather than reliance on remote systems
- Regular checking in, especially during the months following treatment
- Support to manage long term effects such as fatigue, urinary issues, sexual dysfunction, and emotional wellbeing
- Better links with nurses, easier routes to ask questions, and continuity of care
- Several men described feeling forgotten or having to chase their own follow up care.

4. Expand holistic and psychosexual support Respondents highlighted gaps in holistic care, including:

- Mental health support (counselling, anxiety management)
- Psychosexual support, including ED services and sex therapy
- Help to manage hormone therapy side effects
- Support for partners and families
- A number of men noted that holistic care was either unavailable or only accessed after self advocating.

5. Improve access to local services and reduce the need to travel Some reported difficulty accessing care due to distance.

- More local treatment options where possible
- Local support groups for areas without provision
- Consideration for transport support for those who struggle to travel
- Several respondents highlighted the burden of long journeys for treatment or hormone injections.

6. Strengthen workforce and training. A number of men suggested improvements in staffing and knowledge:

- More GPs and better GP support for PSA testing
- Greater awareness among all healthcare staff about prostate cancer pathways
- Better training for nurses conducting PSA tests or administering injections
- More empathetic communication and better bedside manner
- Some respondents shared examples of incorrect PSA handling or distressing clinical encounters.

7. Ensure consistent, high quality clinical pathways Suggestions included:

- Faster decision making and reduced waiting times
- Adhering to cancer pathway timelines
- Better preoperative assessments
- Consistency across hospital trusts
- More regular scans for those on active surveillance
- Access to specialists who understand the nuances of prostate cancer treatments
- Several respondents highlighted gaps between trusts or delays caused by pathway inconsistencies.

8. Connect newly diagnosed men with support groups Many men felt support groups were vital but not always promoted:

- Proactive referrals to local support groups
- Raising awareness of charity-run groups (e.g., Tackle, Macmillan, Maggie's, Prostate Cancer UK, CanMove)
- Peer-to-peer support as a routine offer, not something patients have to find themselves
- Some felt new patients were "left to figure things out alone".

9. Better information on long term side effects Respondents suggested the following:

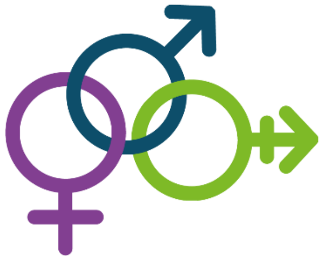
- Clearer, earlier information on ED, urinary incontinence, bowel issues, and hormone therapy effects
- Guidance on managing or preventing long-term complications
- Practical advice such as pelvic floor exercises before surgery
- Many said they would have benefitted from knowing what to expect earlier.

10. Continue what works well A high proportion of respondents said their care was excellent and required no changes. These individuals emphasised:

- The high quality of care at The Christie and other local centres
- Positive experiences with nurses, clinical teams, and support groups
- They felt others might benefit if best practice was shared more widely.

Demographics

The demographic profile indicates that respondents were predominantly older adults, which aligns with the age groups most affected by prostate cancer. **The vast majority were aged 50 and over**, with **the largest proportion falling within the 65–79 range**, meaning the findings mainly reflect the experiences and needs of an older population.



Ethnicity data shows respondents were **overwhelmingly White British**, with smaller percentages identifying as **Black African, Black Caribbean, or Mixed heritage**, and very few representing other ethnic groups. This suggests that minority ethnic communities may be underrepresented in the survey. This underrepresentation is particularly significant given that Black men are at a higher risk of developing prostate cancer. The limited representation means this may not have fully captured the specific barriers, experiences and needs of these communities.

A significant number of respondents reported long term conditions or disabilities, consistent with the older age distribution, while a smaller proportion identified as carers. These patterns reflect the higher health-need profile expected within a population engaging with prostate cancer services.

As prostate cancer affects anyone with a prostate, respondents were asked about their gender identity. The overwhelming majority identified as men, with very small numbers identifying as transgender women or choosing not to disclose. A small group of gender-diverse respondents shared challenges when accessing prostate cancer care, highlighting the need for inclusive and gender-affirming pathways.

Patterns of disability and long-term health conditions suggest many respondents face complex health challenges, and the presence of carers underscores wider support needs within this group.

66%

of survey respondents were within the 65-79 years of age.

Geographical data shows respondents came from a wide area across Greater Manchester, including Bury, Bolton, Salford, Rochdale, Oldham, Stockport, Wigan, and Trafford, alongside others from the wider Northwest and a few from further afield.

Focus groups feedback

We ran three focus groups between September and December 2025 (a mix of in person and online). We heard from men who are on treatment (e.g., radiotherapy and hormone therapy), on active surveillance/monitoring, and long-term survivors (including a local support group lead). A consultant urologist attended one session to observe and talk about early diagnosis. Most participants were in their mid-60s to late-70s.

Key themes

- **Getting help and being diagnosed**

Some men were delayed receiving help due. One person described a 3-year gap between first raising "waterworks" problems at a diabetes review and finally getting referred: *"I should have asked for the GP test in 2019/2020."* A later diabetes review led to an immediate referral and diagnosis.

Others were picked up through general health checks when a high PSA level led to scans and a biopsy (e.g., PSA 14.3; PSA 7.3). People's understanding of PSA testing varied; some felt unsure what it meant or when to ask

- **Communication and information**

Good experiences involved clear explanations, time for questions, and practical tips (e.g., staying hydrated before radiotherapy). One man said: *"They were a team… I felt reassured and safe."* Another described a one-hour planning conversation that really helped.

Others found contradictory advice, especially about hormone-therapy side-effects and self-management. They asked for consistent, trusted information (for example, a single place to find clear guidance).

- **Treatment, side effects, and day to day life**

Routes included radiotherapy, hormone therapy (e.g., Decapeptyl), active surveillance, and in some cases BRCA-related discussions. People praised quick scans, predictable appointment times, and follow-up calls from their GP.

Reported side-effects included urinary urgency/frequency (*"No warning at the beginning… I had to wear pads"*), night sweats, low mood/feeling emotional, erectile dysfunction, and weight gain. Some tried practical workarounds (pads, pelvic-health apps), medicines, or weight-loss support. Practical barriers mattered: lack of public toilets, travel/parking worries, and appointments that clash with work or caring. On the positive side, GP check-ins and easy access to PSA tests built trust: *"GP called me yesterday to see how I was doing… can't praise them enough."*

- **Emotional wellbeing, stigma, and peer support**

Early on, many felt fear, embarrassment, and worry about sexual side-effects. Peer support (local groups or online) helped men feel less alone and talk more openly. People said: *"Take someone with you… never go alone,"* and *"Avoid 'Doctor Google'—use trusted sites and groups."* Some on curative pathways felt "back to normal"; others adapted over time (one man said he and his wife became "*more creative together*").

- **Support for partners and carers**

Many felt partners/carers don't get enough support and must search for help. Some preferred inclusive groups that welcome partners, rather than men-only sessions.

What worked well

- Kind, proactive conversations. Clinicians who asked about risk factors (age, family history, ethnicity), explained choices, and gave practical preparation (e.g., hydration before radiotherapy) helped people feel safe: *"I was reassured and safe."*

- Smooth pathways and timely updates. Fast scans, predictable slots, and plain-English letters/calls reduced anxiety.

- Joined-up GP/hospital support: Quick PSA access, GP follow-up calls, and clear ways to get back in touch if things change.
- Peer and community support: Bolton Prostate Cancer Support Group, Macmillan/Maggie's/Prostate Cancer UK resources, and pelvic-health tools (e.g., the Squeezy app) were helpful.

Limits to the focus group findings

Small numbers and self-selection. **11 men** took part across the reported groups, so findings may not reflect everyone's experience. However, the depth of quotes adds important context to our survey and interview results. Differences between services: Some variation is likely due to different providers and sites.

Men told us they value clear, caring communication, joined-up GP–hospital working, and practical help (toilets, travel, predictable slots). They want consistent information on side-effects, inclusive support for partners, and a simple, standard PSA conversation. These are realistic improvements that can be put in place and scaled across Greater Manchester.

One to one interviews

We held confidential 1-to-1 interviews via telephone and MS Teams with men at different stages of prostate cancer, early/localised disease treated with curative intent, and advanced/metastatic disease after emergency or planned pathways. Interviews let people talk openly about symptoms, decision making, side effects, mental health, practical barriers, and what helped in their own words.

Key themes

- **Routes to diagnosis: from "no symptoms" to medical emergency**

Opportunistic/GP-supported diagnosis: Some men had no symptoms, decided to ask for a PSA after hearing friends' stories or campaign messages, and were diagnosed early.

> *"I had no symptoms at all… eventually I thought I'm just going to go (and get checked over)."*

Recurrent UTIs leading to tests. Repeated infections and worry during long drives prompted GP checks and diagnosis.

Emergency route / late stage. Others presented in crisis with severe back/leg pain, loss of continence, or cord compression. *"I came out of the MRI to be told I had spinal cord compression and cancer on my spine and lungs… mine was 700 [PSA]."*

Confusing early messages: One man initially heard it might be bladder cancer with widespread spread; later scans confirmed metastatic prostate cancer with a better outlook than first told. "*My life expectancy suddenly changed to years instead of months.*"

Long-standing, advanced diagnosis: A patient advocate described being stage 4 at presentation, likely undetected for years: *"If I'd had a PSA test every year from 50 to 60, I'd have been diagnosed early and cured."*

- **Communication, information, and shared decisions**

What "good" looks like: Men valued plain-English explanations, time for questions, written information, and feeling involved: "*It was very much down to me which route I went down… success rates were virtually identical, so I chose brachytherapy.*"

Where it falls short: Some reported brief consultations ("*10 minutes with a urologist, 10 with an oncologist*") and mixed messages between leaflets and verbal advice: "*The leaflets… contradict what they tell you.*"

- **Treatment, side effects, and recovery**

Curative treatment (e.g., brachytherapy): Often rapid and well organised, with minimal side-effects for some: “*Procedure on Friday, home by 3pm, took the dog for a walk.*”

Advanced disease: People described major surgery, radiotherapy, chemotherapy, and hormone therapy, with significant side-effects (temperature changes, fatigue, neuropathy, sexual dysfunction, weight change) and mental health impact. “*It passed its trial on the Friday and I got it on the Tuesday… that’s the one keeping me alive.*”

Living with long-term treatment: Fatigue, bladder/bowel issues, and emotional changes “*similar to menopause symptoms*” were common; local satellite sites (e.g., Christie Macclesfield) reduced travel burden.

- **Aftercare, rehabilitation, and day to day practicalities**

What helped: Access to specialist advice lines (“*I rang the Christie… got clear advice*”), predictable follow-up, and care close to home.

Where it broke down: One man had six months without rehabilitation after discharge, a care package that didn’t fit his needs or dignity, and district-nursing issues that led to an A&E department visit. “*It felt like going home to die almost… because I came out and had nothing.*”

Getting to services: Parking, distance, and poor public transport were common barriers: “*I finished up walking a mile while catheterized to get to Stepping Hill.*”

- **Emotional health, partners, and peer support**

Trusted information over “Doctor Google”: Men recommended Macmillan/Prostate Cancer UK; take someone to key appointments; talk to someone who has “been there.”

Culturally-sensitive support matters: “*It really worked for me… I felt fully welcomed and supported,*” said one man about a community-based group. Others would consider counselling when needed.

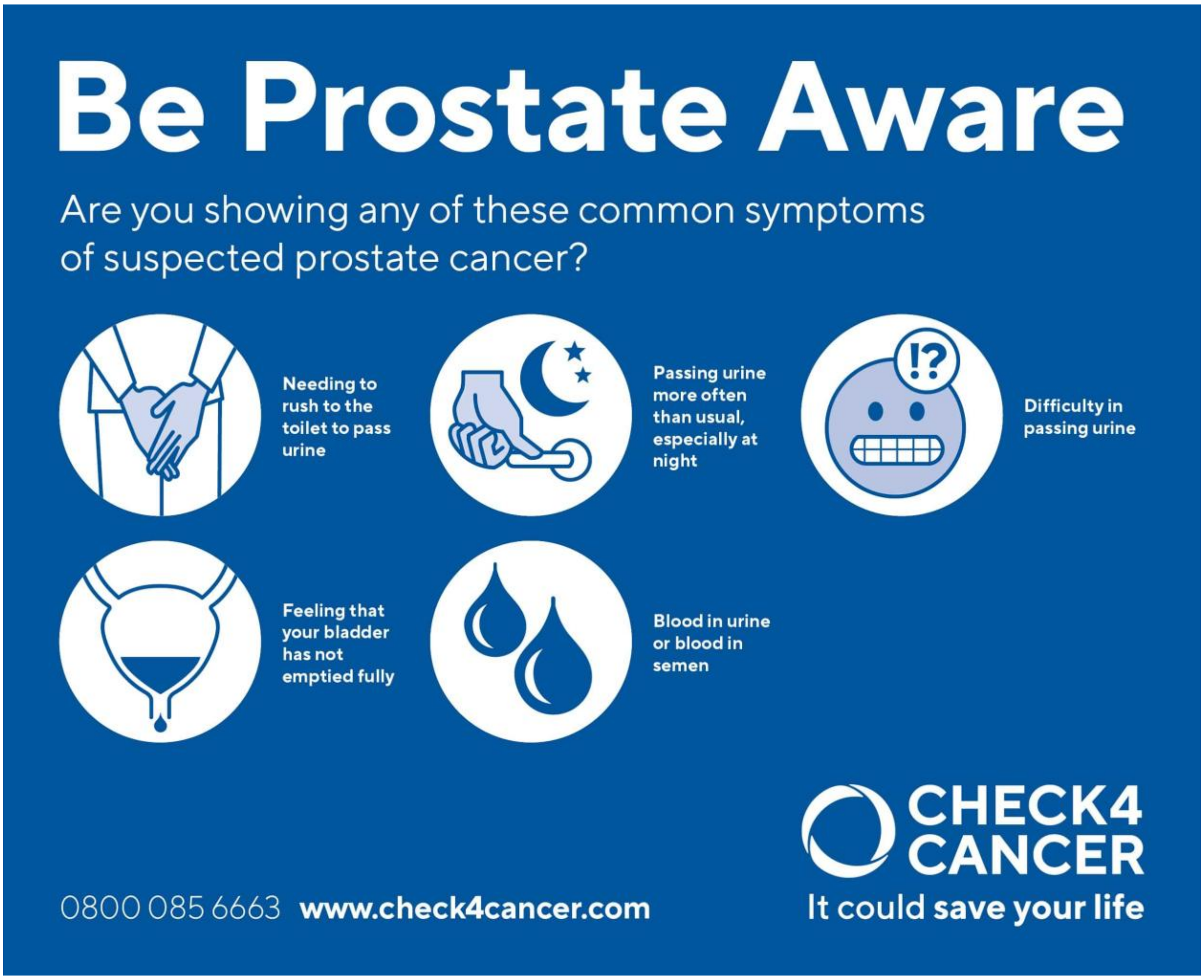
Advocacy perspective: Holistic needs (sexual health, mental health, exercise, nutrition) should be offered, not hunted for; long, generic booklets can overwhelm: “*They all got piled in a bin.*”

- **Wider system reflections from a citizen contributor**
  A local resident wrote about pressure on GP capacity, the need for diagnostic training time, open culture on mistakes, realistic use of digital tech with back-up plans, and diet/public health to reduce future demand. While not specific to prostate cancer treatment, these points reinforce the need for joined-up primary–secondary working and safe digital systems.

Examples of good practice (what patients said worked)

- GPs who support informed PSA testing (pros/cons explained, exam performed, prompt referral).
- Timely, patient-centred decision-making (balanced success-rate discussion; swift scheduling; flexibility for personal events).
- Specialist access and responsive advice (Christie and satellite sites; clear advice lines).
- Comprehensive inpatient support in emergencies (pain, psychology, neuro, bowel/bladder teams).
- Peer-to-peer and community groups (including culturally-appropriate support) that reduce isolation and normalise sensitive topics.

This section reflects interviews conducted between October 2025 and February 2026. Quotations are anonymised and used with consent.



Be Prostate Aware

Are you showing any of these common symptoms of suspected prostate cancer?

Needing to rush to the toilet to pass urine

Passing urine more often than usual, especially at night

Difficulty in passing urine

Feeling that your bladder has not emptied fully

Blood in urine or blood in semen

CHECK4 CANCER

It could save your life

0800 085 6663 www.check4cancer.com

Where to find further information and support?

People who want to find out more about prostate cancer, PSA testing, or support services can access reliable information from the following organisations:

- **NHS – Prostate cancer information**
  https://www.nhs.uk/conditions/prostate-cancer/
  Information on symptoms, PSA testing, diagnosis, treatment options and living with prostate cancer.

- **Prostate Cancer UK**
  https://prostatecanceruk.org
  Provides expert information, a specialist nurse helpline, decision-making tools, and details of local and online support groups.

- **Prostate Cancer Research UK**
  https://www.prostate-cancer-research.org.uk/
  Informing and empowering patients to get the right care

- **Macmillan Cancer Support**
  https://www.macmillan.org.uk/cancer-information-and-support/prostate-cancer
  Offers practical, emotional and financial support for people affected by prostate cancer, including carers and family members.

- **Cancer Research UK – Prostate cancer**
  https://www.cancerresearchuk.org/about-cancer/prostate-cancer
  Clear, evidence-based information on causes, diagnosis, treatments, statistics and research.

- **Your local Healthwatch**
  https://www.healthwatch.co.uk/your-local-healthwatch/list

  Can help residents find local services, support groups and advice on accessing healthcare.

For PSA testing or concerns about prostate symptoms, individuals are encouraged to contact their GP practice to discuss options, benefits and risks.

Local peer support and community services (Greater Manchester)

In addition to national organisations, people affected by prostate cancer may benefit from local peer support groups and community services across Greater Manchester. These groups provide opportunities to share experiences, access emotional support, and receive practical advice in a supportive environment.

Bolton Prostate Cancer Support Group
A local peer support group offering regular meetings for men with prostate cancer and their families.

Bolton & Districts Prostate Cancer Support Group - Tackle Prostate Cancer

Maggie's Centres (Greater Manchester)
Maggie's provides free cancer support, including emotional support, information, group sessions and practical advice, available to people living with cancer and their families.

Support groups | Maggie's

Local Prostate Cancer UK Support Groups and other resources such as Tackle Prostate Cancer (a national charity run by and for men with prostate cancer), the 'Squeezy' app for pelvic floor exercises, and local cancer wellbeing and exercise programmes such as CanMove

Prostate Cancer UK supports a network of local and online peer support groups across Greater Manchester.

Prostate Cancer UK | Prostate Cancer UK

Community and voluntary sector organisations
Local charities and community groups may offer additional wellbeing, peer support or social activities for people affected by cancer.

Availability of local groups may vary, and individuals are encouraged to check current meeting times and locations directly with the organisations listed.

Access to both national and local support services can help people feel better informed, less isolated, and more supported throughout their diagnosis and treatment journey

Acknowledgements

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References

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2. Data and Evidence | Prostate Cancer UK

3. Prostate Progress project to support research through combination of clinical data with patient-reported outcomes – HTN Health Tech News

4. Patient-Reported Outcome Measures Help Patients With Cancer | Oncology | JAMA Network Open | JAMA Network

5. How we're using data to transform prostate cancer research - NHS England Digital

Contact us

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