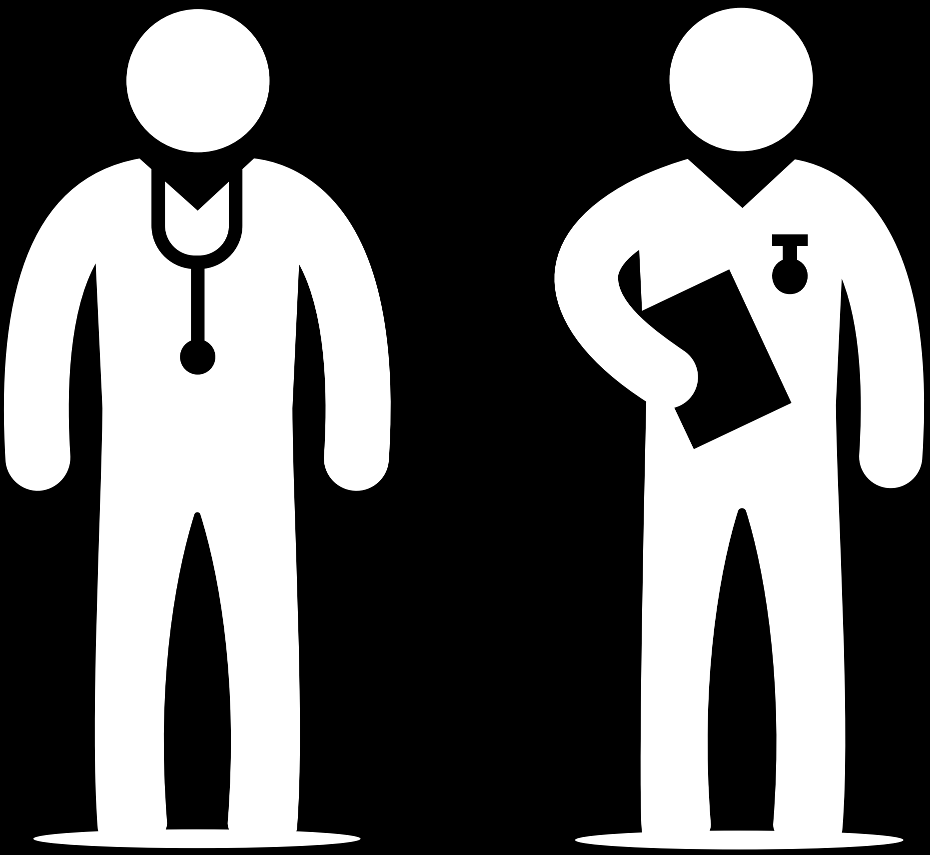
Prostate Cancer Risk Awareness in Primary Care

Addressing NHS ambitions of earlier diagnosis and tackling health inequalities.



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Supporting our NHS

We've created this content to support primary and secondary care colleagues who are working on early diagnosis/ health inequalities workstreams. You could be a health care professional/public health/clinical/cancer lead working for your Cancer Alliance, Integrated Care Board, NHS Trust, Council, Primary Care Network or GP practice. Whatever your role, we hope that this will help you achieve the targets and ambitions set out in the below plans.

1. **The NHS Long Term Plan sets** out key ambitions for 75% of cancers to be diagnosed at early stages 1 and 2 by 2028.
2. Whilst **CORE20PLUS5** addresses health inequalities targeting those in the most deprived areas, with one of the plus5 areas of focus being early cancer diagnosis.
3. The **Primary Care Network DES contract specification 2024/25** continues to emphasise the importance of forging closer links between practices, the broader health and care system and a diverse range of partners in their communities, including the voluntary sector and patient groups.

It's important to note that clinical staff can achieve these agendas by not only working within their primary care setting but by also reaching out to their communities to ensure that healthcare and advice is accessible to all. This holistic approach will help you build trust and engagement in communities that typically have poorer health outcomes.

Which patients should you be targeting?

The below categories of men are those at **highest risk** of prostate cancer.

- **Black men** aged 45-69
- Men with a recorded **family history** of prostate, breast or ovarian cancer aged 45 -69
- Men aged 50- 69

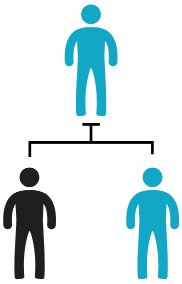
Who is at Risk?

You are more likely to get prostate cancer if:

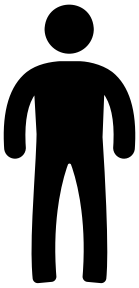
you're aged
50 or over

50+

your father or
brother has had it



you are
Black



How we can support you

The **DES specification** states that a PCN must seek to improve health outcomes for its population using a data-driven approach and population health management techniques in line with **CORE20PLUS5**.

The new specification emphasises the importance of using insightful analytics alongside improving data recording, including ethnicity coding. The purpose of this is to promote targeted care and improve outcomes for those where there's greatest opportunity.

We've outlined the detail of the specification below along with how we can support you with NHS goals

Specification	What we can offer
1. 75% cancers diagnosed at stage 1 & 2 NHS Long Term Plan	• **Email us** for resources and **publications** to raise awareness of prostate cancer risk, ensuring men make informed decisions about their health so they can get checked early avoiding late diagnosis
2. Address health inequalities targeting areas of deprivation CORE20PLUS5	• **Insights** into your demographics, data and how we can support with addressing health inequalities in your area
3. Use insightful analytics	• Data and analysis for your region to inform activity
4. Improve data recording and use, including ethnicity	• The appendices has a series of SNOMED codes for recording Black ethnicity • Guidance for Accurx and Iplato ethnicity questionnaires • Watch our session **on the benefits of collecting data** which includes insights from communities about ethnicity data collection
5. Improve outcomes in population groups where there is greatest opportunity	• Email us at **blackhealthengagement@prostatecanceruk.org** when organising Black community engagement events • **Toolkit** to deliver effective outreach, messaging, behavioural science insights to Black communities
6. Review cancer referral practice in collaboration with partners	• We can support and collaborate with you to understand your data and support with quality improvement work
7. Work to improve early diagnosis	• Guidance outlined below to achieve earlier diagnosis along with support for delivery
8. To address health inequalities, a PCN should: a) work in partnership within local communities to deliver effective outreach and b) target care to address health inequalities that are amendable to primary care intervention	• Our toolkit that provides insights on engaging with Black communities to deliver effective outreach, messaging, behavioural science insights. • Ongoing support from our **Health Services** directorate to help define and deliver your approach/project
For support and advice contact us today	**Email** us and we will be in touch

Why early diagnosis matters

3 IN 5

men don't want to bother their GP without symptoms

...but they may not have any

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Separate fact from fiction and save lives.

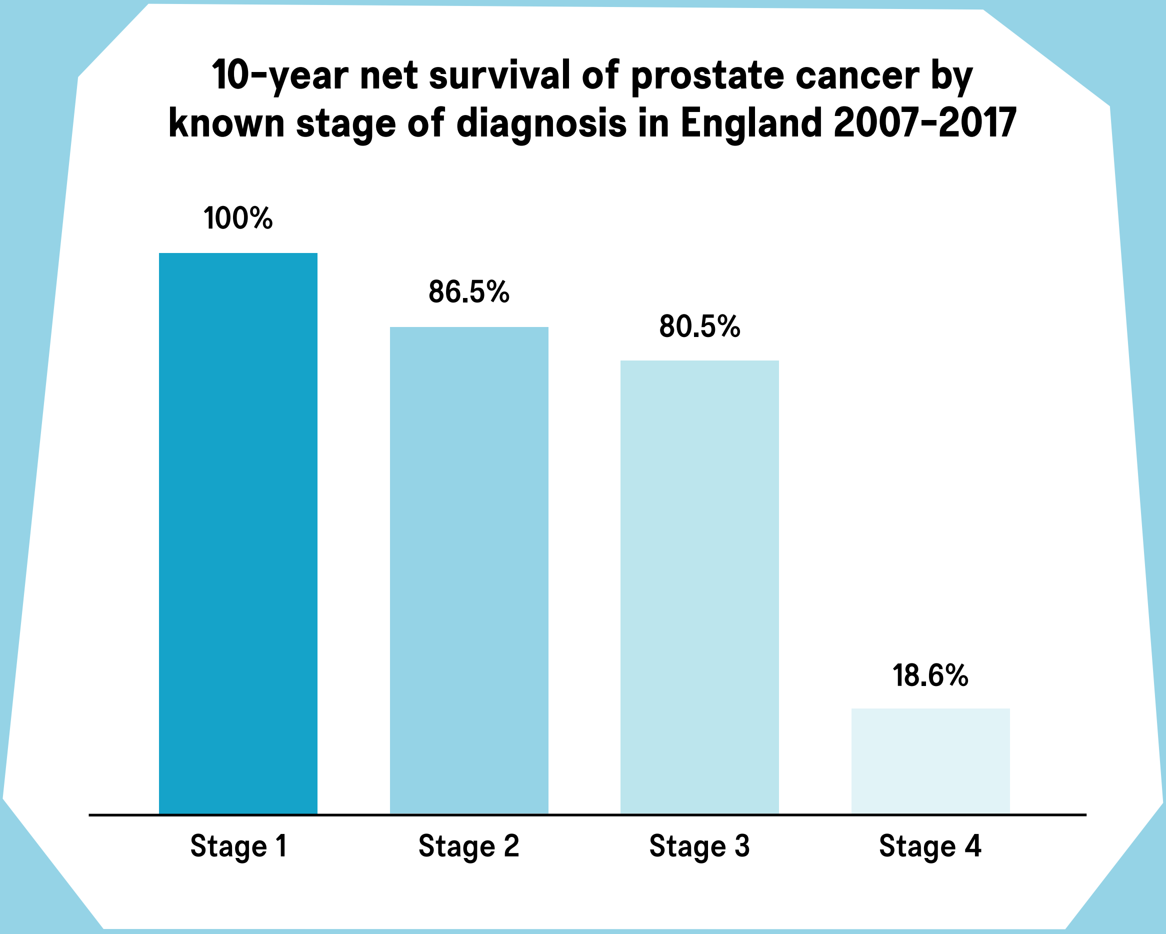
In its early stages, prostate cancer is curable. **However, often it doesn't have symptoms.** This is why we advocate for risk awareness and inform men about what they can do about it.

We've worked with NHS colleagues during the pandemic and after to support with the delivery on the Direct Enhanced Specification (DES) for prostate cancer. You can read more **about the impact of our work with PCNs here**. Our approach was successful in raising awareness of prostate cancer, providing men with consistent information about the pros and cons of the PSA blood test, and supporting them to make an informed choice about the tests available to them.

Men want to know about early diagnosis

Our recent research published in June 2024, in the British Journal of General Practioners found that men want to know what benefits there are to an earlier diagnosis; in order to value and appreciate the difference it'll make to their survival rates. Therefore, it's important to ***provide men with accurate, balanced and non-biased information so that they can make informed decisions about their health***.

The below graph shows the changing survival rates based on 10-year data, which highlights the importance of finding men before their cancer progresses to later stages.



What is clear, is that **men diagnosed earlier have better survival rates than those diagnosed later**. The current evidence cites that only about half of prostate cancer diagnoses are caught early.

To meet the UK's ambitions of diagnosing 75% of all cancers at stage-1 or 2 by 2028, as outlined in the NHS Long Term Plan, **men at risk need to be made aware of their risk** of being diagnosed with prostate cancer and to understand the benefits of an earlier diagnosis.

Role of ICBs

Insightful analytics and data recording

The NHS statement on health inequalities, highlighted the role that Integrated Care Boards in England have in collecting data to support targeted work that will address health inequalities. Furthermore, the 2024/25 PCN DES specification also requests more data-set recording, including ethnicity. This data capture will help to inform action around future work around health inequalities and targeted messaging to specific groups.

There are a number of quality improvement activities that we've outlined for you below to help achieve this.

Top tips

1. Add SNOMED codes for family history of prostate, breast and ovarian cancer and any genetic variation, as this is crucial information in understanding and recognising the increased risk of prostate cancer diagnosis.
2. Secondly, implement an agreed standardised ethnicity coding within your practice area/PCN/ICB so that auditing of patients of certain ethnicities becomes easier and will help to inform project work. We provide some suggestions further on.
3. If your practice is an iPlato or accuRx user, you can also text patients an ethnicity questionnaire, which when completed will be automatically coded into their records.

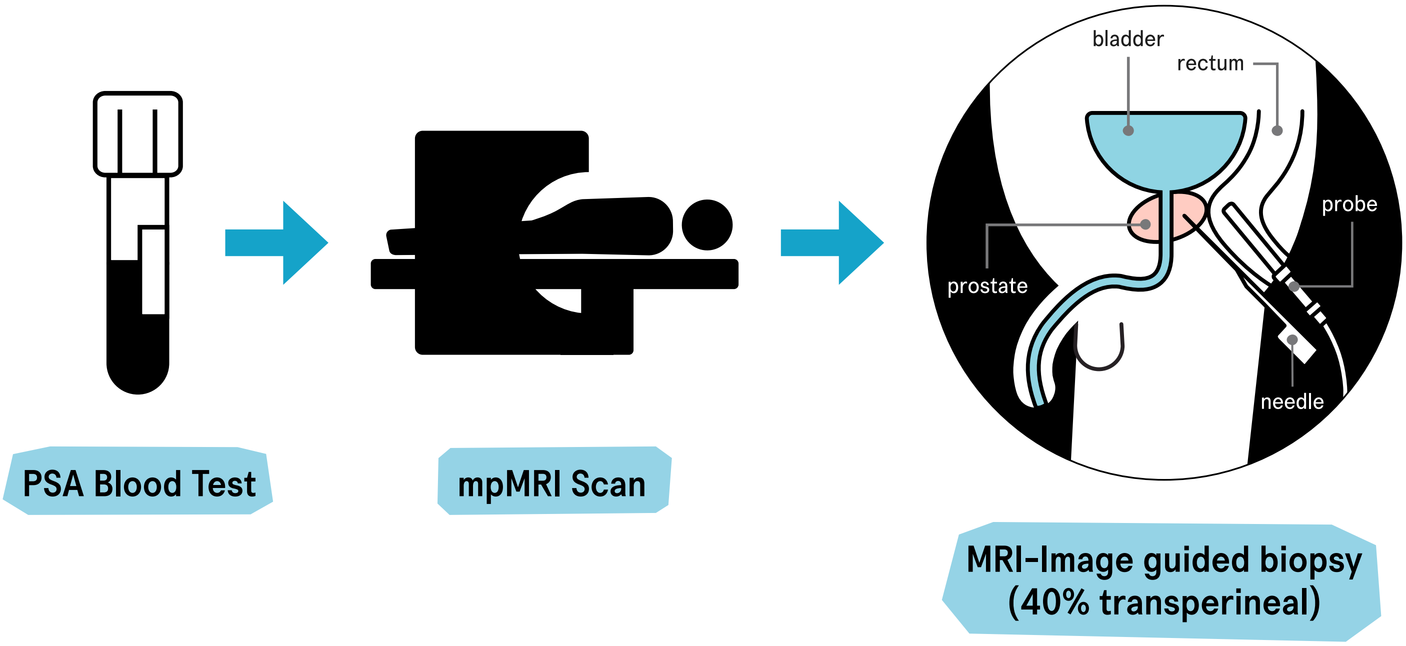
Three ways to address health inequalities

In areas where there is high deprivation and Black communities, we know that health outcomes are poorer for men. One barrier which we hear about regularly is that asymptomatic men are being refused PSA blood tests by their GP, despite being aware of their risk, and the pros and cons of the PSA blood test. To address this, we're sharing with you 3 ways in which health inequalities can be tackled through education, access to health care and awareness raising.

1. Harm to men has reduced

Many primary care GPs are unaware that there are significant changes to the diagnostic pathway for patients referred into secondary care.

- Men now receive a scan and then go onto have a biopsy. This change has resulted in more than 30% of men dropping out of the pathway at the first test avoiding an unnecessary biopsy
- The way that men are given a biopsy has changed as well in line with **NICE recommendations** in January 2023. Many regions are now conducting trans perineal biopsies instead of trans rectal biopsies, reducing the risk of sepsis
- **These changes equate to a reduction in harm to men risk**.



2. Ensure healthcare is accessible to all

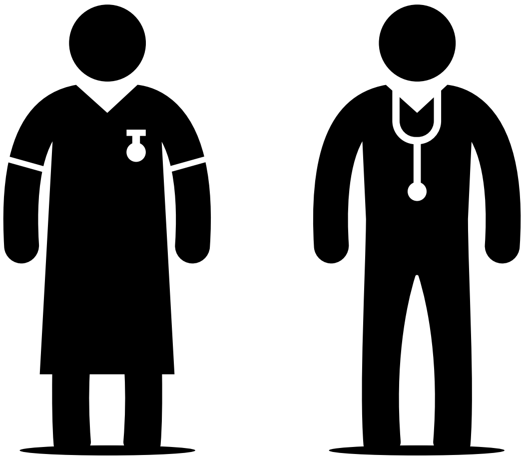
It’s important that healthcare workers remove as many barriers to diagnosis as possible enabling **improvements to effective population health management** as specified within the **DES**.

- This means that whether admin staff are triaging calls with asymptomatic men, or GPs are having conversations with their patients, it is important that they don’t become blockers to men accessing PSA blood tests
- *Men should be able to access these tests if they have made this informed decision*, particularly if they are Black or have a family history due to their higher risk

3. Build trust in disconnected communities

DES2.0.1: asks PCNs to collaborate with non-GP providers, as part of an integrated neighbourhood team, to provide better joined up care. This approach, will begin to engage and build trust in communities which may have had poor experiences in accessing adequate healthcare and ultimately, help to improve health outcomes for your patients.

- Find **our resource** on setting up a project on engaging with Black communities as well as our **publications**
- **Get in touch with us** or our **Education team** team to discuss CPD education packages and opportunities to train non-HCPs as well as VTSs on risk awareness
- Our **Black Health Equity and Engagement team**, attend events organised by community/ groups that engage with their different Black communities on risk awareness. They will provide resources and assess attendance for large scale/high impact events.



Five things to say to your patients

Apart from informing men about their risk, there are a number of other conversations you can be having with your patients. We commissioned research in 2023 to understand people's knowledge on prostate cancer and **barriers to action**. We found there are a number of ***assumptions that men are making on this subject***, this should be addressed urgently with facts.

1. Digital rectal examination

One of the biggest issues that we found, was around the digital rectal examination. 3 out of 5 men, told us that they'd be concerned about having "the finger up the bum" and that this was one of the biggest barriers for them to go to their GP to talk about their prostate health. We found that this changed when men were told that the first step to being diagnosed is with the PSA **blood** test.

We're aware that in some areas, a rectal exam may occur if PSA readings are high. We'd recommend reviewing your use of the DRE as per **GIRFT guidance** and our article in the **British Journal of General Practioners**, provides more detail on its use as a screening tool. Men should be made aware that they can refuse having this test if they wish.

Action:

1. Review your use of the DRE if it's in place in your area as per GIRFT guidance.
2. Order and provide men at risk information with our z cards on prostate cancer and what the PSA blood test is.
3. Create a notice board with information about the prostate, PSA blood tests and order our risk awareness posters highlighting the prevalence of 1 in 8 / 1 in 4 risk for White/Black men.
4. Organise a community event with grass root charities, ensuring clinical staff attend to share/support this messaging to at risk groups and to help enlist trusted members of Black/local communities to pass on the messaging.

2. PSA blood test

Letting men know that the first test to help them understand their prostate health is a simple **PSA blood test** is a great way of addressing the misconceptions that the first and only test is the digital rectal exam. Furthermore, the current Prostate Cancer Risk Management Programme unintentionally promotes and widens health inequalities due to the limitations placed upon GPs.

Action:

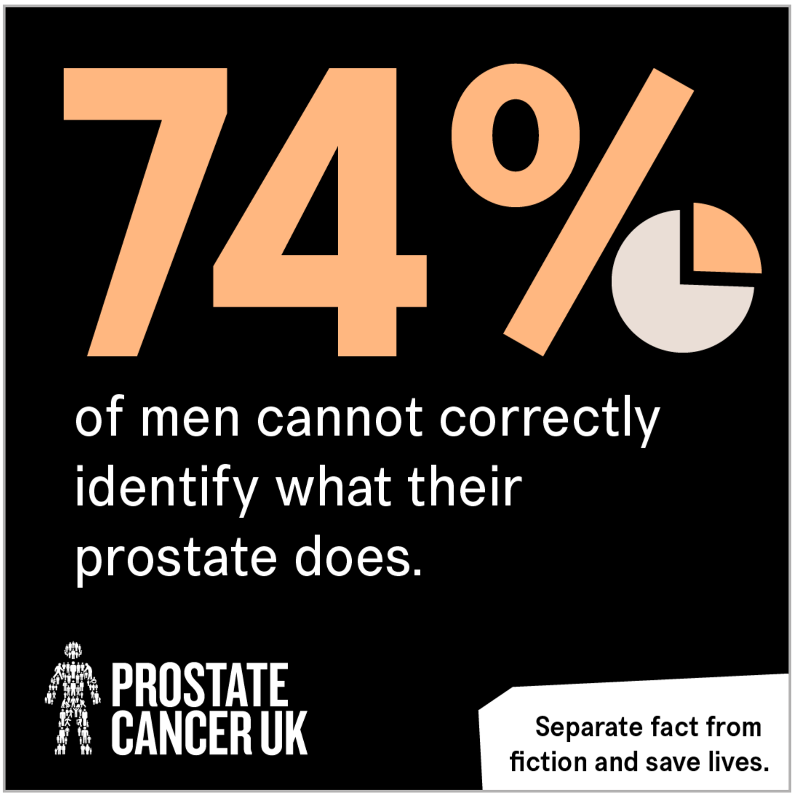
1. Let men at risk know about their risk and that the first test is a simple blood test.
2. Ensure that your staff talk about the PSA blood test and promote its use as a term to be adopted by your clinical and admin staff when talking to men about what the test is.
3. Avoid using scary language that includes number of deaths – our behavioural insights showed that this creates anxiety and stops men from taking action.

3. Low knowledge levels

Prostate cancer is the most common cancer in men with 1 in 8 men being diagnosed with it and for Black men, this doubles to 1 in 4. Through our research, we found that 74% of men couldn't identify what their prostate does. This lack of knowledge about the prostate needs to be addressed and NHS stakeholders should be proactive in providing accurate information so that men are able to make informed choices about their prostate health.

Action:

1. Order and provide men aged 50+ with information , such as our quick guide on prostate cancer and what the PSA blood test is.
2. Organise a health awareness event, in your areas of deprivation, with local grass roots charities targeting populations where health inequalities exist. Provide information, including on prostate cancer risk to improve population health outcomes.



74% of men cannot correctly identify what their prostate does.

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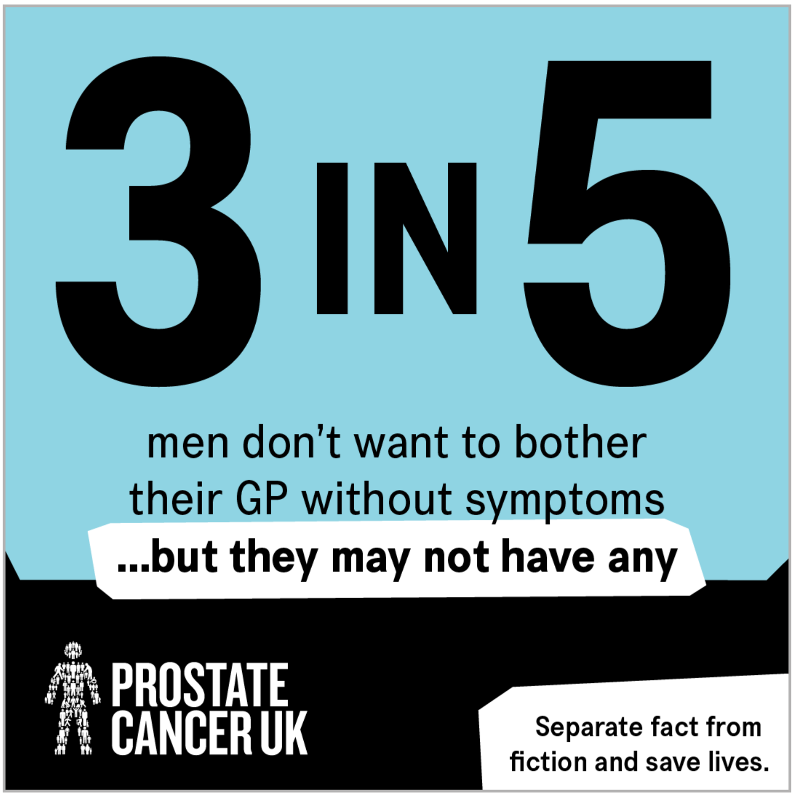
Separate fact from fiction and save lives.

4. Focus on symptoms



Messaging about many cancers focuses on symptoms and for patients to be vigilant for things like blood in their wee, a persistent cough and so on. However, we know that for prostate cancer and earlier diagnosis, a focus on symptoms is not always helpful.

This is why we advocate that men should be aware of their risk and can make informed decisions about whether they want to have a PSA blood test or not. We found that 3 in 5 men won't bother their GP if they don't have symptoms. A shift in approach needs to happen to ensure that men are aware of their risk. The messaging here needs to be clear, they should not wait for symptoms to speak to their GP.

Action:

1. Have proactive conversations with men at high risk about their prostate cancer risk and let them know about the PSA blood test.
2. Order **our resources** to provide to these men.

5. I'll be invited to have a test

Our research, in 2023, found that 1 in 2 men believed that they would be invited to have a test if they were at risk. We can assume from this that these men will therefore not be proactive with their health seeking behaviours. This is a concern, since we know that those who only seek medical advice when/if they start having symptoms could affect stage of diagnosis, treatment choices and survival rates.

Action:

1. HCPs have proactive conversations with at-risk men about their risk levels. Also, give men the option of having a PSA blood test if they are concerned once they have received information about the pros and cons of the test in a balanced, non-biased way.

TRANSFORM screening trial

Our **TRANSFORM** screening study is a large-scale, national trial involving more than 300,000 men, investigating different screening approaches for prostate cancer. It will produce the definitive evidence needed to support a prostate cancer screening programme in the UK. Our recruitment to TRANSFORM will begin in 2025 and part of this set up involves identifying suitable primary and secondary care sites across the UK to take part in the study.

If you're interested in finding out more about how to get involved, **please get in touch**.

Service delivery

It's important to note the concern and anxiety from GPs and secondary care consultants about the impact that awareness raising will have on the capacity of primary or secondary care. We've worked with over 100 PCNs nationally over the past couple of years and can confidently report that primary care colleagues did not experience surges in referrals and that neither primary nor secondary care were overloaded with men wanting to be tested/needing to go on for further tests. In fact, we found that adopting a risk stratified approach targeted the right people and found numerous men who were asymptomatic to be diagnosed with prostate cancer.

Step 1: Set up

1. Discuss the approach that your primary care/project team will adopt to raise awareness about prostate cancer risk. For instance, how you will have conversations with men, set up Saturday morning health clinics offering PSA tests as well as other health checks, flag men at risk, community engagement etc. Use this toolkit to help define outputs, metrics and evaluation.
2. Work out who will lead on your earlier diagnosis/health inequalities work –a clinical lead / cancer champion / an admin member of staff and who you want to collaborate with externally.
3. Once you've decided who'll do this work, let staff know that men without symptoms may start contacting the surgery asking about the PSA blood test or to speak to a GP, ensuring that they have access to a GP/PSA blood test if that is what they want.

Step 2: Gather your data & audit

Your next step is to conduct an audit on how many of your patients fall within the risk categories. We'd recommend prioritising the below in this order based on their risk.

1. Black men aged 45-69
2. Men with a family history of prostate, breast, or ovarian cancer aged 45-69
3. Men aged 50-69

Men should be excluded if they:

- Have a diagnosis of prostate cancer
- Have had a PSA blood test within the last 12-months
- Are on an end-of-life / palliative care pathway

We would recommend that when considering searching for your patients who are Black men, the below ethnic categories are used. We also provide some SNOMED ethnicity codes in the appendices.

ETHNIC CATEGORY ID	**ETHNIC GROUP**	**ETHNIC CATEGORY LABEL**
D	Mixed	White & Black Caribbean
E	Mixed	White & Black African
M	Black	Caribbean
N	Black	Caribbean
P	Black	Any other Black background

Request resources

If you're interested in getting your own specific trackable risk checker link, then please **contact us**. All we need to know is the name of your surgery/PCN.

We have a number of resources that you can order for events / handing to patients. Please see **our website** for more information. for more information.

Action I'd like to request risk checker link

Step 3: Conversations

- Admin staff identify these patients whilst booking their appointments and create an alert for the GP/ health care professional (HCP) pre-appointment.
- GPs/ HCPs can use the below to help structure a very brief conversation:

"We are speaking to men at higher risk to prostate cancer, so that we can provide information about their potential risk. These are men who are over 45 and are Black / have a family history of prostate cancer and men over 50. Would you like to speak to someone in the surgery about this?"

- If your patient wants information, then after you've checked their mobile number, you can share your risk checker link and resources
- Record that you've had this conversation and what the outcome of the conversation was. You can either create your own unique SNOMED code or use the below. This will help, when you come to evaluate the impact of this work.

Opportunistic patient review (procedure)

SCTID: 918771000000104

918771000000104 | Opportunistic patient review (procedure)

What's worked well nationally

There are a number of pilot programmes that have given men at risk easier access to trained healthcare professionals so that they can discuss their prostate cancer risk and have access to the PSA blood test

National projects

- Bristol and London primary care prostate cancer case finding – **British Journal Of General Practice (2024)**
- Prostate cancer case finding project – **Surrey and Sussex Cancer Alliance**
- Improving access to specialists and tests – **University Hospital Southampton**
- Man in Van project – **Greater Manchester Cancer Alliance**
- Man in Van project – **Royal Marsden Cancer Alliance**.

Further innovations

We've also worked with health stakeholders nationally and have showcased these projects in online innovation events with talks from the clinical/cancer/project leads.

- **Health inequalities** – Learn what different areas are doing to tackle health inequalities and finding men at risk of prostate cancer
- **National projects on how to reach men at risk** including our Bristol pilot
- **Innovative projects from PCNs about their risk awareness activities**

Evaluation

There are a couple of ways in which you will be able to measure the impact of your work:

1. Use the above SNOMED code and complete an audit in 6 months' time, to review the number of conversations had with men at risk.
2. Further evaluation can include the number of PSA tests completed, number of Faster Diagnosis referrals made and number of diagnoses.

Risk checker data – if we've created a bespoke URL for your work, we'll be able to tell you the number of risk checker completions, number of men who are in the three risk categories and if they have made an informed decision about their health.

Resource and Guidance

We've a number of resources to support primary care health care professionals. Please let us know if there is anything that you'd like, and we can have a conversation about how to develop this.

Resources

Education resources for GPs

Register for our **online education** for HCPs

GIRFT Guidance 2024

Impact and evaluation report on DES on prostate cancer 2022 -2024

Counselling men on pros and cons of PSA blood test

Risk awareness postcards

GP guidance for men without symptoms

NHS GP Guidance Prostate Cancer Risk Management Programme (PCRMP)

NHS Information sheet for men (PCRMP)

NICE guidance for men with symptoms

NICE NG12 Guidance on symptomatic men

Other useful documents

Our GP guidance for asymptomatic and symptomatic men

Explaining your faster diagnosis referral to patients

Order material for noticeboard/reception/surgery

Are you at risk poster

Display box with quick guide: Know your prostate and PSA blood test

Display box with quick guide: Prostate Cancer and Information for Black Men

Awareness bundle pack

If you want to order in bulk, then you will need to register/sign in

Get in touch via email

Project support - risk awareness, health inequalities, earlier diagnosis, data requests.

Educational support – find out about courses, CPD, training for VTSs, resources.

Black Health Equity and Engagement - if organising an event that's engaging with your Black communities.

Appendices

Ethnicity SNOMED Codes

Country	England 2011 census (finding)	Wales 2011 census (finding)	Scotland 2011 census (finding)	Northern Ireland 2011 census (finding)
Ethnicity	Black or African or Caribbean or Black British: other Black or African or Caribbean background	Black or African or Caribbean or Black British: other Black or African or Caribbean background	Caribbean or Black: any other Black or Caribbean group	Black or African or Caribbean or Black British: other Black or African or Caribbean background
Code	SCTID: 977831000000109	SCTID: 976931000000109	SCTID: 978361000000101	SCTID: 977831000000102
Ethnicity	Mixed multiple ethnic groups: White and Black Caribbean	Mixed multiple ethnic groups: White and Black Caribbean	No coding provided for Scotland	Mixed multiple ethnic groups: White and Black Caribbean
Code	SCTID: 976711000000103	SCTID: 976711000000103		CTID: 977391000000108
Ethnicity	Mixed multiple ethnic groups: White and Black African	Mixed multiple ethnic groups: White and Black African	No coding provided for Scotland	Mixed multiple ethnic groups: White and Black African
Code	SCTID: 976731000000106	SCTID: 976731000000106		SCTID: 977411000000108

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