

Appendices: Supporting Evidence and Detailed Findings

This appendix document accompanies the main report, *Men's Experiences of PSA Testing and Prostate Cancer in Worcestershire (2026)* and provides the supporting detail behind the findings presented.

It brings together the full survey materials, detailed response data, and additional information to offer greater depth and transparency. While the main report summarises key themes and insights, this document enables readers to explore the evidence in more detail.

This document includes:

- **Appendix A – Survey Questionnaire**
Full list of survey questions used to gather responses.
- **Appendix B – Survey Response Tables** (including all verbatim comments)
Detailed breakdown of responses for each question, including all verbatim comments.
- **Appendix C – Reference List**
Sources and evidence referenced throughout the report.
- **Appendix D – Governance and Ethics**
Information on methodology, governance, ethics, and data handling.
- **Table 1 – Technical Term Explainer**
Definitions of key terms used within the report.

Appendix A: Survey Questionnaire

This appendix contains the full list of survey questions used to gather men's experiences of PSA testing and prostate cancer in Worcestershire.

The questions include:

- Multiple-choice questions
- Tick-box responses
- Open-text questions
- Follow-up branching questions where relevant

Survey Questions List

1. Age
2. Ethnic group
3. Family history of prostate cancer
4. Family history of breast cancer
5. If you have received a diagnosis, what stage was the prostate cancer at the point of diagnosis?
6. Tell us about access to your GP when you needed to talk about prostate cancer
7. What prompted you to have a PSA test?
8. Who mainly influenced your decision to have the test?
9. Before having the PSA test, were you aware that if your PSA result was raised it could lead to further tests or treatment?
10. Before the test, were you informed about possible side effects of prostate cancer treatment
11. After the test, if you were told your PSA result was raised, what did you feel was most important to you at that time?
12. Did concerns about potential treatment side effects influence your decision if your PSA result was raised?
13. Which approach best reflects the choice you made or would be most likely to make?
14. Looking back, do you feel you had enough information to make an informed decision about PSA testing and prostate cancer?
15. Please share anything you wish you'd known in advance before deciding to have a PSA test.

Appendix B: Survey Response Tables

This appendix summarises the quantitative responses for each survey question.

PLEASE NOTE: Verbatim comments are reproduced exactly as submitted, with only minimal anonymisation (e.g., removal of names). Some comments may therefore appear incomplete or unclear.

Q1 - Age

Type: Single choice

Valid Responses: 153

No answer: 1

Answer Choices	Percentage	Response
Under 50	1.31%	2
50–59	7.19%	11
60–69	22.88%	35
70–79	52.94%	81
80 or over	15.69%	24
Total		153

Q2 - Ethnic group (based on NHS categories)

Type: Single choice

Valid Responses: 151

No answer: 3

Answer Choices	Percentage	Response
White	98.01%	148
Black or Black British	0.66%	1
Asian or Asian British	0.66%	1
Mixed or multiple ethnic groups	0%	0
Other ethnic group	0.66%	1
Prefer not to say	0%	0
Total		151

Q3 - Family history of prostate cancer

Type: Single choice

Valid Responses: 153

No answer: 1

Answer Choices	Percentage	Response
Yes	25.49%	39
No	62.09%	95
Not sure	12.42%	19
Total		153

Q4 - Family history of breast cancer

Type: Single choice

Valid Responses 151

No answer: 3

Answer Choices	Percentage	Response
Yes	21.19%	32
No	72.19%	109
Not sure	6.62%	10
Total		151

Q5 - If you have received a diagnosis, what stage was the prostate cancer at the point of diagnosis?

Type: Single choice

Valid Response: 148

No answer: 6

Answer Choices	Percentage	Response
Stage 1	5.41%	8
Stage 2	14.19%	21
Stage 3	9.46%	14
Stage 4	5.41%	8
Not sure	8.11%	12
Not diagnosed	47.97%	71
Prefer not to say	2.03%	3
Other (answers shown below)	7.43%	11
Total		148

Verbatim Comments if selected 'other':

No cancer found after biopsy

Dust on testecal

Diagnosed stage 4 then 3 then 2

Biopsy taken

Gleason score of 8

Hopefully clear of it

Enlarged

Not yet diagnosed. MRI only.

Never actually told what stage

Gleason score 7

not diagnosed

Q6 - Tell us about access to your GP when you needed to talk about prostate cancer

Type: Single choice

Valid Responses: 146

No answer: 8

Answer Choices	Percentage	Response
Easy access	47.95%	70
Somewhat difficult access	24.66%	36
Very difficult access	8.22%	12
Discouraged from seeing a GP	4.79%	7
Prefer not to say	4.79%	7
Other	9.59%	14
Total		146

Verbatim Comments if selected 'other':

I didn't want to see a GP

I had to ask for a PSA test, included in an annual 10 point blood test.

Not enquired

Not current surgery

Originally refused PSA test without symptoms

Needed to see an Oncologist

spoke to practice nurse

No need to talk to GP

Discouraged from having a PSA test

Came to notice while in hospital with a kidney problem. Only local access is for injections

Had to fill in a form on line to request a psa test along side other bloods I was having done at my long term review, then had to see a GP who was reluctant to do psa test, did agree in the end. Sould be routine at my age.

Not detected via GP but when hospitalised for a kidney problem

Just given a leaflet and told to look on the website

The Gp was "old school" &I had a good relationship with him .after appalling treatment by Worcester royal I exercised my right to go elsewhere. The Gp backed my decision to go to Wolverhampton for robotic surgery.

Q7 - What prompted you to have a PSA test? (Select all that apply)

Type: Multiple choice (select all that apply)

Valid Responses: 142

No answer: 12

Answer Choices	Percentage	Response
GP recommendation	12.68%	18
Urinary or other symptoms	29.58%	42
Family history of prostate cancer	14.08%	20
Private health check/workplace event	2.11%	3
Personal concern or peace of mind	40.85%	58
Media or public health information	17.61%	25
Advice from family or friends	11.97%	17
Other	16.20%	23
Total		206

Verbatim Comments if selected 'other':

Had back pain

Nurse suggested it during annual diabetes check.

This test was approved by GP when symptoms appeared- previously declined before symptoms

PSA 8

Annual test after infected prostate back in 2012. Left with sig LUTS

Enlarged prostate on MRI done for other reasons

Never been tested

Free PSA at a New Road Cricket Match

Friends colleagues who had been diagnosed with no symptoms some of which had died

It was found during blood tests for asthma

Annual well man's blood test

Knew others who developed the cancer.

A local charity advertised psa checks.

Have had PSA tests yearly since having Turp op

CONTINUED Verbatim Comments if selected 'other':

My cousin has prostate cancer.
See answer to previous question
My oncologist wants me to have psa test
Don't have a computer so did nothing
Prostate cancer information stand at car show grounds
Part of my routine testing
requested at a routine visit
Just wanted to be checked out
Being treated for years for an enlarged Prostate

Q8 - Who mainly influenced your decision to have the test?

Type: Single choice

Valid Response: 142

No answer: 12

Answer Choices	Percentage	Response
GP or healthcare professional	21.83%	31
Myself	56.34%	80
Family or friends	16.90%	24
Other	4.93%	7
Total		142

Verbatim Comments if selected 'other':

Na
Hospital consultant
Very difficult to persuade GP to give me a PSA test until I changed GP practice.
Reading up on risk
Hospital Consultant
Media
Media coverage

Q9- Before having the PSA test, were you aware that if your PSA result was raised it could lead to further tests or treatment?

Type: Single choice

Valid Response: 124

No answer: 30

Answer Choices	Percentage	Response
Yes, fully aware	69.35%	86
Somewhat aware	21.77%	27
Not aware	8.87%	11
Total		124

Q10 - Before the test, were you informed about possible side effects of prostate cancer treatment (e.g. incontinence, erectile dysfunction)?

Type: Single choice

Valid Response: 123

No answer: 31

Answer Choices	Percentage	Response
Yes	39.84%	49
No	46.34%	57
Not sure	13.82%	17
Total		123

Q11 - After the test, if you were told your PSA result was raised, what did you feel was most important to you at that time?

Type: Single choice

Valid Responses: 114

No answer: 40

Answer Choices	Percentage	Response
Having further tests as soon as possible	39.47%	45
Taking time to think about my options	5.26%	6
Understanding the possible benefits and risks of treatment	8.77%	10
Following my clinician's recommendation	26.32%	30
I was unsure what to do	3.51%	4
Other	16.67%	19
Total		114

Verbatim Comments if selected 'other':

Test is only 50% accurate, like a coin toss. Why risk an operation.

So far PSA level is normal

Results were ok

Advice was disjointed and incorrect appointments arranged.

I'm awaiting results of psa test

Not told that PSA was raised - Negative test

Having had a value of 1 for 12 yrs and then getting a val of 3.7 I was told that was normal for my age and clinic nurse did not want to repeat. Eventually GP agreed and new val was 6.4

level not raised

PSA result was not raised

PSA normal

Not raised

PSA low enough to not be of concern

PSA not raised

No follow up after psa test

Not raised

Not had a test

CONTINUED: Verbatim Comments if selected 'other':

Getting away from the uniformed staff at Worcester royal who wanted to cut me open and find a better way and group of competent understanding medical staff

Decided to have a regular annual PSA test to look at trends

Not tested yet

Q12- Did concerns about potential treatment side effects influence your decision if your PSA result was raised?

Type: Single choice

Valid Responses: 118

No answer: 36

Answer Choices	Percentage	Response
Yes, they strongly influenced my decision	15.25%	18
Yes, they influenced it somewhat	16.10%	19
No, they did not influence my decision	48.31%	57
Not applicable / no treatment decision yet	16.10%	19
Other	4.24%	5
Total		118

Verbatim Comments if selected 'other':

See above.

No treatment required

Not had a test

I wanted to live

Yes, decided not to have the PSA test

Q13 - Which approach best reflects the choice you made or would be most likely to make?

Type: Single choice

Valid Response: 118

No answer: 36

Answer Choices	Percentage	Response
Active surveillance / monitoring	38.14%	45
Immediate treatment (e.g. surgery, radiotherapy)	52.54%	62
Undecided at the time	4.24%	5
Chose not to proceed with further tests or treatment	2.54%	3
Other	2.54%	3
Total		118

Verbatim Comments if selected 'other':

This is a stupid question as choice depends on diagnosis

See above

2 year repeat testing agreed with GP

Q14 - Looking back, do you feel you had enough information to make an informed decision about PSA testing and prostate cancer?

Type: Single choice

Valid Responses: 121

No answer: 33

Answer Choices	Percentage	Response
Yes	66.12%	80
No	23.14%	28
Unsure	10.74%	13
Total		121

Q15 : Please share anything you wish you'd known in advance before deciding to have a PSA test.

Type: Open-ended

Valid Responses: 50

No answer: 104

Please note: All comments above are reproduced verbatim, exactly as submitted by respondents. Spelling, grammar and punctuation have not been corrected.

- I think everyone over 45 should be able to have PSA test as woman have breast screening. Only reason mine was found was due to another issue
- I was pleased to have the test as I like to know if there is a problem. I continue to have tests at 6 monthly intervals.
- What other tests are available that are more accurate, even if I have to pay.
- I feel all men over 50 should be invited to have a yearly check with no upper age limit
- Nothing
- My father died with it, not of it clearly it makes sense to be aware and take the necessary action.
- I should have been advised not to have a PSA test close to a Shingles booster inoculation, which caused the raised PSA level over previous tests. I informed the nurse taking my blood test about the inoculation, but she said it didn't matter.
- I wish I had been aware that a PSA test was readily available, rather than too late!
- I left 18 months before getting a follow up test and it was too late
- In 2011 I had no idea what Prostate Cancer was, and thought I was going to the Doctor's with a urinary infection. Subsequent PSA test showed an elevated PSA and I was then sent for a biopsy which confirmed Prostate Cancer. There was no media publicity/information then like there is now. My Mother had Breast Cancer but any possible link that I could be more at risk due to this was never pointed out to me. Had I known I would have requested a PSA test at regular intervals following my 45th birthday. Following the biopsy I had my Prostate removed but unfortunately the Cancer has spread to my bones.
- I had to Google PSA after the nurse took the sample to understand potential cancer risk.
- Consultant over three years has either moved appointments back 6 months on 3 occasions. has said I was not answering phone calls on 3 occasions, Never had a call back at least 15 messages left on secretary's phone, complete no functioning contact system losing all trust in Worcs NHS and its control systems.
- More information about the latest treatments
- I was told there was no correlation between family history and PC. I subsequently decided this was no excuse for saying a test wasn't needed and insisted on a test
- That you will know all the facts and what treatment can give you the best outcome and equal opportunities to have the treatment relevant of cost if it gives you prolonged time and quality of life.
- Ability to talk to an Oncologist and get out of the clutches of Urology surgeons .
- That I could have asked sooner
- What is a normal average result, what result is considered high, If the result is high when should the next PSA be done.

- I have received drugs since the age of 50 and am pleased with the treatment apart from side effects with breast enlargement
- unable to put this anywhere else but thought it important. GP suggested test as routine rather than asking for it. a great idea.
- Not on my part but the clinic nursing staff should have been aware that it is the PSA doubling that is important and not the value. If men are dissuaded from having a test they will never be able to look back and compare the doubling time.
- I was very lucky to catch the cancer on a routine PSA test (6.1ug/l). I had no symptoms and when the biopsy came back it was a very aggressive cancer (T3b 4+4). The worst part was waiting for surgery and it was only initiated after blood was observed in my semen. Had the wait for surgery been less the cancer would not have spread to my seminal vesicles and the surgery could have been less aggressive.
- I wish I had known that I would be informed by phone that I had cancer with very little information on the effects of treatment
- That the PSA test should be available to any man aged 50 or over. Earlier diagnosis could have meant less difficult treatment with less problematic side effects.
- I was head of the Biochemistry department from 1986 and at the request of introduced PSA testing into Worcestershire. This included offering a same day turnaround for his one stop urology assessment clinics. I also collaborated with a local charity to analyse samples for there screening testing service. I am extremely pleased that the service I was able to introduce has had a positive effect on many individuals.
- Not had a prostate test
- Should be offered -IASK for it yearly
- Just wish I'd been able to have a routine test to catch my cancer sooner. Aiming for a cure of locally advanced highly aggressive cancer is hard news to hear.
- I didn't have a choice to have tests and immediate treatment to survive. Treatment is still a terrible shock and life changing for myself and partner
- I wish it was a routine test like mammograms for women. It is a really difficult task to get an appointment for the blood test. I didn't want a consultation before the blood test and couldn't get an appointment for one. It just slows down the process and puts you off bothering to get the blood test. It should be encouraged not massive obstacles put in the way.
- Wish it was a regular service offered by GPs
- Nothing- read up before test - saw gp afterwards who said levels were normal - and physical examination which said prostate was slightly enlarged but not of concern
- The causes of BPH and the prognosis of the disease!
- Potential issues post biopsy as I've suffered groin pain for 4 months since and it's not easy getting cause diagnosed PLUS the pain during biopsy itself
- I've had several PSA tests, some of which led to biopsies. Fortunately no cancer was detected on each occasion, so there wasn't a full discussion about treatment and possible side effects. I hope I am lucky enough to remain cancer free, but nevertheless I'd like to understand more about what treatment might entail
- I wish I had known that the Test is so unreliable and that even the professionals have a lack of faith in the Readings.
- Wish I'd understood more about prostate cancer and alternative repurposed drugs like Ivermectin, Fenbendazol and menbendazol.

- Following Test MRI 10 years ago, following Tests to see if raised PSA. Examination again and seemingly much larger than before. Test raised so MRI increased in size to 180 from 75 no cancer it seems but further testing around 6/12 months.
- More information of age group psa level profiles. More information on benign prostate enlargement.
- A need to be assertive about follow-up actions. Consultant informs and advises: patient decides.
- There seems to be a lot of confusion about early identification of prostate cancer, not sure who to believe.
- I was discouraged from having the test, and believe that had I not done so I would not be alive today.
- Whether my father had PC problems
- It did not come across as urgent or important compared with the kidney issue- especially as only having one.
- Given no info so had no test
- I wish I'd have known about prostate cancer earlier, until seeing information desk at local car show , I'd not heard of it. I would have definitely been tested earlier if I'd have known
- I only got relevant information at my meeting with a consultant at Wolverhampton. He explained everything in a human manner. I fully understood the procedure and the range of possible outcomes. My wife attended and she also understood. It was a pleasure to be treated by ALL the staff at Wolverhampton as they were kind & considerate , unlike the " agricultural " approach of Worcester.
- My PSA tests were carried out by a local charity organising testing sessions. I had several tests which showed a gradual increase in PSA level. The notification letters were copied to my GP but I had no response about the need for further tests. I didn't realise that my PSA levels (4-5) were getting into an area where I should have had further tests (MRI, biopsy)
- N/A
- Never offer at drs as they say it not in their remit would have to go private for test and treatment

Appendix C – Reference List

Numbered References (cited in the report)

1. Healthwatch Worcestershire (2024). *Spotlight Report: PSA Testing*. Available at: <https://www.healthwatchworcestershire.co.uk/sites/healthwatchworcestershire.co.uk/files/HW%20%20Spotlight%20report%20PSA%20testing.pdf>
2. Healthwatch Worcestershire (2025). *Position Statement on Prostate Cancer and PSA Testing*. Available at: <https://www.healthwatchworcestershire.co.uk/sites/healthwatchworcestershire.co.uk/files/HW%20Position%20Statement%20on%20Prostate%20Cancer%20and%20PSA%20testing%20May%202025.DOC.pdf>
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- ICB Response (2025). *Response to Position Statement*. <https://www.healthwatchworcestershire.co.uk/sites/healthwatchworcestershire.co.uk/files/NHS%20HW%20ICS%20response%20to%20Position%20Statement%2009.25.pdf>
4. UK National Screening Committee. *Draft Recommendations*. Available at: <https://nationalscreening.blog.gov.uk/2025/11/28/uk-nsc-opens-consultation-on-draft-prostate-cancer-screening-recommendation/>
5. Healthwatch Worcestershire. *PSA Testing: The Conversation Men Aren't Having (But should)* — Full Podcast. Available at: <https://www.youtube.com/watch?v=HqaVcdZHSrU>
6. Healthwatch Worcestershire. *Phil's Story – Short Clip*. Available at: <https://youtube.com/shorts/SBKxMcq1os0?si=jfjID3C5DOeilgll>
7. Prostate Cancer UK. *Check your risk in 30 seconds – Risk Checker*. Available at: <https://prostatecanceruk.org/risk-checker>
8. NHS. *PSA Test – NHS Guidance*. Available at: <https://www.nhs.uk/tests-and-treatments/psa-test/>
9. Prostate Cancer UK. *TRANSFORM Trial – Research Overview*. Available at: <https://prostatecanceruk.org/research/transform-trial>
10. <https://www.gov.uk/guidance/prostate-cancer-risk-management-programme-overview>

Additional Sources (not cited in text)

These support context but are not numbered in-text:

-Prostate Cancer UK. *Why our TRANSFORM trial is the key to prostate cancer screening for all men.*

<https://prostatecanceruk.org/about-us/news-and-views/2025/11/transform-key-to-screening-programme>

-Prostate Cancer UK. *Am I at Risk? Prostate Cancer Risk Factors.*

<https://prostatecanceruk.org/prostate-information-and-support/risk-and-symptoms/are-you-at-risk>

-GOV.UK / UK NSC. *UK NSC consultation on prostate cancer screening closes (24 Feb 2026).*

<https://www.gov.uk/government/news/uk-nsc-consultation-on-prostate-cancer-screening-closes>

-NHS HW ICB. *Prostate Cancer Awareness — Campaign page.*

<https://www.hwics.org.uk/priorities/campaigns/cancer-campaigns>

Appendix D - Governance and ethics

Governance and ethics

This work was undertaken as a Healthwatch listening exercise / service evaluation to understand local people's experiences of PSA testing and prostate cancer pathways in Worcestershire, and to inform improvement discussions with system partners. The survey approach and materials were approved through Healthwatch Worcestershire's internal governance processes.

Participation was voluntary. Respondents chose whether to complete the survey and which questions to answer, including optional free-text questions. The report presents findings in aggregate, with a limited number of verbatim comments used to illustrate themes.

To protect confidentiality, we did not seek to identify individuals in analysis or reporting. Verbatim comments are reproduced as submitted, with minimal anonymisation (for example, removing names) as noted in Appendix B. Where necessary, identifying details were removed or avoided in the narrative sections of this report.

Data were handled in line with Healthwatch Worcestershire information governance arrangements. Survey data were stored securely and used only for the purposes of analysis, reporting, and sharing learning with partners. No personal identifiers were collected.

As this activity was a service evaluation / engagement exercise, formal NHS Research Ethics Committee review was not sought. This is consistent with service engagement activity. We nonetheless aimed to minimise burden and potential distress by using clear, respectful questions and by presenting findings in a way that supports learning and service improvement. Any reader with concerns about prostate cancer or PSA testing should seek advice from their GP (as signposted in this report).

Technical Terms Explained – Table 1

Term	What it means	Why it matters in prostate cancer care
PSA (Prostate-Specific Antigen)	A protein found in the blood. A PSA test is a blood test that can help indicate prostate problems, including prostate cancer.	A raised PSA can be an early sign of prostate cancer and should trigger clear advice, follow-up and, where appropriate, further tests.
PSA Test	A PSA test is a blood test that measures the level of prostate-specific antigen (PSA) in the blood. Higher PSA levels can be linked to prostate cancer, but can also be caused by other conditions such as an enlarged or inflamed prostate.	The PSA test can help identify possible prostate problems at an earlier stage, including cancer. However, as results are not cancer-specific, clear information, balanced discussion and appropriate follow-up are important to support informed decision-making and timely care. Anyone concerned about prostate cancer or PSA testing should speak to their GP.
mpMRI (multiparametric Magnetic Resonance Imaging)	A specialised MRI scan that produces detailed images of the prostate using several imaging techniques.	mpMRI helps doctors decide whether a biopsy is needed and reduces unnecessary invasive tests. Limited access can delay diagnosis.
ICB (Integrated Care Board)	The NHS organisation responsible for planning and funding local health services across an area.	ICBs influence primary care guidance, diagnostic capacity (such as mpMRI), and consistency of local prostate cancer pathways.
Primary care	Frontline healthcare services, mainly GP surgeries, where patients usually have their first contact with the NHS.	Most PSA discussions and early identification should happen in primary care, making consistency and confidence here critical.
High-risk men / higher-risk groups	Men more likely to develop prostate cancer, including those with a family history, Black men, older men, or certain genetic factors.	Identifying higher-risk men early allows targeted conversations and earlier diagnosis, improving outcomes.
BRCA genes (BRCA1 / BRCA2)	Genes linked to DNA repair. Certain inherited changes (mutations) increase the risk of	Men with BRCA mutations have a higher risk of developing aggressive prostate cancer and

	several cancers, including prostate cancer.	may benefit from earlier or closer monitoring.
Risk-based conversations	Discussions between clinicians and patients that take account of personal risk factors, such as age, ethnicity and family history.	These conversations support informed decision-making rather than a “one-size-fits-all” approach to PSA testing.
Proactive identification	Actively identifying people at higher risk rather than waiting for them to come forward with symptoms or questions.	Reduces reliance on self-advocacy and helps address health inequalities by supporting earlier engagement.
Variation (within and between practices)	Differences in care, advice, access or outcomes between GP surgeries or areas.	Unwarranted variation means patients can receive different levels of care depending on where they live or which GP they see.
Pathways (care pathways)	The agreed sequence of steps that should happen after a test result, including referral, imaging, diagnosis and follow-up.	Clear pathways help ensure timely action, reduce delays and provide consistent care across all practices.
Late-stage diagnosis	Cancer identified at a more advanced stage (e.g. Stage 3 or 4).	Later diagnosis usually means fewer treatment options and poorer outcomes compared with early detection.
Shared decision-making	A process where clinicians and patients make decisions together, using the best evidence and patient preferences.	Supports informed choices about PSA testing and next steps, especially when benefits and risks must be balanced.
Health inequality	Differences in health outcomes linked to social, economic or demographic factors rather than medical need alone.	In prostate cancer, inequalities can arise through awareness gaps, access barriers and inconsistent advice.
Safety-netting	Agreed steps to ensure follow-up happens, such as repeat tests, referrals or clear instructions on when to return.	Prevents patients being lost in the system after a raised PSA or inconclusive result.

This explainer is intended to support shared understanding between patients, clinicians and decision-makers. Clear and consistent use of terminology can help reduce confusion, variation and delay in prostate cancer care. Any reader who has concerns about prostate cancer and/or PSA testing should contact their GP for advice.