PROSTATE CANCER UK

BLACK HEALTH EQUITY STRATEGY

Prostate Cancer UK

INTRODUCTION

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Prostate cancer is the most commonly diagnosed cancer in men in the UK. Despite substantial advances in early detection/prevention and treatments, and improved outcomes in recent decades, prostate cancer continues to disproportionately affect Black men.

Almost 1,600 Black men are diagnosed with prostate cancer each year, that's 1 in 4 compared to 1 in 8 for White men and 1 in12 for Asian men. Black men are more likely to develop prostate cancer at a younger age and to be diagnosed at a later stage. There are also huge disparities in treatment for Black me with prostate cancer.

Prostate Cancer UK Black health equity

Prostate Cancer UK is striving for a world where no man dies from prostate cancer. And we'll leave no man behind. There is a moral imperative to urgently address the health equities that Black men are experience when navigating prostate cancer.

This strategy will anchor the core principles of our Black health equity work:

- **Risk** awareness preventing late-stage diagnosis
- **Right** to parity of treatment and care
- **Options** are communicated effectively and consistently

Three beliefs

- If we can dismantle the multifaceted barriers that are preventing more Black men from being diagnosed at a curable stage, we can do the same for all men.
- If we can achieve treatment parity for Black men, we can ensure all other men are adequately supported and well informed about their treatment options.
- If we can create support services that are inclusive and culturally sensitive, this will benefit all men.

Because if we get it right for Black men,
we raise the game for everyone.

EXECUTIVE SUMMARY

BHE MISSIONS

MISSION 1

Black men diagnosed early

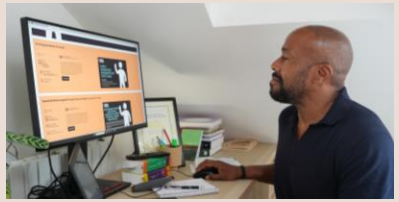
Diagnostic pathway

Risk stratified methods

MISSION 2

Treatment disparity ended

Treatment pathway



Self-advocacy and campaigns

MISSION 3

Support is personalised, culturally informed and improves QoL

Support pathway

Test & learn with a growing network

STATE OF THE MISSION

STATE OF THE MISSION

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ENABLING OBJECTIVES

Increasing trust & agency

Improving information and understanding

Building internal confidence and sustainable structures

MISSION 1: BLACK MEN DIAGNOSED EARLY

OVERVIEW

To work towards this mission, we will develop a responsive, impactful national network that will be an exemplar of tackling health inequity through community partnerships.

We will invest in understanding and dismantling the drivers of late-stage diagnosis of prostate for Black men, starting in the West Midlands. Through the investment we will design a phased delivery model that will identify the very best tactics of creating and supporting partnerships between communities, community organisations and PCNs.

KEY STRATEGIC PRIORITIES AND ACTIVITIES

Launch and embed the Black Health Equity National Network – a new approach to optimising national targeted engagement

Introduce a pilot model of delivery for equitable outcomes for Black men

WHAT DOES WINNING LOOK LIKE?

- More Black men diagnosed at a curable stage
- Reach and activate more Black men into making an informed choice about their prostate cancer risk
- Increase in % of Black men calling Risk Information Service
- Increase understanding within clinical community of Black health inequity in prostate cancer
- Policy changes made so that GP guidelines encourage proactive conversations with asymptomatic men at highest risk

IN FIVE YEARS' TIME:

More Black men who have prostate cancer are being diagnosed at a curable stage

MISSION 2: TREATMENT DISPARITY ERADICATED

OVERVIEW

Critical to achieving this mission is expanding our understanding of the clinical experiences of Black men throughout their treatment journey, and closing the evidence gaps that currently exist.

While we recognise that genetic predisposition to prostate cancer may influence outcomes, there should be no disparity in access to treatment. Our aim is to identify the underlying drivers of these disparities and develop an action plan to turn insight into best practice.

KEY STRATEGIC PRIORITIES AND ACTIVITIES

Increase our understanding of clinical practice for Black men utilising data from NPCA, Get Data Out^

Establish a working group to engage the NHS Trusts most commonly treating Black men with prostate cancer to develop a pilot model that understands and responds to identified barriers to treatment parity.

IN FIVE YEARS' TIME

We want more Black men reporting feeling supported in making an informed decision about their treatment choice, thereby reducing the occurrence of treatment regret.

WHAT DOES WINNING LOOK LIKE?

Understanding and tackling treatment disparity:

- Increased understanding within clinical community of treatment disparity for Black men

Greater awareness of treatment options:

- More Black men report feeling supported in making an informed decision about their treatment choice
- Increased number of Black men visiting the Black Health Equity microsite providing tools and information to support treatment choice
- Increased number of Black men accessing the treatment buddy services in pilot NHS Trusts

Increased understanding of how Black men are affected by prostate cancer – risk, treatment disparity, and quality of life

- Growing research community focused on Black health equity in prostate cancer
- Increased proportion of Black men participating in Patient and Public Involvement (PPI) shaping research and service design.
- Increased diversity of prostate cancer medical researchers

MISSION 3 – SUPPORT IS PERSONALISED, CULTURALLY INFORMED AND IMPROVES QUALITY OF LIFE

OVERVIEW

Critical to delivering on this mission is ensuring that our existing and new support services (both delivered and commissioned) are culturally informed and personalised.

We will incorporate what we know about the experiences that Black men face when navigating prostate cancer to improve existing services and inform new services that ensure we provide more Black men with the right support at the right time.

KEY STRATEGIC PRIORITIES AND ACTIVITIES

Support the development and delivery of a bespoke peer-to-peer support service for Black men with prostate cancer

Develop an end-to-end visualisation and critical review of a Black men's journey through our in-house and commissioned support services

WHAT DOES WINNING LOOK LIKE?

- Increased number of Black men calling the Prostate Cancer UK specialist nurse service
- Increased number of Black men using Prostate Cancer UK's support services – both delivered and commissioned
- More Black men feel that prostate cancer support services are culturally sensitive, personalised and improve their quality of life

IN FIVE YEARS' TIME:

More Black men are using available prostate cancer support services because they feel that they are culturally sensitive, personalised and improves their quality of life.

OUR APPROACH: INTERNAL ENABLING OBJECTIVES

OVERVIEW

We have identified key enabling objectives which are essential for us to deliver on the missions effectively. The successful delivery of the missions is dependent on the organisation's cultural advocacy readiness. If the Black health equity strategy is to be a directive to the whole organisation, the whole organisation needs to understand and feel confident about the contribution they will be expected to make.

ENABLING OBJECTIVES	KEY PRIORITIES AND ACTIVITIES
Increasing confidence, trust and agency We will improve trust in Prostate Cancer UK as a serious actor in the BHE space so that our staff and partners feel confident and well supported to maximise impact in their communities	Develop a culture of race advocacy, where all colleagues understand and proactively engage in Black Health Equity work
Improving information, willingness and understanding - Within Black communities - Amongst medical practitioners and peer organisations - To influence and effect systemic change	Develop an external and an internal communication plan for Black Health Equity work
Building sustainable structures within Prostate Cancer UK and the Black Health Equity Network We will build the internal structures so that BHE is a shared responsibility throughout the organisation, and so that there is a clear mechanism to enable the mutual engagement with community partners	

DISCOVERY SUMMARY

CONSULTATION PROCESS BEGAN IN JANUARY 2025

ENGAGEMENT IN CONSULTATION

With support from Clear Thinking Consultancy

Internal stakeholder engagement

- Ongoing engagement with the Black Health Equity (BHE) team
- Internal consultation with the BHE Working Group
- Sense-checking and consultation with CEO and members of Leadership Team
- 11 semi-structured interviews with staff

External stakeholder engagement

- 5 meetings with the Black Men's Health Advisory Group (BMHAG)
- Semi-structured interviews with CAHN and Race and Health Observatory
- Progress update and review with Movember

ENGAGEMENT IN CONSULTATION

Consultation focussed on gathering views on:

- Which Black men were felt to be most likely to experience health inequity and at what points;
- The main barriers that inhibit them in navigating prostate cancer
- How and where systemic racism shows up within the barriers Black men face to navigating prostate cancer.
- What else Prostate Cancer UK should be doing to tackle these issues

Feedback was collated and analysed to identify recurring themes.

A summary of three key themes is presented on the following slides.

DIAGNOSTIC PATHWAY – SYSTEMIC BARRIERS TO EARLY DIAGNOSIS

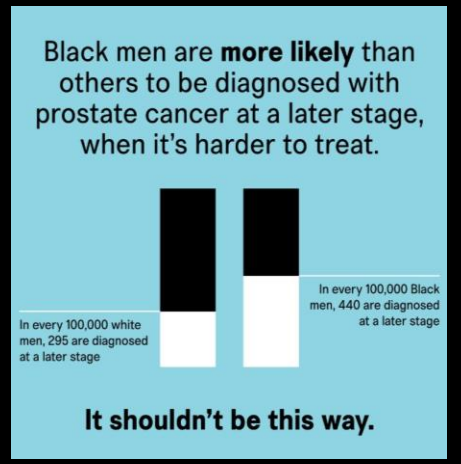
There is a lack of information and knowledge about prostate cancer amongst Black men, including lack of information about family history of prostate and breast cancer.

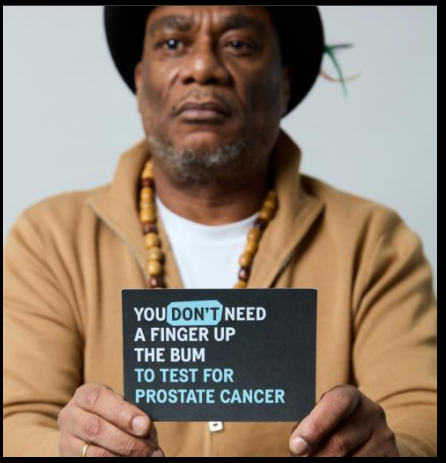
For many, this is combined with a hesitancy to engage with medical profession and diagnosis, with previous negative experiences being an important barrier.

Medical practitioners are not always aware of elevated risks for Black men, and current guidelines don't encourage speaking to men most at risk.

There is a lack of awareness of rights (eg to a PSA test) and inconsistencies in application of guidance – e.g. instances of being refused PSA test.

Prostate Cancer UK has made good progress in awareness-raising activities in Black communities but limited in capacity and largely London-focused.





1 in 4 Black men will get prostate cancer in their lifetime

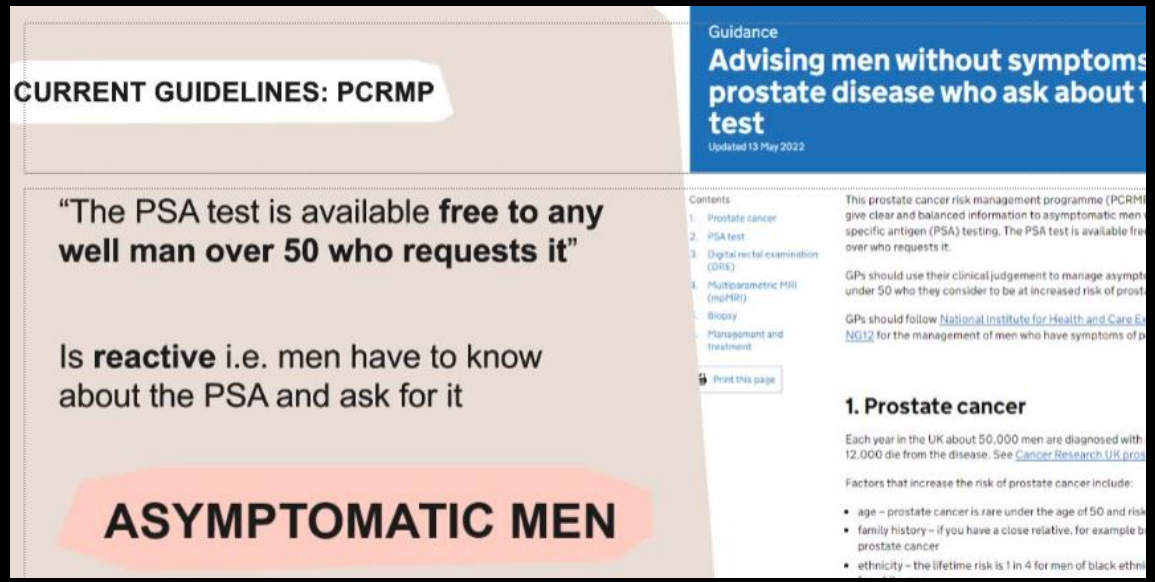
Twice the risk of dying

Black men likely to develop prostate cancer at a young age

Experience of the health care system varied

Some Black men will experience additional barriers to diagnosis – e.g. those with NRPF, men not registered with GP, with language barriers, or those who are digitally excluded.

NO TARGETED SCREENING PROGRAMME



TREATMENT PATHWAY – SIGNIFICANT TREATMENT DISPARITIES

Black men's access to treatment and research trials is variable and differs by area.

There are instances when men navigating prostate cancer have shared information about clinical trials with those who would not otherwise have been aware of them, highlighting the inconsistent access and lack of communication on what is available.

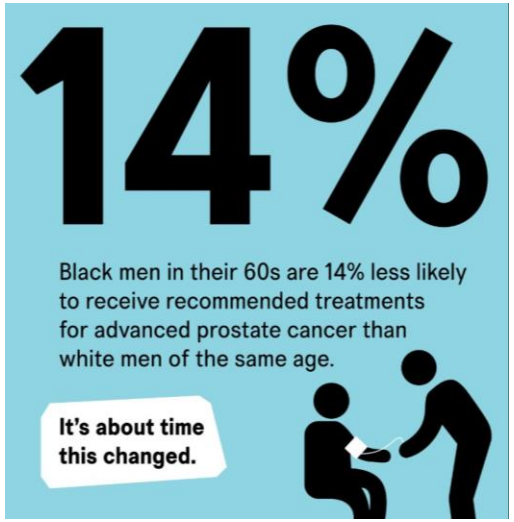
The evidence base is not strong enough on the differences in treatment responses for Black men.

Concerns about impact on work may affect treatment decisions; more needs to be done to highlight how working age men may be impacted.

More research is needed to understand lack of treatment parity

Nearly 1 in 4 (23%) ethnic minority adults reported that they did not trust pharmaceutical companies to test treatments and devices on them. This was highest among Black/African/Caribbean adults (29%). Ispos 2024

Lack of diversity within clinical research community



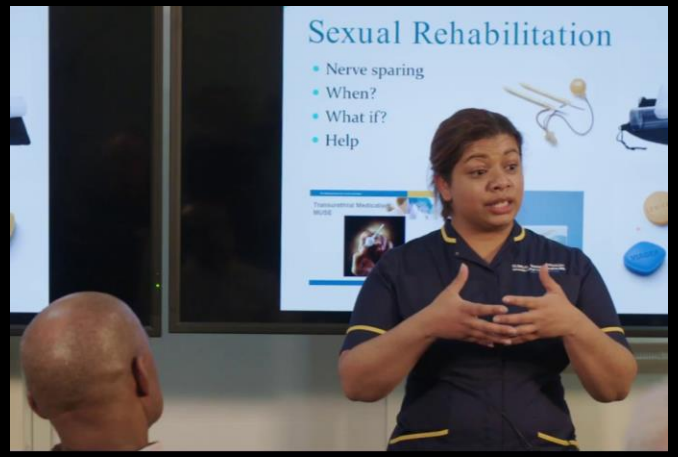
SUPPORT PATHWAY – PERSONALISED EXPERIENCE OF CARE

Early diagnosis is important, but support for men living with prostate cancer is also vital.

Support needs to be culturally appropriate and relevant to Black men – connecting with Black men with lived and shared experiences who can share information about e.g. changes to their body and impact on relationships is important.

Support needs to respond to the diversity of experiences of Black men with prostate cancer – spaces need to be psychologically safe for members of the LBTQI community for example, and Prostate Cancer UK's partnerships and ambassadors should uphold the inclusive ethos of the organisation.

There are lots of local organisations with a strong reach into Black communities providing support across the country



Lack of accurate data about Black men using specialist nurse service, but thought to be as low as c. 4% currently

Historical lack of trust in the organisation means that Prostate Cancer UK's specialist nurse service is not currently well used by Black men

BLACK HEALTH EQUITY STRATEGY

Our Missions

Risk, Rights, Options

Mission 1: Black men diagnosed early

New Activities
Launch the Black Health Equity National Network
Embed a new approach to optimising national targeted outreach work – raising awareness of health inequities in prostate cancer, starting with Black men
Introduce a pilot model of delivery that encompasses the processes, methods and strategies that effectively and efficiently dismantle systemic barriers to equitable outcomes for Black men.
Proliferate in priority regions a model of delivery that encompasses the processes, methods and strategies that effectively and efficiently dismantle systemic barriers to equitable outcomes for Black men
Develop a new microsite for Black Health Equity – informed by the 'Black experience' and the needs of Black communities

Enhanced BAU
Campaign for the introduction of an Early Detection Programme, including changing PCRMP rules allowing GPs to proactively talk with men most at risk of prostate cancer, including Black men
Extend and expand our risk awareness work through strengthened partnerships and effective collaboration
Invest in high impact partnerships with the voluntary community sector, health equity activists and community leaders.
Produce high quality and effective health information materials including, physical resources to raise awareness and provide advice and guidance - informed by the 'Black experience' and bespoke to the needs of Black communities

Mission 1: Black men diagnosed early

New Activities
Establish a Black health equity working group with the Black Parliamentary Caucus to influence key policy priorities set out in Faster. Fairer. Better
Embed a new approach using the Prostate Cancer UK Risk checker and Risk Information Service to lead more Black men, 45 years+ to enquire about PSA blood test
Develop a corporate partnership and strategic collaboration plan to raise our profile as legitimate advocates in Black health equity
Develop a Black Health Equity Volunteer Recruitment Programme to grow our pool of volunteers supporting our national targeted outreach work
Foster a global community of real-world data analysts working at the intersection of health equity and prostate cancer

Enhanced BAU
Influence local practice & local pathways by incorporating risk, rights, and options for Black men into our education programme for health care professionals
Number of Black men doing Prostate Cancer UK's risk checker remains above 10% of Black men at risk reached/yr NB: there are 360k Black men aged 45-70 in the UK
Increase representation of Black men in PPI decision-making process and PPI involvement in clinical research
Conduct in-house data analysis to uncover and measure inequalities in prostate cancer diagnosis and treatment, and provide insights into prostate cancer trends for Black men in the UK

Mission 2: Treatment disparity eradicated

New Activities
Establish a working group to engage with the NHS Trusts most commonly treating Black men with prostate cancer to develop a pilot model that understands then dismantles barriers to treatment parity for Black men
Develop an internally built tool that supports men with treatment choice decision making informed by the 'Black experience'
Introduce a treatment buddy programme for Black men starting their treatment journey co-developed with the Black Peer Support Steering group
Increase our understanding of clinical practice for Black men utilising data from NPCA, Get Data Out^

Enhanced BAU
Produce high quality and effective health information materials about treatment options including, physical resources - informed by the 'Black experience' and bespoke to the needs of Black communities
Influence local practice & local pathways by incorporating risk, rights, and options for Black men into our education programme for health care professionals
Increase representation of Black men in PPI decision-making process and PPI involvement in clinical research
Share our research in prostate cancer and Black men with the research community through peer-reviewed journals, meetings, and conferences
Campaign for increased diversity in prostate cancer research community, starting with existing and prospective Prostate Cancer UK grant holders

Mission 3: Support is personalised, culturally informed and improves quality of life

New Activities
Support the development and delivery of a bespoke peer-to-peer support service for Black men with prostate cancer
Develop an end-to-end visualisation and critical review of a Black men's journey through our in-house and commissioned support services
Support the EAU Diversity in Prostate Cancer PROMs study and subsequent findings to shape legislation, clinical guidelines and influence how healthcare providers deliver care.
Support the piloting of a sexual wellbeing prehabilitation service for men referred for prostate cancer treatment – ensuring that it is informed by the 'Black experience'

Enhanced BAU
Optimise data capture on ethnicity of service users thereby reducing % of 'unknown'
Grow the % of callers with self-recorded Black ethnicity accessing our specialist nurse service
Produce high quality and effective health information materials on support services including, physical resources - informed by the 'Black experience' and bespoke to the needs of Black communities
Grow the number of Black men that participate in our programmes that combine information, group support and goal-setting following prostate cancer treatment.
Embed the practice of incorporating the views and experiences of Black men and Black communities during service conception, development, and performance review

WHAT DOES WINNING LOOK LIKE?

Mission 1: Black men diagnosed early

More Black men diagnosed at a curable stage

- Reach and activate more Black men into making an informed choice about their prostate cancer risk
- Increase in % of Black men calling Risk Information Service
- Increase understanding within clinical community of Black health inequity in prostate cancer
- Policy changes made so that GP guidelines encourage proactive conversations with asymptomatic men at highest risk

Mission 2: Treatment disparity eradicated

A: Understanding and tackling treatment disparity:

- Increase understanding within clinical community of treatment disparity for Black men

B: Greater awareness of treatment options:

- More Black men report feeling supported in making an informed decision about their treatment choice
- Increase number of Black men visiting the Black health equity microsite providing tools and information to support treatment choice
- Increase number of Black men accessing the treatment buddy services in pilot NHS Trusts

C: Increased understanding of how Black men are affected by prostate cancer – risk, treatment disparity, and quality of life

- Grow a research community focused on Black health equity in prostate cancer
- Increase % of Black men participating in PPI
- Increase diversity of prostate cancer medical researchers

Mission 3:Support is personalised, culturally informed and improves quality of life

- Increase number of Black men calling the Prostate Cancer UK specialist nurse service
- Increase number of Black men using Prostate Cancer UK's support services – both delivered and commissioned
- More Black men report feeling prostate cancer support services are culturally sensitive, personalised and improves their quality of life

IN 5 YEARS' TIME…

1. More Black men who have prostate cancer are being diagnosed at a curable stage

2. More Black men report feeling supported in making an informed decision about their treatment choice, thereby reducing the occurrence of treatment regret

3. More Black men are using available prostate cancer support services because they feel that they are culturally sensitive, personalised and improves their quality of life.

BLACK HEALTH EQUITY STRATEGY

Our enabling objectives

Black Health Equity and Positive Change

Context

- Our mission is to support men to navigate prostate cancer, so no man is left behind. We know that not all men have the same risk of prostate cancer – **Black men face double the risk.**

- To deliver impact for the communities we serve, we **need to be an organisation that thrives on diverse thinking and inclusion** -recognising differences in ethnicity, cultural and socially relevant needs ,

- **Understanding and endorsing our Black health equity work is a key area of impact** and an essential part of our roles for all current and future colleagues.

What does this mean for us?

- We need to **confidently and clearly explain why and how we're reducing health and structural inequalities** for Black men and their communities.

- We must be ambassadors for positive change, not only driving a broad inclusion agenda but also where **we proactively challenge racism and are recognised by Black communities as legitimate advocates and allies** for their needs.

- To do this, **we're on a journey to build an organisation that's inclusive, open minded and committed to learning.** Where we recognise and embrace unique experiences and perspectives.