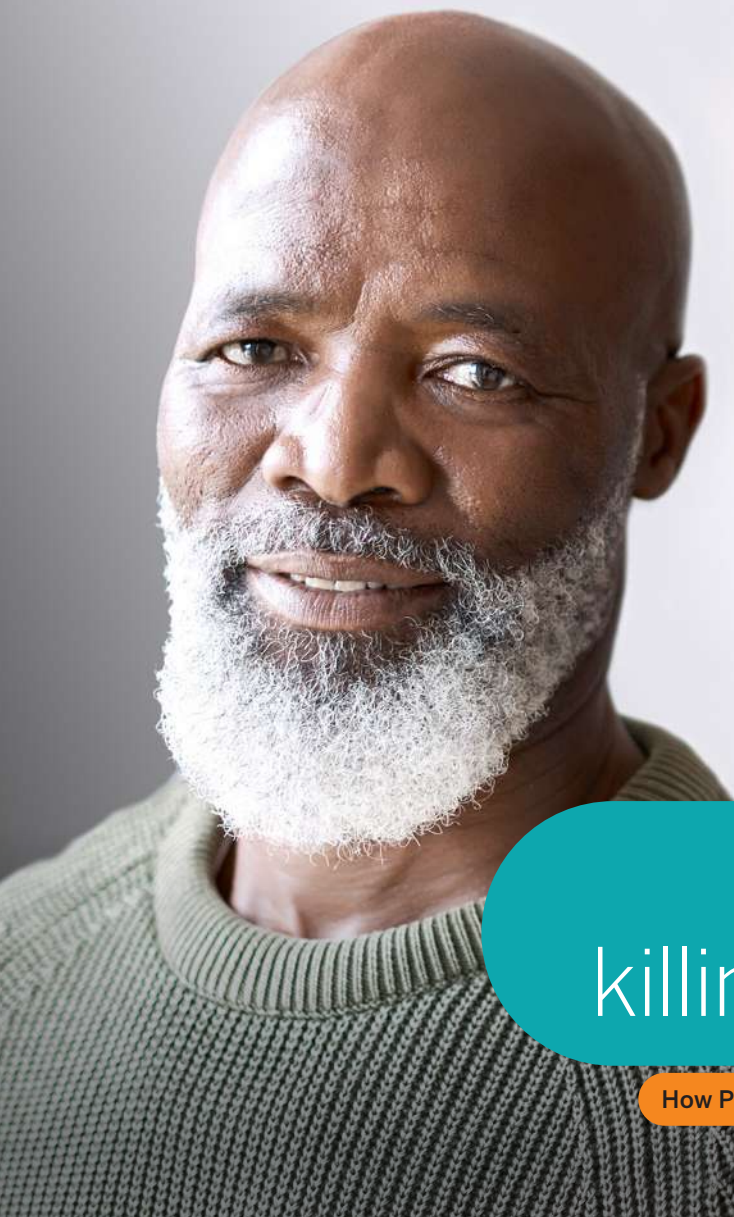




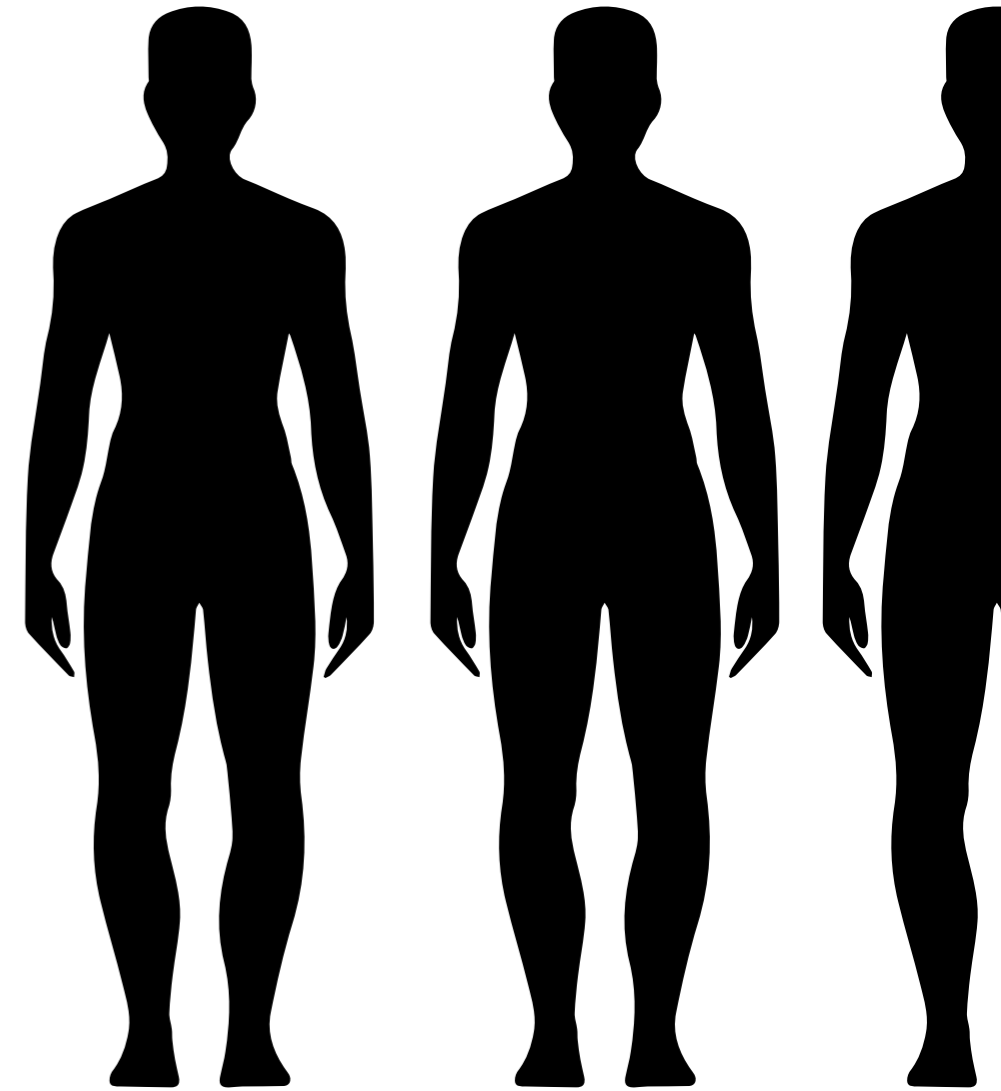
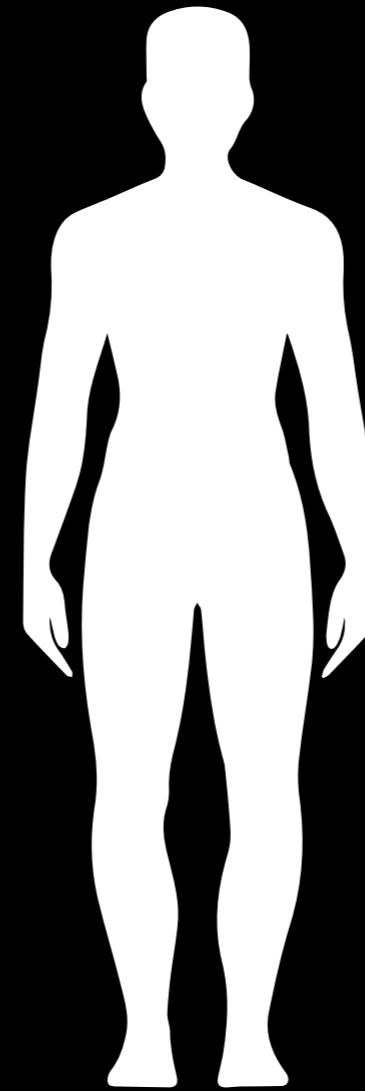
Prostate
Cancer
Research

pccr.org.uk



Prostate cancer is killing more Black men

How PCR is tackling inequality for Black men with prostate cancer: 2024



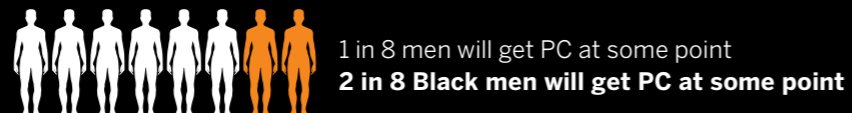
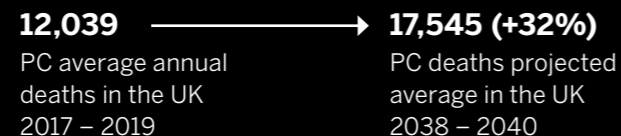
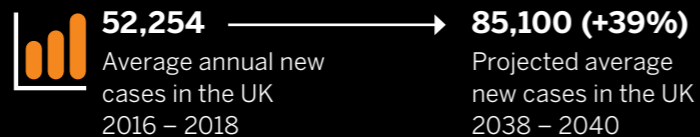
Black men are 2.5 times more likely to die from prostate cancer than white men



The black & white facts

The statistics for prostate cancer (PC) in the UK are alarming, and for Black men they are dangerously biased.

+ PC is the most common cancer in men in the UK
PC is the second most common cause of cancer death in men



4 key areas of under-service



Differences in care

Black people believe that the government is doing the least to tackle health inequality, with just 47% of respondents believing they would get the same care as a white person from the NHS.



Testing

1 in 3 respondents believed discrimination had stopped them from getting tested or treated for any medical problem, with 25% believing discrimination has stopped them being tested for prostate cancer.



Representation in research

84% of Black people believe there should be more medical research including Black people, with 83% of agreeing more Black people should take part in medical research and 73% believing that things will only improve if more Black people take part in medical research.



Support

Across all age groups and regions, Black people consistently believe that if they were to get cancer they would get support from their family (80% Black woman and 74% of Black men), with 63% believing they would get support from the NHS (62% Black women and 64% Black men).

A unique poll on Black people and their thoughts on prostate cancer

Survey responses

While there's plenty of evidence for healthcare disparities in data, we don't know enough about what the community thinks. So, we asked them.

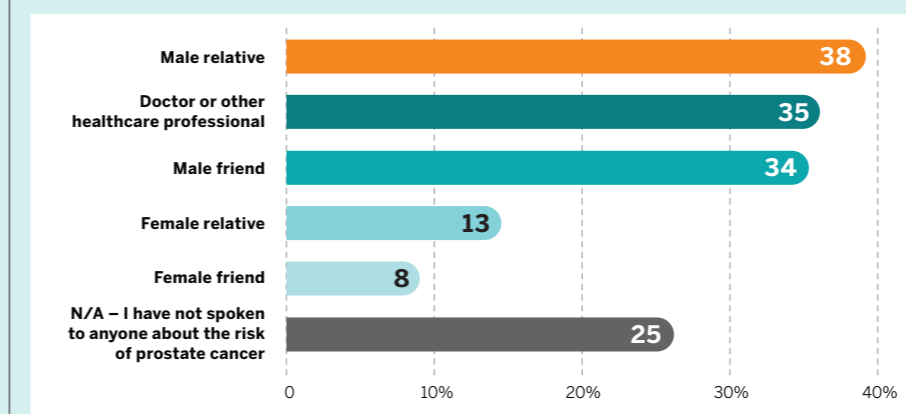


OUR SURVEY

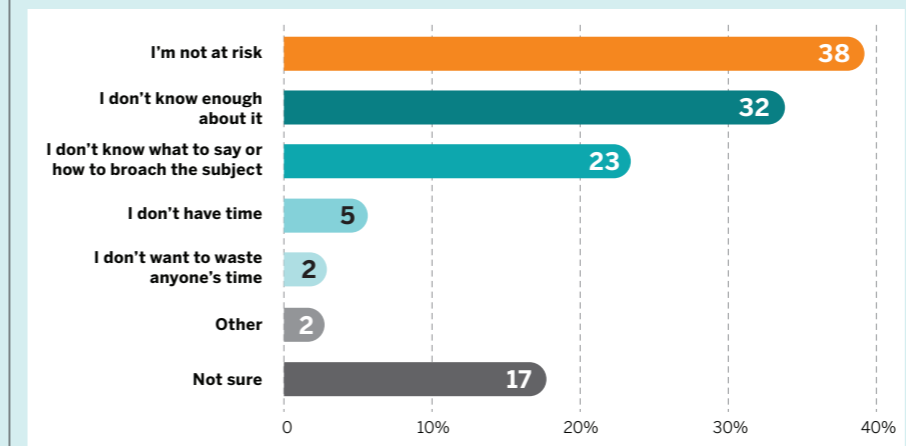
Commissioned OnePoll – the trusted voice in market research
 14-27 March 2024
 Polled 2,000 Black adults living in the UK
 50:50 split between men and women

Why men don't talk

Q: Whom, if any, of the following have you spoken to about the risk of prostate cancer



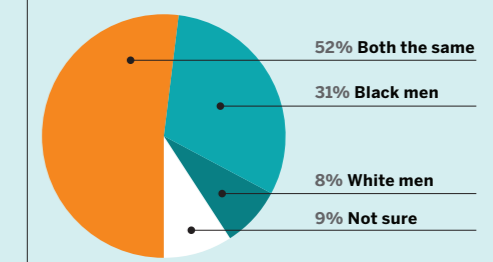
Q: Why have you not spoken to anyone about the risk of prostate cancer?



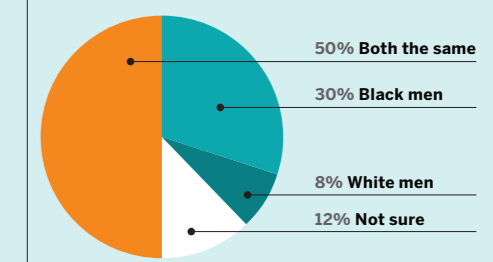
Key insight
 Positively, 64% of Black men would be comfortable discussing prostate health. However, not knowing enough about it or what to say are preventing lifesaving conversations.

Most Black men don't know their risk level

Q: Who do you think is more likely to get prostate cancer?



Q: Who do you think is more likely to die from prostate cancer?



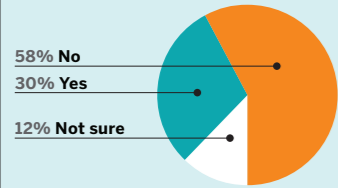
Key insight
 Less than one in three members of the Black community are aware that Black men are at double the risk from prostate cancer.

Read about our initiatives:

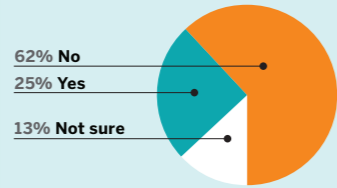
- Real Talk campaign to raise awareness and reduce stigma, pages 22-23
- Our patient platform, the infopool, pages 18-19

Concerns about racial issues and discrimination

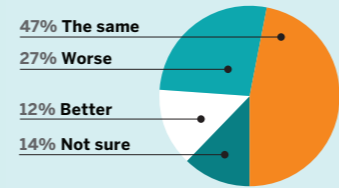
Q: Do you believe racial discrimination has stopped you/a loved one from getting tested or treated for a medical problem/illness?



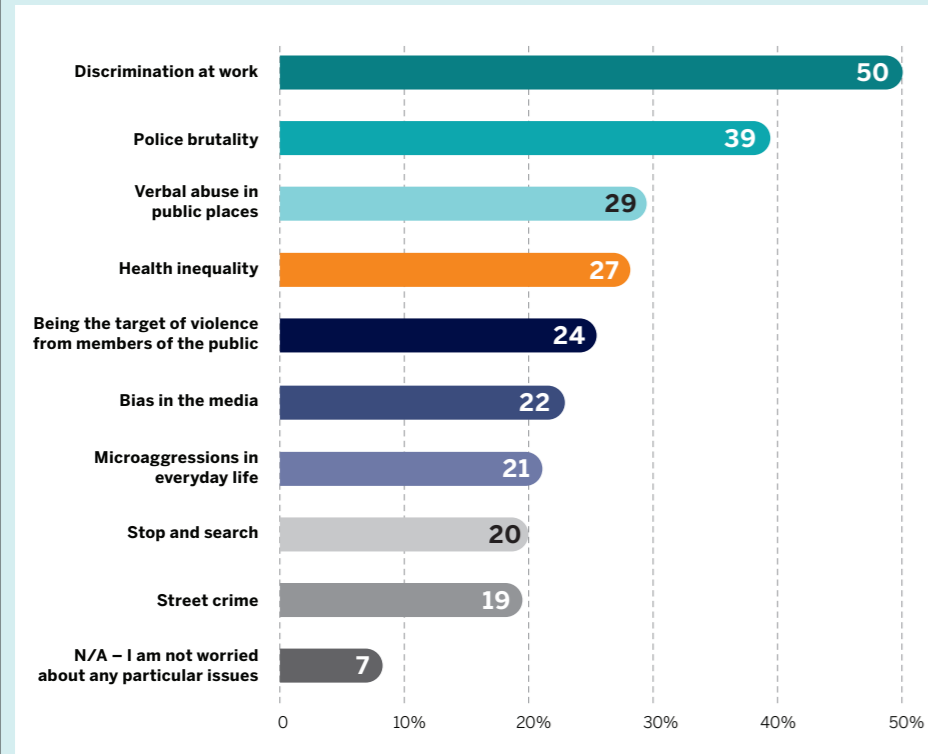
Q: Do you believe racial discrimination has stopped you/a loved one from being routinely screened for prostate cancer?



Q: Compared to a white person, do you believe that the care you will receive from the NHS will be...



Q: As a Black person, what are the racial issues that you most worry about?

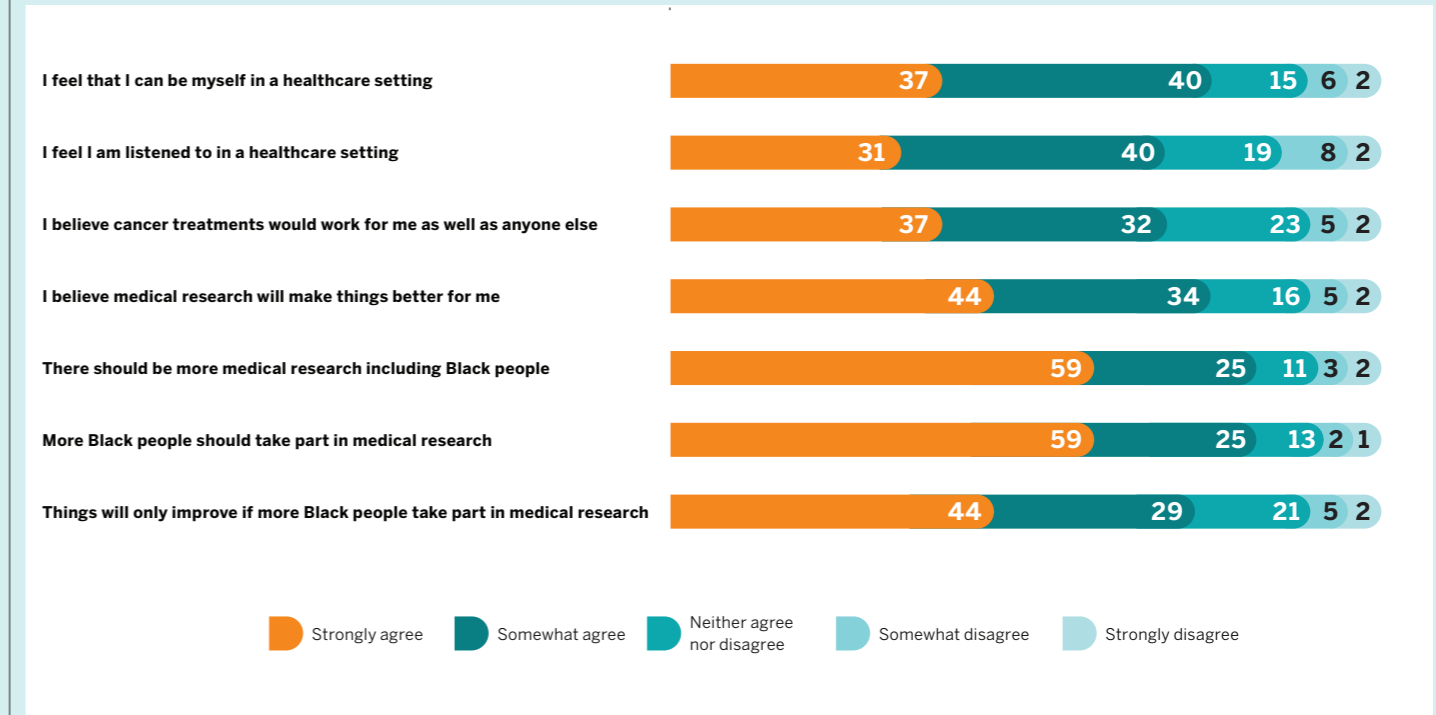


Key insight

Health inequalities are just one of a number of racial issues the Black community in the UK has to contend with, but racism in healthcare is a serious concern.

Feelings on healthcare and medical research

Q: To what extent do you agree or disagree with the following statements?



Key insight

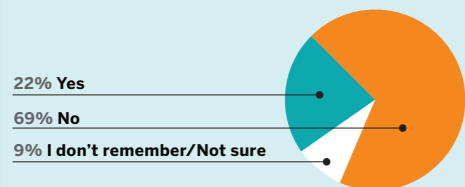
The majority of the Black community believe in the power of research, especially if there is more medical research involving Black people and more Black people take part in research.

Read about our initiatives to solve these issues:

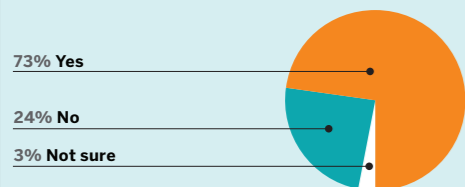
- Our research projects to tackle racial inequalities, pages 16-17
- Our patient data platform, Prostate Progress, pages 20-21
- Our cross-departmental initiative to build trust and equity in healthcare, pages 24-25

Getting tested for prostate cancer

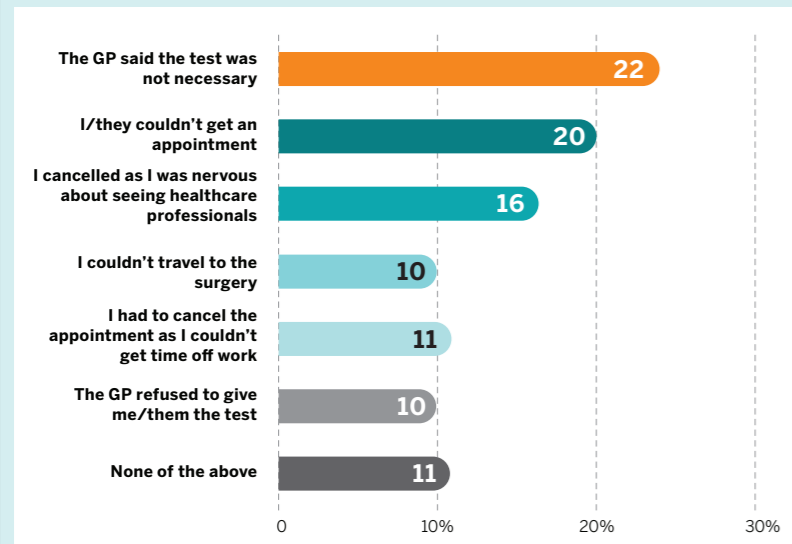
Q: In the past year, have you or a loved one requested a prostate cancer test at your GP?



Q: Did you or your loved one have a prostate cancer test?



Q: Why did you or your loved one not have the prostate cancer test?



Key insight

Almost 1 in 4 members of the community who requested a prostate cancer test over the past year were not able to get one. Many experienced barriers at their GP.

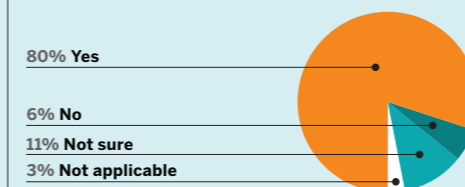


Screening for prostate cancer

Q: Regarding prostate cancer specifically, would you be willing to get tested?



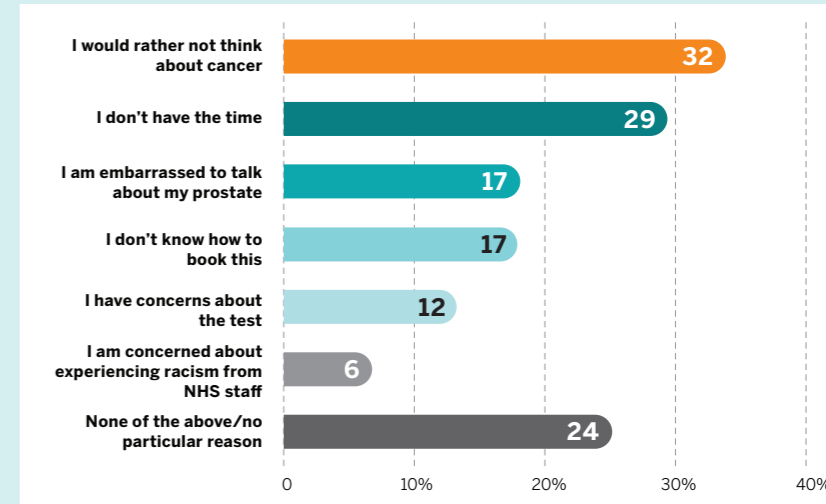
Q: If there was a national prostate cancer screening programme for Black men would you go for screening or encourage your loved one(s) to go for screening?



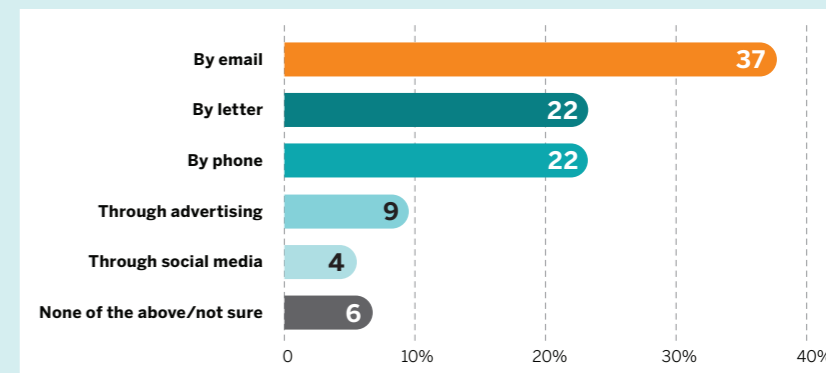
Key insight

A prostate cancer screening programme for the Black community would be welcomed. Read about our campaign to get a national screening programme for Black men as high risk individuals, page 26.

Q: Why would you not be willing to get tested for prostate cancer?



Q: If there was a national prostate screening programme for Black men, how would you prefer to be invited to take part?



A combination of biology, societal factors, and a lack of targeted research and action mean that Black men face greater risks from prostate cancer.

The scale of the problem

Prostate cancer is the most common cancer in the UK, claiming the life of one man every 45 minutes, and bringing side effects which severely impact quality of life. Alarming, that looks to get worse if action is not taken: a staggering **32% rise in prostate cancer fatalities is projected by 2038 – 2040**.

The cost of treating prostate cancer is rising more rapidly than the cost of treating any other cancer; estimated at **£320M annually in the UK**.

Black men face twice the risk of getting prostate cancer and 2.5 times the risk of dying from it than white men. They are also diagnosed younger, in a world where the majority of treatments and diagnostics have been designed based on data from white men, and in which the health of Black men can also be affected by factors such as: entrenched racism, barriers in accessing care, economic injustice, nutrition, and education.

Black men's health and lives are in danger due to things that no individual can solve, they need interventions at a wider scale. **Solving this problem solves one of the greatest disparities seen in any cancer.**

Why PCR?

We are pushing boundaries.

We aren't afraid of change and are willing to change the way things are done internally and across the medical research sector.



Unprecedented

Supporting new ideas and early career scientists



Ground breaking

Identifying new ways to provide and utilise health information



Trusted partner

with patients, communities, charities, NHS and pharma

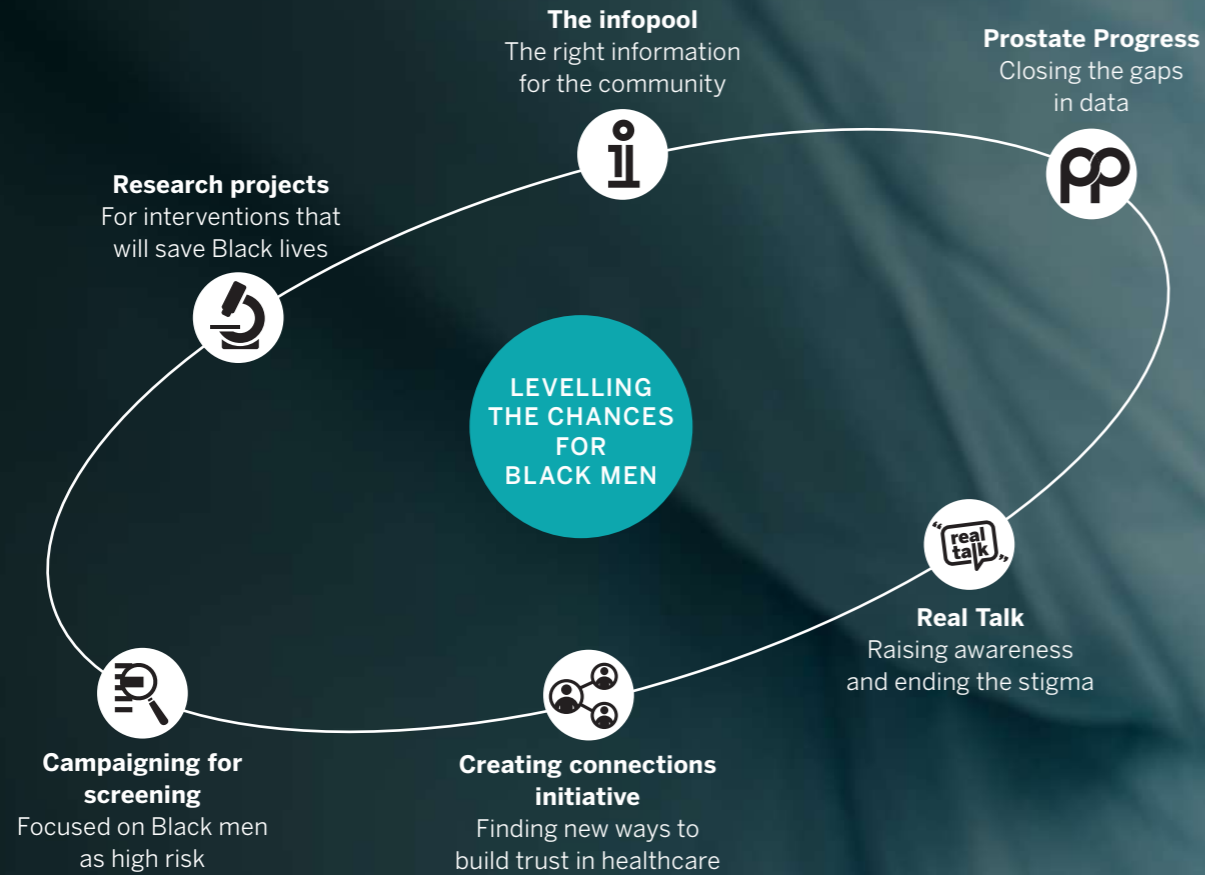


Influencing

Voicing the needs of research for diversity and advanced stages

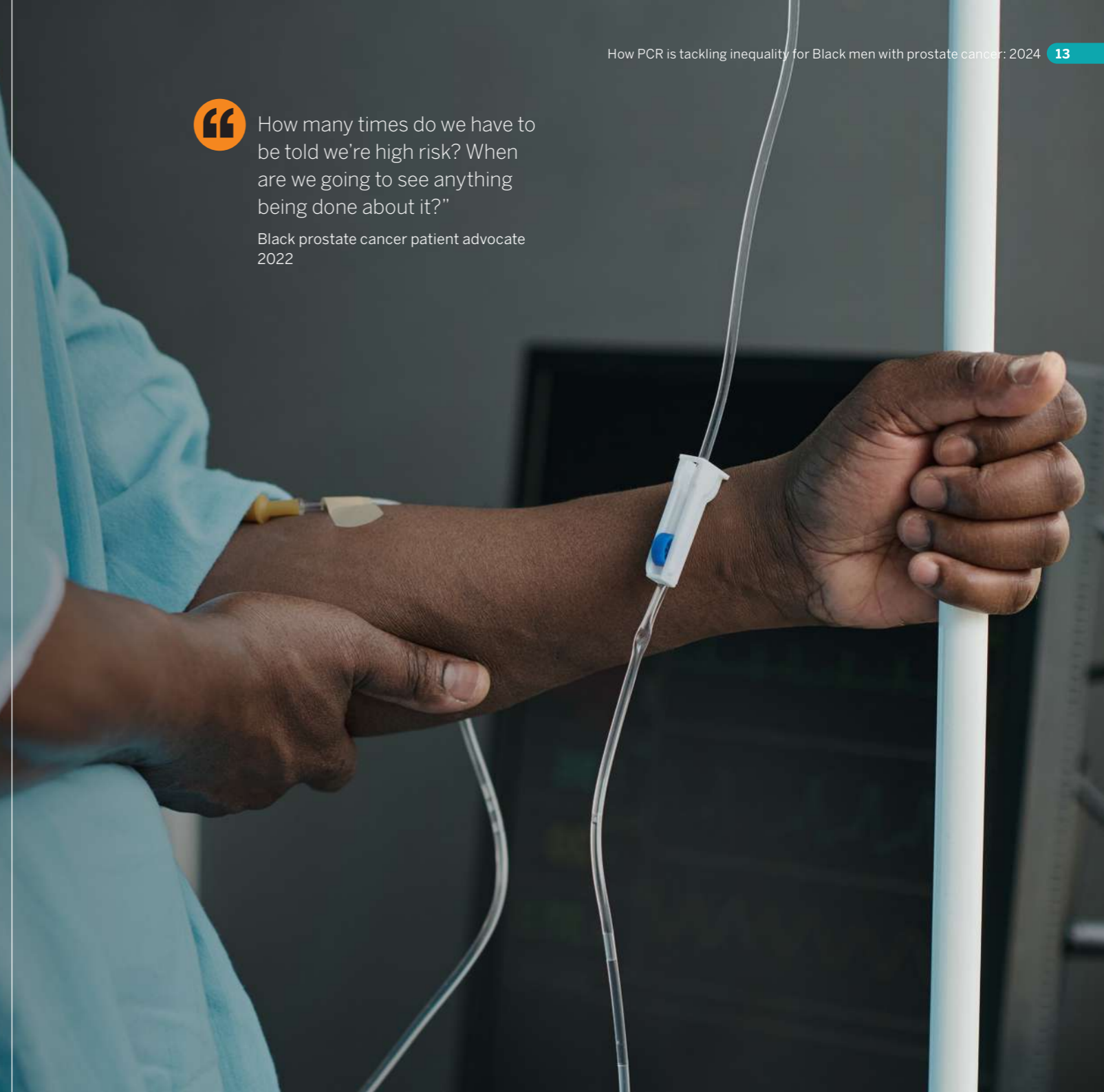


Our 6 initiatives to level the chances for Black men



“How many times do we have to be told we’re high risk? When are we going to see anything being done about it?”

Black prostate cancer patient advocate 2022



Our impact targets

THE WIDER BENEFITS



LEVELLED CHANCES FOR BLACK MEN



Better use of preventative healthcare

- Increased early detection
- Reduced incidence and severity of the co-morbidities which reduce PC survival and quality of life



Avoiding the danger of misinformation

- Increased use of beneficial therapies and supports
- More empowerment and shared decision-making
- Reduced harms from non-medical routes



Full benefit from existing therapies

- More benefit from increased treatment adherence
- 50% of people do not take medications according to its intended use



Representation in research

- More knowledge about how the disease works in Black people
- Treatments and diagnostics that work, with better understood side effects



Improved overall health and healthier ageing

Through better use of preventative health



More equity

6% of health inequity could be solved by increasing trust



Increased social cohesion

WHO states that health inequity is a threat to political stability and the wellbeing of the entire population



Economic benefits

Preventing financial costs associated with poor health and lack of trust



Transferable strategies

To other communities experiencing health disparities and other conditions in which disparities exist

Be part of the change

We are committed to developing innovative and effective solutions to the challenges that patients face and maximising our impact for the people to whom it matters most. If you would like discuss how we can work together, we would love to hear from you.





Research projects tackling racial inequalities

pcr.org.uk/our-research



Charity Times Awards judges praised this work for its design, execution, and likely global impact

The striking racial disparities in prostate cancer exist in a world where the majority of treatments and diagnostics have been designed based on data from white men, and in which the health of Black men can also be affected by factors such as entrenched racism, barriers in accessing care, and socioeconomic disparities.

Harnessing the power of research, we responded to this challenge not with words, but with targeted action at a level that could change the paradigm.

We created the UK's first prostate cancer-specific research programme designed purely to tackle the racial disparity in the diagnosis, treatment, and care of prostate cancer.

In 2022, we launched eight new projects. Some of these have already delivered results, including:

- Genetic changes that may explain Black men's higher risk (featured in The Guardian)
- The development of a community initiative which has already resulted in Black men registering with GPs and going for tests (featured in Nature Careers)
- Evidence that health systems-focused interventions (transportation, social support) can narrow disparities in prostate cancer



£1M invested so far with new research funding planned in 2024



I saw this and felt like I had won the lottery.

Black prostate cancer patient's reaction to our research programme



Read more > our research

Our ongoing research projects take a range of approaches to close this disparity, all the way from developing more representative lab-based tests and investigating biology, to developing treatments to target the genetic differences that make this disease so prevalent in the Black population. Thanks to this research programme, we also now have a greater and growing understanding of how to work with a community to ensure social barriers do not lead to more deaths. Since we launched our projects, we have:

- Spoken at charity conferences to share our learnings
- Given advice on best practice to charities, international consultancies, and civil servants
- Submitted evidence to the All-Party Parliamentary Group on medical research to showcase the role of research in tackling disparities

We have so far invested over £1 million of research funding into tackling this disparity, and will be calling for more racial disparities research proposals in the autumn of 2024. **Science makes advances. Our targeted research makes sure everyone benefits from them.**

OUR RESEARCH PROJECTS



Tackling barriers to early diagnosis of prostate cancer for Black men
Dr Floor Christie-de Jong, Professor Jonathan Ling, Dr Judith Eberhardt, Dr Marie Kotzur, Dr Olugbenga Samuel Oyenyi, Professor Katie Robb, John Kabuye
 UNIVERSITY OF SUNDERLAND
 UNIVERSITY OF GLASGOW



Genetic test for prostate cancer in Black men
Prof Dmitri Pshezhetskiy
 UNIVERSITY OF EAST ANGLIA



Identifying Black men at increased risk of developing prostate cancer
Dr Greg Brooke, Dr Antonio Marco, Dr Ana-Maria Dumitrana
 UNIVERSITY OF ESSEX



Treatment and Adherence Support for Minorities (TRANSFORM)
Prof Robert Horne, Dr Jonathan Shamash, Dr Zoe Moon, Dr Kenrick Ng, Dr Edward Christopher Dee
 UNIVERSITY COLLEGE LONDON
 MEMORIAL SLOAN KETTERING CANCER CENTRE



Reducing prostate cancer disparities via novel targeted therapy
Dr Xin Li, Alira Danaher, Nicholas Cook
 CLARK ATLANTA UNIVERSITY



Reducing barriers to screening in Black men with prostate cancer
Prof Timothy Rebbeck, Prof Hari Iyer, Dr Charlie Roscoe, Mingchao He, Chidinma Opara
 DANA FARBER CANCER INSTITUTE
 HARVARD
 RUTGERS INSTITUTE NEW JERSEY



Discovering genetic drivers of prostate cancer in Black men
Dr Panagiotis Katsonis, Dr. Deyana Lewis, Dr. Lesley Chapman Hannah
 BAYLOR COLLEGE OF MEDICINE



Linking the immune system to prostate cancer disparities
Dr Geou-Yarh (Stancy) Liou
 CLARK ATLANTA UNIVERSITY

The infopool the patient resource

theinfopool.co.uk

While there is a wealth of written information on cancer out there, it's not suitable for everyone, and pre-existing information rarely addressed the needs of the Black community.

"I opened the brochure; I didn't see one Black man in it. I closed it. This was obviously not information that was relevant for me."

We at Prostate Cancer Research have developed a ground-breaking platform, the infopool.

The infopool provides clear, easy-to-understand information on testing, treatment, side-effects and clinical trials in a mixture of formats, including animations, infographics, cartoon-style strips and real world stories, designed to work for people who feel overwhelmed by their diagnosis, and for the half of the population who have low health literacy. Health literacy is about a person's ability to understand and use information to make decisions about their health. Low health literacy increases cancer mortality and is also associated with increased visits to A&E, increased hospital stays, and people less likely to take medication as recommended, placing huge strain on the individual and on the system.

The infopool was co-designed with members of the community, is culturally representative, and includes experiences from a diverse and inclusive community.

"I feel that by sharing my story I could be helping other people and that in a way is helping me."

Crucially, the infopool centres real people talking about the impact of decisions they have made, including what it's like to live with the effects of different treatments. We believe integrating filterable stories from people who look and sound like those watching and reading them, is a revolutionary way of educating and empowering the hardly reached groups: Black men and people with low health literacy. It also helps ease the burden on the NHS by empowering people with prostate cancer to have better conversations with healthcare professionals, reducing the need for follow-up.



It is the best thing out there because it's got more things related to Black men across different aspects of prostate cancer, than any other tool.

Donald
Black prostate cancer patient

INFOPOOL STATS

- 125,000+ users
- 87% satisfaction rating
- 1,000+ patient stories
- 150+ UK hospitals signposting patients



Making it easy to find a clinical trial

Black representation in clinical trials has always been low. This is a double blow; clinical trials need to be representative to make sure treatments and diagnostics work for everyone, and clinical trials can be the first chance patients have to access new and cutting-edge new treatments.

One of the ways we're working to address that is through our free clinical trial finder, which makes it easier to find, learn about and ultimately join a clinical trial. We connect people to UK clinical trials in four easy steps, allowing them to find personalised clinical trial recommendations within two minutes. We provide support and clear, simple information all along the way to the patient enrolling, or choosing not to.



The infopool will be of value to all men but particularly to Black men and their families... The infopool will help them come to terms with their own diagnosis, understand more about their treatment choices and give them pointers to what the future may hold for them.

Professor Frank Chinegwundoh MBE
Consultant Urological Surgeon
Barts Health NHS Trust



Read more >
the infopool



pp Prostate Progress
our patient data platform
prostateprogress.org



This year, we launched Prostate Progress, a first of its kind prostate cancer patient data platform and virtual registry.

Everyone tells us that there's data, but that accessing it, and linking it up, is a problem.

- Patients tell us they want to give access to their data so their experiences can better inform research and to play an active role
- Researchers tell us the lack of access to data dramatically slows research
- Clinicians tell us that flow of data between NHS providers needs to be improved for patient care
- Industry tell us they want speedier access to data and samples, and support with design and recruitment of clinical trials

Prostate Progress is another tool we have developed to harness the power of research to advance prostate health, and advance health equity. Through Prostate Progress, we are building a diverse and inclusive patient community, and bringing together clinical data, genetic data, and what patients themselves tell us for the first time. This will put data back into the hands of the patient so that they can see all their genetic, clinical and patient reported outcomes in one place, helping patients to:

- Better manage their side effects and symptoms
- Predict the course of their disease
- Connect with relevant clinical trials and new medicines
- Contribute to a growing body of research

We believe our platform will become a national exemplar for how health data is used in the future by putting patients at the heart of research, which is the cornerstone of delivering innovations that truly meet their needs.



Register >
Prostate Progress



Prostate Progress represents a beacon of hope in the fight against prostate cancer. By harnessing the power of our own health information, we empower researchers to unlock vital insights, leading to groundbreaking advancements in prostate cancer research. We can help bring the world a step closer to a future where this disease no longer poses a threat. That is why I am excited to be taking part in Prostate Progress.

Stephen Fry



It's part of my kind of advocacy to help raise awareness of the need to contribute to research that is ethical and well managed, which I think Prostate Progress is. I think you should join this kind of programme wholeheartedly because it is actually protecting the future of your children and your grandchildren.

Alphonso Archer
Prostate cancer patient



Real Talk

our new awareness campaign

With only 1 in 3 members of the Black community knowing they are at higher risk, we knew that we had to get creative around raising the awareness that would save lives.

It's a hard subject to talk about with those closest to us but we need to get real and start discussing men's health. Talking candidly and openly to help highlight the disparity Black men face in prostate cancer diagnosis, treatment and outcomes could make all the difference.

"Unless we start talking about this openly and honestly the stigma will remain."
Prince Sanyang, clinical nurse specialist



I know you may be fearful, I know this might rock your strength but what's more important, taking action and living longer or staying silent and dying? It's time to get real about prostate cancer.

Colin McFarlane
Actor and prostate cancer patient



Our Real Talk campaign uses a short comedy film centred around Black men having a real talk about prostate cancer in a barber shop to grab the attention and kick-start the conversation. The film is fronted by Black men, and cast and crewed by a Black creative team. The script was created in consultation with members of the community and the actors given license to be authentic.



Multi-platform campaign via a website, social postings and films, created to reach Black people wherever they may be looking

We also created an interview video featuring real Black patients and healthcare professionals telling their stories, and a series of personalised videos (available versions from your aunt, brother, cousin, daughter, friend, nephew, niece, partner, sister, son, uncle, and wife) people can send to their loved ones – if it's too difficult to have that real talk about prostate cancer yourself, our video will have it for you.

The films combined with a micro site, social assets and video books will be rolled out across conferences, press and in pop up events over the coming months. In conversations with Black patients, we often hear "We're not hard to reach, we're hardly reached out to," so we are working in partnership with others to take Real Talk into the heart of the communities that need them. We aim to disseminate our campaign via GP surgeries in key boroughs, via Black Faith Groups and Churches, prostate cancer support groups for Black men, and local football clubs, gyms, and independent cinemas. We anticipate real impact in terms of building trust within the community, and direct community outreach may result in the recruitment of community champions or ambassadors to help amplify our campaign in a true grassroots, community-led way.

We want to lessen the stigma around cancer in the community, make sure Black men know their risk, and build trust between the community and the organisations taking action to close the gap.

"If we educate the men about what to look for, family history, the general risks – you've got the power back in your hands."
Joe, athlete and prostate cancer survivor





Creating connections initiative to build trust in healthcare

We know that lack of trust from the Black community is well-founded and rooted in past and present injustices. However, a vicious cycle is all too often formed whereby a lack of trust prevents Black people from accessing healthcare and being represented in research, which in turn further entrenches the disparity.

We are currently planning a major multi-year and cross-departmental initiative to build trust in healthcare. The initiative will be split into three phases, with strong community representation and co-creation throughout.

By involving community members, healthcare professionals, and organisations at all stages and most especially in the development of interventions, we aim to ensure that the solutions are not only relevant and culturally sensitive but also have a higher likelihood of acceptance and success when implemented.



1 The Research Phase will identify and understand the specific barriers to trust within the Black community, and identify opportunities for building stronger relationships between the Black community and the healthcare sector.



2 The Co-creation Phase will, in partnership with Black-run organisations, across Europe, co-create tailored interventions that are informed by the research findings and which are culturally appropriate, effective, and sustainable.



3 The Roll-out Phase will amplify community voices and collaborate with the community to facilitate comprehensive engagement of the Black community with the healthcare system, addressing disparities in access and participation at every stage of the healthcare journey.



We have initiated the research phase by speaking to Black patients and experts in a series of interview videos which we are rolling out publicly so we can share our learnings with all who wish to work with us to build trust and close healthcare disparities.

Ultimately, we believe that implementing and scaling up these initiatives to build trust would lead to substantial long-term impacts on the healthcare engagement and outcomes of the Black community.

Over the next five- to ten-years, we could expect a significant increase in the awareness and participation of Black men in clinical trials, moving towards equal participation rates with their white counterparts. This would not only enhance the diversity and inclusivity of clinical research but also improve the relevance and effectiveness of healthcare solutions for the Black community.

We could also expect that increasing trust across the healthcare journey — from early detection and diagnosis of prostate cancer through treatment and follow-up care — would likely lead to improved healthcare literacy, greater access to innovative treatments, and more informed decision-making among Black individuals. By fostering strong partnerships with community organisations and healthcare providers, these initiatives would build ongoing trust and collaboration between the Black community and the healthcare system.

We also anticipate that the methodologies and interventions developed through this project, while initially focused on prostate cancer within the Black community, have the potential to serve as a blueprint for addressing healthcare disparities across a range of diseases within the Black community. We are also committed to sharing learnings so that our approach could be modified for other groups in the UK and globally who experience health disparities, which are exacerbated by a lack of trust.





Campaigning for screening making change happen

pccr.org.uk/prostate-cancer-screening-petition

A lack of accurate tests has meant that there is no national screening programme for prostate cancer. However, as technology and practices are improving, we believe that developing a universal screening programme to diagnose aggressive prostate cancer early should be a priority. As a minimum, a targeted screening programme for those at higher risk of prostate cancer should be introduced as soon as possible.



As Black men are at higher risk of prostate cancer, we are working to influence politicians to make screening for them a priority.

To help accelerate improvements in the UK's approach to prostate cancer screening, PCR have commissioned Deloitte UK to develop a macro-economic model. The model will enable the impact of a series of screening scenarios, and the introduction of newer technologies to the pathway, to be tested both in the general population and in groups of men at higher risk. The model will also enable the impact of such strategies to be examined in the context of current regional disparities. We have also undertaken a study to better understand the risks and impacts of over-diagnosis and over-treatment. Taken together, these two initiatives will make important evidence available by the autumn of 2024, both in relation to universal screening and targeted screening programmes.

85,000+ have signed the petition



Join in > see the petition



I was diagnosed before I even knew we were at a higher risk than others. We don't talk about it, so how are you meant to know if it's not talked about. Awareness is key, knowledge is key.

Dee
Prostate cancer patient



No man left behind: A world free from the impact of prostate cancer

pcr.org.uk • 020 3735 5444 • info@pcr.org.uk    



Prostate
Cancer
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