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The uncomfortable reality of prostate cancer in black African-Caribbean men

A report by Rose Thompson
BME Cancer Communities, February 2013

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All views expressed in this report are those of the author and do not necessarily represent the views of, and should not be attributed to, Janssen.



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About the author

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In 2003, after a 9 month secondment, and the loss of her twin sister to breast cancer, she joined Europe's leading cancer information and support charity, Cancerbackup (now merged with Macmillan Cancer Support). She was the charity's Black and Minority Ethnic Cancer Information Specialist (2003 -2007) and the first black allied health professional to be employed by Cancerbackup.

She founded and is developing BME Cancer Communities as a response to the unmet cancer needs of BME communities in the UK. Rose has a strong family history of breast cancer.

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BME Cancer Communities is based in Nottingham and specialises in providing cancer information and supporting BME and low income communities.



Contributions to the report

I am grateful to Dr Frank Chinegwundoh, Consultant Urological Surgeon and Chair of Cancer Black Care for his invaluable contributions to the report.

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Endorsements

The following support this report and its recommendations:

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Foreword

Cancer will affect all of us at some point in our lives, whether it is through personal experience or that of a loved one or friend. Prostate cancer is the most common cancer in men; fortunately many will survive prostate cancer and go on to lead fulfilling lives.



But there is an uncomfortable reality in prostate cancer - black African-Caribbean men are 30 per cent more likely to die from prostate cancer than white men. Black men have a three-fold greater risk of prostate cancer than white men and are more likely to encounter prostate cancer at a younger age.

This is a stark and unacceptable inequality. We must take action to close the gap in outcomes for black men with prostate cancer; and we must do this for two reasons.

Firstly, cancer inequalities matter. I have seen the profound impact prostate cancer has on the lives of the men affected and their families in my constituency. When one group in society has worse outcomes than others, not only is it unjust but it has an impact on relationships and trust in communities.

Secondly, we will only reduce cancer deaths and improve our cancer survival rates compared to that of our European neighbours by tackling inequalities in cancer outcomes. To achieve this we need a concerted effort and commitment to improve awareness and access to health services, along with research and evidence on disadvantaged groups.

This report sets out clear recommendations on improving the outcomes of black men with prostate cancer. At a national level, there must be an increased focus on ethnicity data collection and recording, so that we can measure and understand prostate cancer inequalities.

At a local level, local authorities in their new public health role must work with and support local community groups to promote awareness of prostate cancer in black men. Whilst on the frontline, healthcare professionals must be more aware of prostate cancer in black men, along with cultural differences and sensitivities.

I want to note my thanks to Rose Thompson of BME Cancer Communities for this important report, and for the excellent work she and others do helping black and minority ethnic men and women with cancer. I also want to thank Janssen for their support for this project.

David Lammy
MP for Tottenham

Black African-Caribbean men have a 3-fold greater risk of developing prostate cancer and are more likely to present with prostate cancer at a younger age



Executive Summary

In 2010, the Coalition Government made a commitment to saving 5,000 lives from cancer every year by 2014/15 in its cancer strategy, *Improving Outcomes: A Strategy for Cancer*.¹ It also made promoting equality a priority for NHS cancer services, recognising that narrowing the inequalities gap in cancer will improve overall cancer survival rates.¹

Black African-Caribbean men have an approximately 3-fold greater risk of developing prostate cancer and are more likely to present with prostate cancer at a younger age.^{2,3} The death rate from prostate cancer is 30% higher in black men compared to their white counterparts.⁴ Prostate cancer in black men is a clear health inequality.

High quality data on prostate cancer and black men of African-Caribbean or African descent is essential to evaluate the quality and outcomes of cancer care and investigate differences in cancer incidence, survival and access to treatment. In England, despite improvements in current ethnic data collection, there is still an incomplete picture of prostate cancer in black men due to inconsistent ethnic data collection in the NHS over many years.

The limitations to data on ethnicity means prostate cancer may not be properly prioritised in specific cancer or general health equality initiatives, and local commissioners lack robust data that are needed to commission services to meet the needs of BME cancer populations.

The lack of data and on prostate cancer and ethnicity may be widening the inequality gap.

An audit of five Joint Strategic Needs Assessments (JSNAs) in areas with high black populations in England provides a snapshot of the variation in tackling prostate cancer in black men at a local level. Some areas, aware of the higher incidence of prostate cancer in black men, identified the unmet need suggesting action to improve awareness or access to services. However other areas with a significant black population, failed to prioritise cancer and ethnicity as a health concern.

In addition to a paucity of national and local data, there has been little research on prostate cancer in different ethnic groups in the UK, and there is a need for further research to better understand the risk, cause, access to treatment and outcomes in this area.

Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst black men.⁵ Anecdotal reports also indicate low awareness amongst some GPs, with some black men (who may be at an

increased risk of prostate cancer) are being refused a PSA (Prostate-Specific Antigen) test.⁶

The combination of lack of cancer awareness in the black and other BME communities, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer (see Hugh Dwyer's story).

People from BME communities have consistently reported poorer experiences of NHS cancer services than white people.⁷ Black men with prostate cancer have also described insensitive behaviour on the part of some healthcare professionals.⁸ Communications between healthcare professionals and black men, and stereotyping have also been identified as challenges for black men with prostate cancer.⁸

The report highlights some of the barriers to treatment, with first generation black men less likely to proactively ask healthcare professional questions about their condition or treatment,⁸ and with myths and misinformation in the black community also potentially inhibiting understanding of cancer.⁹

A way forward: recommendations

The report makes a number of recommendations for national policy-makers and local organisations to improve the outcomes of black men with prostate cancer.

Recommendations for national policy-makers

- The National Institute for Health Research (NIHR), the National Cancer Research Institute (NCRI) and partner organisations to fund further research on the experience and outcomes of black men with prostate cancer in England, including a better understanding of the cultural barriers and their support needs.
- The National Cancer Intelligence Network (NCIN) to continue to collect and analyse cancer data on ethnicity. NCIN to produce online evidence-based reports on ethnicity and cancer.
- The new NHS improvement body should identify a lead director on cancer and ethnicity to continue the work of the National Cancer Action Team (NCAT) programme tackling cancer inequalities.
- Public Health England to fund a national campaign to raise awareness of prostate cancer for all men, with emphasis where appropriate on black men, delivered locally in partnership with community groups.
- Public Health England to fund a national campaign to raise awareness of prostate cancer in high risk BME communities. The campaign should be delivered locally to reach BME communities.
- Prison services and mental health services to ensure all black men have access to information about their increased risk of prostate cancer, and access to tests, treatments and a cancer information helpline.
- The Department of Health and prostate cancer charities to fund and support evaluated prostate cancer awareness raising sessions in prisons and mental health facilities for staff and men with an increased risk of prostate cancer.
- The National Institute for Health and Clinical Excellence (NICE) to ensure that future guidelines and quality standard on prostate cancer include a focus on black men and prostate cancer.
- The National Institute for Health and Clinical Excellence (NICE) to ensure that future guidelines and quality standards on prostate cancer include a greater focus on black men and prostate cancer, and the effectiveness of treatments for men of African genetic heritage.
- The national cancer patient survey to further investigate the experiences of men with prostate cancer to gain a better understanding of the support and care they receive, as well as aim to increase responses from BME patients.
- The Department of Health to ensure that equality metrics for the NHS Outcomes Framework and Improving Outcomes: A Strategy for Cancer include data and indicators on ethnicity.
- The BME Cancer Alliance '10 Calls for Action', launched in the House of Commons in December 2012, to be a recognised resource to inform policy makers.

Recommendations for local organisations

- Strategic Clinical Networks and commissioners to prioritise prostate cancer services and focus on unwarranted variations in service and outcomes, including those of black men.
- Clinical commissioning groups and local authorities should contract local arrangements to enhance identification and early diagnosis of men who are at higher risk of prostate cancer, including black men
- Health and Well-Being Boards should appoint a BME lead to ensure strategy and interventions tackle health inequalities are delivered.
- Health and Well-Being Boards should ensure that JSNAs review health data on BME groups, including black men with prostate cancer. Where data is not available, measures should be taken to address this.
- Local authorities in their public health remit should provide BME cancer awareness training for GPs and other healthcare professionals to highlight the increased risk of prostate cancer in black African-Caribbean men and other cancers that disproportionately affect BME groups, and the importance of equality data recording.
- Local authorities should fund community outreach workers on BME and cancer issues to raise awareness of prostate cancer and other cancers in local BME communities.
- Commissioners should adopt 'reverse commissioning' and engage with local BME communities and local providers to ensure services are in place to meet local needs.

Introduction

In 2010, the Coalition Government made a commitment to saving 5,000 lives from cancer every year by 2014/15 in the cancer strategy *Improving Outcomes: A Strategy for Cancer*.¹ The strategy also made promoting equality a priority for NHS cancer services, recognising that narrowing the inequalities gap in cancer will improve overall survival rates.¹

This report sets out evidence to demonstrate that prostate cancer in black African-Caribbean is a significant health inequality in England, and that a lack of data on prostate cancer and ethnicity widens the inequality gap. The report also examines other factors such as barriers to accessing health services and cultural concerns, and makes recommendations to improve outcomes and experiences of black African-Caribbean men with prostate cancer in England.

About prostate cancer

Prostate cancer is the most common cancer diagnosed in men in the UK and it is the second most common cause of death from cancer in UK men after lung cancer.¹⁰ In 2008-10, prostate cancer took the lives of 10,427 men in the UK (8,840 in England).¹¹ During the same period, 40,460 men in the UK (34,115 in England) received a diagnosis of prostate cancer.¹¹ One-year survival from prostate cancer in England for the general population is currently 93 out of every 100 men diagnosed and the five year relative survival rate is 81 out of every 100 men (2005-09).¹²

The prostate is a small gland found in men, women do not get prostate cancer. The prostate gland is at the base of the bladder, surrounding the urethra. It is about the size and shape of a walnut.⁹

Cancer occurs in the body when the reproduction of cells starts to grow in an uncontrolled way. If this happens in the prostate gland, prostate cancer can develop. What makes the cells in the prostate become cancerous is unknown.¹⁴

Prostate cancer differs from most other cancers as small areas of

cancer within the prostate are very common and may stay dormant for many years.¹⁵ Approximately half of all men over 50 may have cancer cells in their prostate, and 8 out of 10 men over 80 have a small area of prostate cancer. In most cases the cancers grow slowly and are unlikely to cause any problems.¹⁵

As with most cancers, prostate cancer develops in different stages. The stage of prostate cancer will determine treatment options for those affected. Below is a summary of the stages of prostate cancer and some treatment options:

Prostate cancer has a significant impact on the quality of life of patients; men report high levels of psychological distress, extreme pain, reduced mobility and difficulty undertaking usual activities.¹⁹ The symptoms of advanced prostate cancer include acute bone pain, urinary symptoms, tiredness, constipation and sleeping difficulties.²⁰

Prostate cancer research studies are helping to identify what increases our risk of developing cancer. The established risk factors for prostate cancer are age, family history and ethnicity, with black African-Caribbean men having a greater risk of prostate cancer.²¹ A World Health Organisation study, the European Prospective Investigation into Cancer and Nutrition (EPIC) points to lifestyle as a risk factor. The EPIC study found that a high intake of dairy protein and calcium from dairy products and high serum concentration of IGF-I (a hormone linked to growth) were associated with an increased risk of prostate cancer.²²

Stages and treatment of prostate cancer

Localised prostate cancer

Cancer which has been confined to the prostate gland.¹⁶

Stage 1 – the cancer is very small and completely inside the prostate gland.¹⁷

Stage 2 – the cancer is still inside the prostate gland, but is larger and a lump or hard area.¹⁷

Locally advanced prostate cancer (stage 3):

Cancer which has spread outside the prostate gland, it may have grown into the tubes which carry semen.¹⁷

Metastatic (advanced) prostate cancer (stage 4):

Cancer which has spread from the primary site in the prostate to the

lymph nodes, bones or other parts of the body.¹⁶

Around 20-30% of prostate cancers are not diagnosed until the cancer is advanced (stage 4).¹⁸

Only one in three men with advanced prostate cancer survives beyond five years.¹⁸



“Tackling health inequalities in England is essential to improving outcomes and achieving cancer survival rates which match the best performing countries in the world.”

*Improving Outcomes: A strategy for Cancer*¹

Cancer inequality is a health priority

In England, overall cancer survival rates are improving. However, survival rates continue to lag behind the best-performing countries in the world, including Canada, Australia, Sweden and Norway.²³

In 2010, the Government introduced a new cancer strategy focused on improving cancer survival rates in England. The strategy, *Improving Outcomes: A Strategy for Cancer* set out a commitment to save an additional 5,000 lives from cancer every year by 2014/15.¹ To improve cancer survival rates, the strategy outlines a number of priorities including tackling preventable causes of cancer, ensuring access to information for patients and better early diagnosis. Reducing inequalities in cancer is also a key element of the strategy, as it states:

“Tackling health inequalities in England is essential to improving outcomes and achieving cancer survival rates which match the best performing countries in the world.”

*Improving Outcomes: A strategy for Cancer*¹

The NHS Constitution also makes clear that a core duty of the NHS is to promote equality,²⁴ and this is reflected in the NHS Mandate which emphasises the specific legal duties of the NHS Commissioning Board to ‘advancing equality’ and tackling health inequalities.²⁵ Additionally, the 2007 Cancer Reform Strategy made promoting equality a “high priority” for NHS cancer services “ensuring that action is taken to reduce these inequalities”.²⁶

Action on reducing cancer inequality

The National Cancer Action Team (NCAT), part of the National Cancer Programme, supports improvements in cancer outcomes. Part of NCAT’s remit is to address equality issues and reduce inequalities across the cancer care pathway. It does this through a number of programmes to raise awareness of cancer in BME groups, examine patient experience and collate data. The National Cancer Equality Initiative (NCEI), run by NCAT, brought together equalities experts

and new sources of data to create a picture of the extent and nature of cancer inequalities in England.

In 2012, NCAT launched the *Cancer Does Not Discriminate* campaign, which aimed to raise cancer awareness in BME communities through funding local events and activities. The campaign engaged with and provided small grants to local BME and community groups; it also distributed four NCAT newsletters

for BME audiences and developed resources and publications to help promote awareness of cancer in BME communities.²⁷ (The Ethnic Minority Cancer Awareness Week small grants format provided NCAT with a template to follow, see box overleaf).

The UK’s first National Cancer Director, Professor Mike Richards, and the National Cancer Team should be commended for improvements to cancer outcomes.

Additionally, NCAT has a patient experience team and has established a 'Cancer and Ethnicity Resource Portal', which collates literature on cancer and ethnicity. Grey literature (published academic research) provides a vital evidence base on ethnicity and cancer.

Due to the current reforms to the NHS, NCAT will cease to function after March 2013. Elements of NCAT will transfer over into the new 'Improvement Body'.²⁹ The Improvement Body will be tasked with building "improvement capability at scale across the NHS to enable delivery of transformational change".³⁰

It is hoped that elements of NCAT will continue in the new body, this includes programmes concerned with health inequalities, including supporting further development of multidisciplinary teams, informing and involving patients and their carers, and improving patient experience and care.²⁹ It is unclear whether NCAT's remit on reducing cancer inequality will be transferred to the new body, and who will lead on cancer and ethnicity going forward.

There is also concern amongst patient support groups and BME groups that the closure of NCAT

will mean that intelligence and evidence on cancer that currently supports ethnic groups may be lost. Importantly too, the trust and relationships that have been developed between NCAT and patient support groups, BME organisations and volunteers will have to be rebuilt with the new organisation's staff. Activities such as the *Cancer Does Not Discriminate* campaign have involved local groups, (including The Irish Centre in Nottingham) to support awareness raising events in BME communities.³¹



Champions of Change

NCAT commissioned the *Champions of Change – cancer services*, a project run by Bright Ideas Nottingham aimed at giving young people from BME communities affected by cancer a voice in NHS cancer services.

The project ensures that services can be improved to meet the needs of all people affected by cancer. It also aims to raise awareness of the early signs and symptoms of cancer.

Champions are local people from visible and non-visible BME groups, together they volunteer their time to provide their views and opinions.²⁸



Cancer Equality

Cancer Equality is a charity that founded and coordinates Ethnic Minority Cancer Awareness Week (EMCAW) which takes place annually in early July. The purpose of the week is to raise awareness about cancers that disproportionately affect ethnic groups, and the importance of healthy lifestyles in BME communities. The EMCAW selects a different theme or topic each year.

In 2012, over 40 BME and other community organisations supported the awareness week with nearly 3,000 individuals taking part in events and activities. This was almost double the previous year.

EMCAW's management team, which consists of

volunteers with an expertise in BME community issues and outreach, raise funds to distribute small grants to community groups to hold events and activities to promote cancer awareness.

EMCAW's major sponsor was NCAT and with the demise of NCAT, the EMCAW

management team are concerned about the future funding of the awareness week. The management committee will need to source additional funding for EMCAW in 2013, described as "An uphill struggle in the current financial climate" by one committee member.



3,000

individuals took part in Ethnic Minority Cancer Awareness Week events and activities

Who is affected by cancer inequality?

Disadvantaged groups have higher incidence and mortality rates, and poorer outcomes from cancer which contribute to lowering England’s overall performance on cancer survival. Disadvantaged groups can be identified as “socio-economically deprived groups, black and minority ethnic groups, older or younger people, men or women, people with disabilities, people from particular religions or with particular beliefs and the lesbian, gay, bisexual and transgender (LGBT) community”.¹

For instance, the incidence of cancer and likelihood of successful treatment is linked to socioeconomic status.³² Additionally, men as a group face some inequalities. It is reported that men have a lower awareness of the signs and symptoms of cancer and a lower uptake of screening than women. Some men also find GP services to be inaccessible.³³ Finally, with respect to prostate cancer, men have reported poor patient experience.³⁴

People from BME groups are at a greater risk of some cancers. It is known that black people have higher rates of prostate cancer than other ethnic groups; as is the case with stomach cancer and multiple myeloma.³⁵ Whereas, the risk of mouth cancer is higher in Asian women and cervical cancer is nearly twice as high in Asian women aged over 65 than white women.³⁵ Research from Cancerbackup (now Macmillan Cancer Care) indicated that the South Asian community were the largest minority ethnic group making inquiries to their helpline and centres followed closely by the black community.³⁶

A survey conducted by BME Cancer Communities in Nottingham in 2009 found that 36 % of BME

people in Nottingham were not sure or unfamiliar with the signs and symptoms of cancer and 47 % did not know how to reduce their cancer risk. At the same time, 55 % had a family member who had experienced cancer.³⁷

In addition to differing rates of risk for some cancers, inequalities in outcomes may also be accounted for by a number of different factors:

- Lifestyle choices in BME communities may contribute to cancer inequalities. Smoking rates amongst men appear to be higher among a range of different BME communities, including Bangladeshi, Caribbean, and Chinese.³⁸
- BME communities generally have a lower awareness of cancer than white men and women.³⁹
- Uptake of screening e.g. for breast and cervical cancer, is generally lower in BME groups.³⁹
- There are lower levels of awareness of hospice and palliative care and language differences amongst BME groups can limit their use of services.³⁴
- Patients from BME groups report less favorable experiences of patient care than white people.⁷

People from BME groups are at a greater risk of some cancers.

Black people have higher rates of prostate cancer than other ethnic groups

Risk of mouth cancer is higher in Asian women

Deprivation is another important element. Many people from BME communities experience higher rates of poverty than white people related to income, benefits use, worklessness, lacking basic necessities and deprivation by area.⁴⁰ Socio-economic deprivation has been linked to poorer health outcomes and cancer outcomes.²³ People from BME communities may therefore experience ‘multiple disadvantage’ as a result of being from an ethnic group and their socio-economic status, age or another inequality factor. It is well documented that black men suffer discrimination in the workplace and as job seekers.⁴¹

For example, in Nottingham City the black community has the highest rate of unemployment amongst all ethnic groups; 16 % black and black British people are unemployed compared to 6 % of white people. The mixed ethnic group in Nottingham has 12.9 % unemployment.⁴²

In the current economic climate, with unemployment rising amongst young black men,⁴³ this could add a further challenge in improving the cancer outcomes of black men.

¹ This report notes prostate cancer rates in other BME communities, including the South Asian community. However, the focus of this report is prostate cancer in black African-Caribbean men.

Prostate cancer in black African-Caribbean men¹

Black men of African-Caribbean descent have a higher risk of prostate cancer. In America, African-American men have an estimated 55% greater risk of prostate cancer than white men and are 2.4 times more likely to die from prostate cancer than white men.^{2,3} Furthermore, a study in Kingston, Jamaica found that black men had the highest incidence rate in the world.²

Table 1: Rate per 100,000 of men with prostate cancer by ethnic group (adapted from Ben-Schlomo et al., 2007)²

Rate per 100,000				
Age	White	Black	Black Caribbean	Black African
40 – 44	0.6	0	0	0
45 – 49	4	15	27	7
50 – 54	23	84	72	102
55 – 59	52	284	284	273

In the United Kingdom, the first large study comparing incidence rates of first-generation black migrants from either Africa or the Caribbean found a 3-fold greater risk of developing prostate cancer in black men.² It also observed higher incidence of prostate cancer in younger black men, those in their late 40s and 50s, compared to younger white men, as indicated in the table above. In addition, black men were diagnosed an average of 5.1 years younger compared with white men.³

The table above also indicates higher rates of prostate cancer in African men in their 50s. It is important to note that African

men living in the UK migrated in significant numbers from a variety of African nations, where prostate cancer rates vary.⁴⁴

Recent data on mortality from prostate cancer further demonstrates the inequalities in outcomes for black prostate cancer patients. The death rate from prostate cancer in black men is 30 % higher than in white men.⁴

Although the reasons for the higher risk of prostate cancer in black men are not fully understood, researchers believe there to be a number of factors contributing to the higher prostate cancer incidence in black men including genetic susceptibility,

migration, lifestyle effects and socioeconomic issues.^{2,3} Studies have suggested that a number of possible genetic mutations predisposition black men to prostate cancer.⁴⁵ Evidence now shows that there is a four times greater chance of men developing prostate cancer than other males if they carry the mutated BRCA1 gene. The mutated BRCA1 gene is also found in people with a family history of breast cancer and ovarian cancer.⁴⁶

In summary, the evidence indicates that black men have higher risk of prostate cancer, are more likely to get it at a younger age and have a higher death rate than white men.

Wayne's story

Wayne's father had visited his GP numerous times to find out why his health was deteriorating, and had even visited a private doctor in Leicester. The family became so concerned; they made an emergency trip to A&E, where he was finally diagnosed with prostate cancer. A week later Wayne's father lost the use of his legs, and he died in hospital just two weeks hence. He was 65.

Following his father's death, Wayne began his own investigation into prostate cancer. Wayne discovered that he had an increased risk of prostate cancer due to his father's diagnosis at a relatively young age. Wayne requested tests, and despite a borderline PSA blood test result, his local Urology Consultant suggested a biopsy. Wayne was found to have an early stage aggressive type of prostate cancer. His prostate gland was removed and he remains well. At diagnosis, Wayne was 45, with a young family.



The missing data on prostate cancer in black African-Caribbean men

As outlined in the section above, black men have a higher risk of prostate cancer, are more likely to present at a younger age (approximately five years younger than white British men), and have a higher death rate from prostate cancer. Despite these important statistics, there is an incomplete picture of prostate cancer in England due to the significant limitations in data collection by ethnicity in the NHS. This paucity of data affects: commissioners' ability to plan and commission services at a national and local level to meet the needs of these men and their families; the ability to investigate differences in cancer incidence, survival and access to treatment to inform programmes aimed at reducing inequalities; and the evaluation of the quality and outcomes of cancer care.

The Prostate Cancer Charter Equality Action Plan, published in 2006 by the Prostate Cancer Charter for Action, called for improvements in recording ethnicity data on prostate cancer incidence and outcomes either through the British Association of Urological Surgeons (BAUS) Registry or the UK Cancer Registries.⁴⁷ In 2010, the Government's report *Reducing cancer inequality: evidence, progress and making it happen*, stated that central to the cancer inequalities programme are "new sources of data to create an unprecedented

picture of the extent and nature of cancer inequalities in England".⁴⁸ The report recommended national and local actions to reduce inequalities in cancer care including data collection, analysis and publication, targeted interventions and training.

However, the National Cancer Intelligence Network (NCIN), which collates and coordinates data and information on cancer patients to provide analysis and insight on cancer outcomes for commissioners has limited data on ethnicity and prostate cancer. This is due, in part,

to the repeated failure to prioritise ethnic data collection amongst healthcare professionals in the NHS. This also has an impact on the data collected by cancer registries which rely on NHS data.

The NCIN's online 'Cancer e-atlas' shows no ethnicity data on prostate cancer and its 'Equalities Portal' holds few statistics on prostate cancer and ethnicity. The purpose of the 'Equalities Portal' is to provide commissioners with local data on "the equality and inequality characteristics of their cancer populations, as well as how their

performance compares with other areas” to help “tackle embedded inequalities in cancer care at every stage of the pathway.” But in terms of prostate cancer, the portal includes only incidence ratios (Black:White and Asian:White) at a national level. In terms of ‘all cancers’, the e-atlas includes data on symptom recall (cancer symptom awareness) and recorded ethnicity at a national rather than local level. Thus, commissioners and clinicians have very little local data available on the outcomes of black men with prostate cancer.

At times, ethnicity is not being examined when analysing cancer inequalities. In October 2012 the National End of Life Care Intelligence Network published a report, *Deaths from Urological Cancers in England, 2001-10*. The report presented the latest available data on deaths from urological cancers including prostate cancer; it examined variations between gender, age and deprivation but failed to include data on ethnicity.⁴⁹ In addition, the Prostate Cancer factsheet, produced by the Urological Cancers Hub at the South West Public Health Observatory, does not provide data on ethnicity in relation to prostate cancer.⁵⁰

The *NHS Outcomes Framework for 2013-14* includes an indicator on under 75s mortality for all cancers.⁵¹ The Department of Health published an *Equality Analysis* alongside the Framework to outline what data is available and possible to collect by different ‘equality metrics’ e.g. age, gender, ethnicity, disability, sexual orientation. The Framework states that data on ethnicity in relation to all cancers is possible to construct but not currently available.⁵² In December 2012, the Department of Health’s *Improving Outcomes: A Strategy for Cancer – Second Annual Report 2012* set out ‘high level equality metrics’. However, in some cases the metrics on ethnicity are



The focus on gender, age and deprivation are of course important, but deprivation should not replace ethnicity as an indicator when examining cancer outcomes

inadequate. The document states that data on ethnicity for one year survival rates and the proportion of emergency presentations will be categorised as “White, Non-White and Not Recorded”.⁵³

The focus on gender, age and deprivation are of course important, but deprivation should not replace ethnicity as an indicator when examining cancer outcomes; instead multiple disadvantage should be noted.

The limitations to data on ethnicity and cancer mean commissioners are unable to fully understand the extent of cancer inequalities in BME communities. At a national level, the lack of data means

prostate cancer may not be properly prioritised in specific cancer or general health equality initiatives.

At a local level, the commissioning cycle is dependent on regular and robust needs assessments in the local population, deciding priorities, working collaboratively with community partners. However, as data on cancer and ethnicity at a national and local level are limited, the ability of commissioners to understand the extent of a cancer inequality in their area and commission services to address the inequalities is restricted. This is further demonstrated by the review of needs assessments in local authorities conducted for this report in the next section.

Ethnicity monitoring – the case for reverse commissioning

In the UK, ethnic data monitoring became compulsory for inpatient services from April 1995, but there are still a significant number of people who are not asked the ethnicity question.

It is suspected that the purpose of collecting ethnic data in health services is unclear for a significant number of healthcare professionals, as well as BME community members, resulting in staff being wary of asking patients about their ethnicity.

This reluctance to collect the data creates a ‘catch 22’ situation. Health bodies

want evidence, preferably from local data, to fund awareness campaigns and interventions for the BME groups. That evidence comes from ethnicity data which healthcare professionals are reluctant to engage in because they do not understand the need or purpose of ethnicity monitoring.

When local data on cancer in BME populations is not available, commissioners should undertake ‘reverse commissioning’, making use of existing evidence held by local providers and emphasise the need for BME communities to engage with healthcare professionals. In addition, commissioners should empower healthcare professionals to ask patients questions about their ethnicity through simple training and awareness.

This is particularly important with ‘less visible’ and seldom heard ethnic groups, such as the Irish, Turkish, East European and Gypsy/ Traveller communities. Data on cancer or other health outcomes for these groups may be very limited. Also, as lifestyle factors are linked to an increased risk of prostate cancer, some ethnic groups that currently have low incidence of prostate cancer, may in future years face a rise in prevalence.



Regional disparities: a snapshot

Deaths from prostate cancer vary across the regions of England. Mortality in the East Midlands is higher than the England average, whilst mortality in the South East is lower on average.⁴ The table below demonstrates the high level of variation in incidence and mortality from prostate cancer in the East Midlands, highlighting the need for local solutions to their specific health challenges.

Table 2: Prostate cancer incidence and deaths in the East Midlands

Unitary authority	Incidence (Directly age-standardised rate per 100,000 men, 2007-09)	Deaths (Directly age-standardised rate per 100,000 men, 2006-08)
Shropshire UA	83.7	27.0
Nottingham UA	96.9	26.4
Herefordshire, County of UA	107.8	24.7
Telford and Wrekin UA	72.2	24.5
Stoke-on-Trent UA	77.8	23.9
Rutland UA	104.7	22.1
Derby UA	89.2	21.4
Leicester UA	79.8	19.3

Source: NCIN and South West Public Health Observatory, Urological Cancer Profiles – Unitary and Local Authorities, available at www.ncin.org.uk/profiles/la_profiles/atlas.html

Nottingham Unitary Authority has the second highest death rate from prostate cancer, after Shropshire⁵⁴, despite the efforts of statutory bodies to raise cancer prostate cancer awareness in the inner city. Nottingham has the highest black population in the East Midlands.⁵⁵ The reason for Shropshire’s higher death rate is probably because it has a greater percentage of people aged over 65 years than is the case nationally.⁵⁶ However, interpreting data in a meaningful way, by region or local authority is difficult because data according to ethnicity is not available at a local level.

To gain further insight on the regional story of prostate cancer, this report has examined several Joint Strategic Needs Assessments (JSNAs) in English locations outside London with significant black populations: Birmingham, Wolverhampton, Leeds, Nottingham and Manchester.⁵⁵ The purpose of this was to provide a snapshot of whether local health bodies in areas with a high black population are prioritising cancer and prostate cancer in BME groups. London and Bristol are excluded from this review because the PROCESS study, which is discussed in further detail in the next section, was conducted in these areas.

The JSNAs pull together data on health outcomes and trends for each local area. Based on the evidence presented in the JSNA, Directors of Public Health in local authorities will develop Health and Well-Being Strategies, which set out the health needs and priorities of the local community.

Five areas with significant black population were chosen for the analysis. The JSNAs from these five areas were analysed against criteria aimed at determining whether the location recognised prostate cancer in black men as a health concern and what emphasis is placed on cancer in ethnic groups. The criteria are as follows:

- Does the JSNA highlight cancer as a health priority?
- Does the JSNA demonstrate a connection between cancer and ethnicity? Is there any local data on this?
- Is prostate cancer indicated as an area of need locally?
- Does the JSNA link prostate cancer to black men?
- Does the JSNA call for further action on prostate cancer in BME men?

The table below provides a breakdown of the review.

Table 3: Assessment of JSNAs against criteria²

JSNA/location and year of publication	Proportion of black population	Review of JSNAs against evidence criteria				
		Highlights cancer in health priorities	Connects cancer and ethnicity	Indicates prostate cancer as an area of need	Links prostate cancer and ethnicity	Call for further action on prostate cancer in BME men
Leeds (2012) ⁵⁷	2.51%	Yes	Yes	Yes	Yes	Yes Recommends improving BME access and experience of services.
Manchester – (North) (2012) ⁵⁸	4.84%	Yes	Yes	No	No	No
Wolverhampton (2008) ⁵⁹	5.16%	Yes	Yes	No	No	No
Nottingham (2012) ⁶⁰	4.69%	Yes	Yes “raises issue of lower BME access to services”	Yes	Yes	Yes “Call to improve understanding of poor survival for prostate cancer in Nottingham”
Birmingham ⁶¹ (2012)	6.57%	Yes	Yes “More research on cancers by ethnic group is required”	Yes	Yes	No*

² It is important to note that it was not possible to compare JSNAs from the same year. This means some of the JSNAs used are the most recent, or in the instance of Wolverhampton the 2009 JSNA is currently publicly available and the 2012 JSNA is currently in development.

To summarise the findings, it is clear that the JSNAs in Nottingham and Leeds considered the higher incidence of prostate cancer among black African and African Caribbean men, suggesting action should be taken to “improve understanding of poor survival” or improve access to services. Birmingham also recognises cancer and ethnicity as a health concern, but despite having the highest black population in this sample; it does not set out any specific actions to address BME cancer inequalities. The JSNAs for Wolverhampton and Manchester connected cancer and ethnicity as an issue, but they failed to recognise prostate cancer and black men as a health concern to monitor. Thus, this snapshot indicates that without adequate local data on prostate cancer in black men, local authorities and commissioners will not prioritise this health need.

The case for further research

To date there has been little research on prostate cancer in different ethnic groups in the UK. Research on this issue has been more common in the USA, where evidence suggests that black men have worse prostate cancer-specific survival than other groups.⁶² Although the American studies are useful, the results may not directly correlate to the black population in the UK for a number of reasons, such as the lack of access to healthcare in America, differing patterns of deprivation, lifestyle differences and differences in migration and the experiences of the black population.

The two major studies undertaken in the UK are the PROCESS study and a study by Jack *et al* (2009)⁶² in the South East. The PROCESS (Prostate Cancer in Ethnic Subgroups Cohort Study)² was conducted in North Bristol and London (South East, South West and North West) over 5 years. The study investigated the incidence rates and relative risk of black men compared to white men in prostate cancer and found that incidence of prostate cancer in black men is higher.

A further investigation of the PROCESS cohort study group found no evidence of difference in disease characteristics at the time of prostate cancer diagnosis, nor of under-investigation or under-treatment in black men.⁶³ Black men were more likely to be referred to a hospital, and had higher PSA levels than their age-matched white counterparts.³

In contrast, research carried out in the South East points to differences in treatments offered between ethnic groups.⁶² In the South East, black men are less likely to receive surgery than white men. Black men are also less likely to receive radiotherapy than white men, this difference increased when adjusted for socioeconomic status and stage.⁶² White men are more

likely to have cancer surgery and hormone therapy recorded than either black or Indian/Pakistani men.⁶² However, the same study also found black and Indian/Pakistani men had better overall survival than white men.

Whilst the PROCESS and South East studies have made incredibly valuable contributions, they have been limited by geography and a lack of data on ethnicity respectively. The data used in these studies is also becoming outdated. The PROCESS study was a 5 year study published in 2007. Similarly, data for the South East study was extracted from the Thames Cancer Registry from 1998 to 2003.

Additionally, the PROCESS study primarily investigated men of West African and African-Caribbean heritage. As prostate cancer rates vary across the regions of Africa, research is needed on the ethnically diverse African population in this country.⁴⁴

Research should also be conducted on the impact of multiple morbidities in black men with prostate cancer. Multiple morbidities have been shown to affect prostate cancer survival and outcomes. An American study found that men with heart disease

were more likely to regret having prostate cancer treatment than men without heart problems.⁶⁴ Furthermore, in the UK black African-Caribbean adults are twice as likely to have a stroke as the rest of the population and have a higher prevalence of diabetes.⁶⁵ Further research is needed to understand the impact of conditions such as heart disease, stroke and diabetes in black men with prostate cancer.

There is an urgent need to conduct further research on prostate cancer in black men across the country to better understand the risk, cause, access to treatment and outcomes of this group of men.

There is an urgent need to conduct further research on prostate cancer in black men across the country

“I went to the doctor to ask about a PSA test but was told by the GP I was too young to get prostate cancer, it was something men in their 60s and 70s got.”

BME Cancer voice member diagnosed with prostate cancer, aged 57 (Nursing Times, 2012)⁶

Low awareness and perceptions of prostate cancer in the black community

Awareness of cancer is generally lower in BME groups than amongst white men and women, as is the take-up of screening in these communities. Evidence also indicates that for some cancers, people from BME communities are more likely to present later with symptoms, which may be more advanced.⁴⁸

58%

of prostate cancer was diagnosed through urgent or routine GP referral

9%

of prostate cancer being diagnosed in A&E

30%

of black Caribbean men mentioned prostate cancer as the most common cancer in men



More broadly, there is also evidence that improvements could be made in the diagnosis of prostate cancer in for all men. A study of the routes to diagnosis found that prostate cancer was diagnosed through urgent or routine GP referral in 58% of cases, with 9% of men being diagnosed in A&E.⁶⁶

Despite the higher risk of prostate cancer in black men, awareness of prostate cancer is low amongst this group of men. An Ipsos Mori survey in Westminster found that that 30% of black Caribbean men and 32% of black African men mentioned prostate cancer as the most common cancer in men, this was lower than in male Westminster residents in general; 37% of whom mentioned prostate cancer as the most common cancer in men.⁵

There is also low awareness amongst healthcare professionals. Anecdotal reports indicate GPs have refused to give Black African-Caribbean men a PSA test or are

unaware of the higher incidence rates in these communities.⁶

BME Cancer Communities service users have also been refused tests on the grounds of having no symptoms, when it is well documented that early prostate cancer is unlikely to cause symptoms.

At present there is no national screening programme for prostate cancer. However, the NHS Prostate Cancer Risk Management Programme aims to ensure that men who are concerned about their risk of prostate cancer receive clear and balanced information about the advantages and disadvantages of the PSA test and treatment for prostate cancer. It also provides GPs with information including the increased risk of prostate cancer in black African-Caribbean men.⁶⁷

It is important that black men have access to PSA testing and patient information, when appropriate. The relative youth of black men presenting with prostate cancer

compared to white men and their 3-fold greater risk of prostate cancer must be taken into account by healthcare professionals.

A lack of experience of cancer in BME communities may also drive low awareness. In-depth interviews and focus groups conducted by the Genetic Alliance UK with BME people with a family history of cancer found that some BME people see cancer as a 'new condition'; they do not have experience of it. Some people from BME backgrounds also saw cancer as a disease affecting white people.⁶⁸

Furthermore, a study found that black men had little experience or understanding of prostate cancer, although once aware or diagnosed with it they were able to identify relatives who had either died or were living with the disease. The men in the study recalled a 'stoppage of water' that affected older men in the West Indies, but had little knowledge of it.⁸

The men also described insensitive behaviour on the part of healthcare professionals, who, in some cases, gave little regard to the personal dignity of the men particularly in relation to continence and sexual function.⁸

Communication between healthcare professionals and patients and stereotyping were also noted as problematic,⁸ as was mistrust of the healthcare system and a lack of trusting relationships with healthcare professionals.⁶⁹ The men in the study tended not to ask many questions of healthcare professionals, but this was not a reflection of their lack of interest.⁸

Delayed referrals are also an increasing concern amongst BME organisations engaging with BME cancer patients. Delayed referrals are not confined to people whose first language is not English, but includes the English speaking first generation.⁶⁸

Barriers in accessing health services

Patients from BME communities report poorer experiences of NHS cancer services than white patients.⁷ Patient information, communication and after care have been identified as areas relating to poorer experiences.⁷ This is reinforced by the first qualitative study of black men with prostate cancer, conducted in Birmingham in 2010.⁸ The study examined the men's accounts of prostate cancer within the context of their personal history and social environment. Through interviews, it was found that the men had limited knowledge of prostate cancer when they were diagnosed and they described their initial reluctance to seek medical attention from their GP. Their reluctance due, in part, by a failure to take symptoms seriously, but also a fear of cancer which was seen as resulting in death and a fear of loss of sexual function.⁸

People from BME communities are more likely to have different experiences of palliative care. A study on the place of death of prostate, breast, colorectal and lung cancer patients in South East England found that black African, black Caribbean and Chinese patients were less likely to die at home than white patients. Asian, black African, black Caribbean and Chinese patients were all significantly more likely to die in hospital than the white patients. Research also found that more black Caribbean bereaved representatives than white bereaved representatives felt that they, or the deceased, were not given adequate choice regarding their place of death. Hospices are also not always perceived to be appropriate for different religious, spiritual and cultural needs of patients from BME groups.⁷⁰

Research has shown that people from BME groups with a significant family history of cancer appear less likely to access clinical genetics services than others in the UK. BME people face a number of challenges in using clinical genetics services effectively including language barriers; cultural sensitivity and being required to complete a Family History Questionnaire before assessment - some patients found this difficult if their relatives were abroad.⁶⁸

The research identified what worked well in services engaging with BME communities. Referral by a 'trusted' clinician was valued, as was having person-to-person communication and being offered more than one appointment and receiving additional or follow-up information on risk and prevention, including being offered regular X-rays or examinations to detect cancer early.⁶⁸

The tragedy of delayed diagnosis and referrals

Cynthia Dwyer's husband Hugh died for prostate cancer aged 59 in June 2010. Despite having symptoms akin to early prostate cancer for three years, he was not given a rectal examination of the prostate cancer or a PSA blood test by his GP.

After changing GP and pressure from Cynthia, Hugh was eventually seen by an oncologist at Warwick Hospital and treated with hormone therapy, radiotherapy and chemotherapy. Sadly, the diagnosis and treatment came too late for Hugh.



Cultural barriers

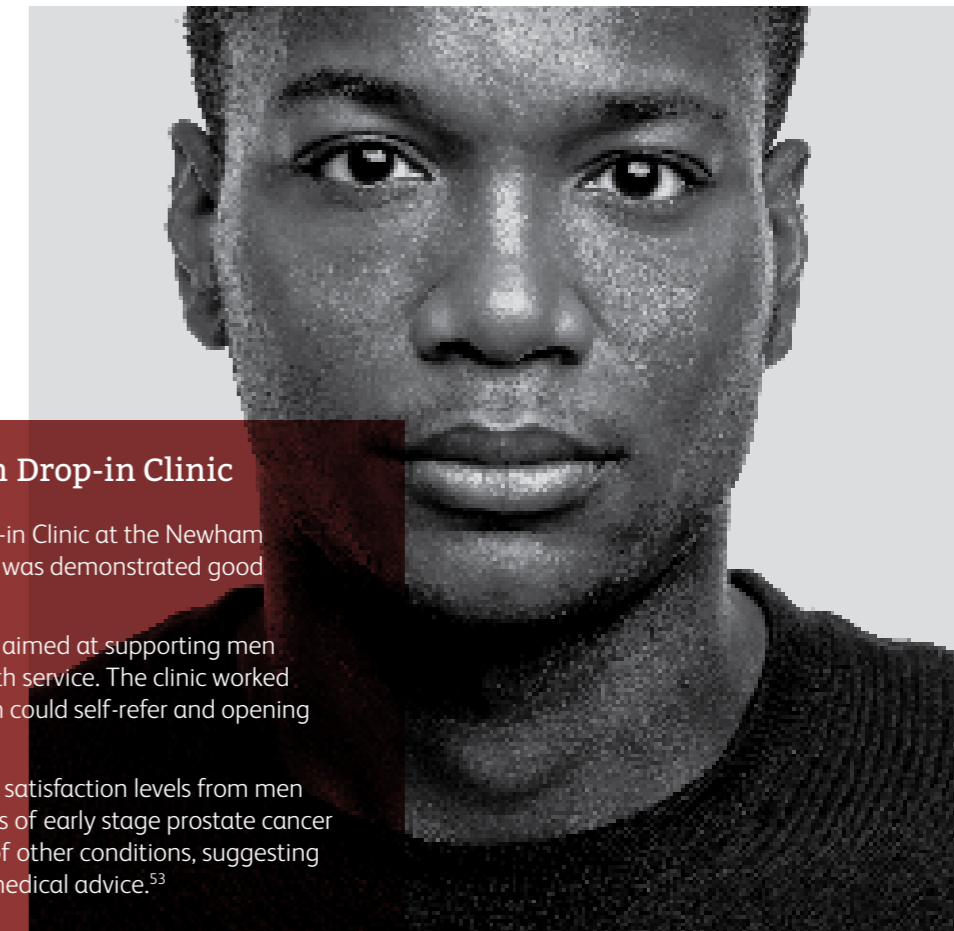
Cultural influences may, in the case of some black men, create barriers to accessing health services. A study on the generational changes in health and the determinants of health of the black Caribbean population in the UK identified differences between the first and second generations in relation to various health conditions: in terms of mental health services second generation black Caribbean patients express less satisfaction with services than first generation black Caribbean and white patients.⁷¹ Additionally, research by Genetic Alliance UK found that cultural influences of those born or educated in the UK can affect their trust of healthcare professionals.⁶⁸

With regards to prostate cancer, a study found that first generation black Caribbean men were less likely to proactively ask healthcare professionals questions about their condition or treatment. The elderly men interviewed saw the consultant role as authoritative, and were therefore less likely to ask questions.⁸

It has also been the experience of BME Cancer Communities that some black men, particularly older men, diagnosed with low risk early prostate cancer may not understand active monitoring or may not be aware of the side effects of treatment. Advice and information given to men on treatments and

their side effects must be clear and up-to-date. This should include any technological advances and new procedures in radiotherapy and other services.

Myths in the black community about cancer can also inhibit understanding of prostate cancer. Research, including from America, also indicates that there are some cultural misunderstandings regarding methods of diagnosis and treatment are widespread, with prostate cancer testing and treatment being perceived as a threat to men's sense of masculinity.⁶⁹



Newham Prostate Health Drop-in Clinic

The Newham Prostate Health Drop-in Clinic at the Newham African-Caribbean Resource Centre was demonstrated good practice in the community.

The clinic was an innovative model aimed at supporting men that may feel excluded by the health service. The clinic worked to meet the needs of the men. Men could self-refer and opening hours were flexible.

Evaluations of the clinic found high satisfaction levels from men using the clinic. Nine new diagnoses of early stage prostate cancer were made, along with diagnoses of other conditions, suggesting men used the clinic for accessible medical advice.⁵³

Elijah's story

Elijah Ashanti Israel, a professional musician and poet, was not aware of his increased chances of developing prostate cancer until he offered to volunteer at a community led BME cancer awareness event.

As a result of listening to the stories of men affected by prostate cancer and healthcare professionals, Elijah, in his own words, "became uncomfortably aware that I am indeed, a black male, pushing 65... I took heed and immediately after the event made an appointment with my doctor."

His doctor listened to his concerns and arranged a PSA test after asking him why he wanted the test, and if he had any symptoms. Elijah said he had "slight irregularities in my water works, which I think are probably due to wear and tear, but nothing specific."

Just over a month later, Elijah was diagnosed with early stage aggressive (or high risk) prostate cancer. Elijah has since had hormonal treatment and completed radiotherapy treatment at the end of 2012.

Elijah has written a song about his experience of radiotherapy called "Tree Cups of Chrystal Clear Waata". He was asked to drink three cups of water during his radiotherapy treatment. The song will be used to raise funds for BME prostate cancer support.

Elijah is now an ambassador for prostate cancer awareness raising.



Family and community: support and care for black men with prostate cancer

Men and their families are profoundly affected by the diagnosis of prostate cancer. Being diagnosed and undergoing treatment can leave many feeling significant anxiety and depressive symptoms.⁷² Men have described care and help from their family, friends and communities as being key. Churches have also been cited as highly valued source of help outside the family.⁸

Prostate cancer support groups can offer valuable support and information to men affected by prostate cancer. The charity Prostate Cancer UK has an online database of over 70 support groups across the country.⁷³ The Prostate Cancer Support Federation also enable men with prostate cancer and their carers to contact local support groups.⁷⁴

The Prostate Cancer Equality Action Plan called for the creation of a series of community outreach workers on BME and cancer issues, as the expert working group believe that the most effective way to raise awareness of prostate cancer in

black men is through sustained, community-based action.⁴⁷

The North London based charity Cancer Black Care and the African-Caribbean led Association of Prostate Cancer Awareness also provide established supportive services for black men and carers affected by prostate cancer. Communities without support services could learn from the experiences of these organisations.

Friends and Bredrins project⁷⁵

Friends and Bredrins is a support group aimed at helping African Caribbean men and anyone with a shared experience of cancer in the East Midlands. The majority of the group's members are men with prostate cancer. Along with educational talks and information on cancers, the group provide peer-to-peer support and advice to one another. BME Cancer Communities and Self Help Nottingham assisted prostate cancer patient Wayne Marston to set up the group.

The official launch in October 2012 helped to raise awareness about the *Cancer Does Not Discriminate* Campaign.



Amdani Juma, Chief Executive, African Institute for Social Development

The African Institute for Social Development (AISD) is a volunteer African-led community organisation in Nottingham that enables people of African origin to access health services, information and support.

Four years ago, one of our founding members was diagnosed with advanced prostate cancer. He was treated for prostate cancer but sadly

passed away. He was in his early 50s and his sudden death was a shock to us all.

His life was cut short due to a lack of awareness. None of us recognised his symptoms (such as urinating frequently), as we did not have any knowledge of cancer in our communities.

We are now involved in promoting cancer in our

communities. In 2012 we joined the NCAT *Cancer Does Not Discriminate* campaign and we continue to work with BME Cancer Communities to promote and inform men and women in our community of cancer.

Prostate cancer and cancer is a massive issue for us now. We want to see more research on prostate cancer in African communities.

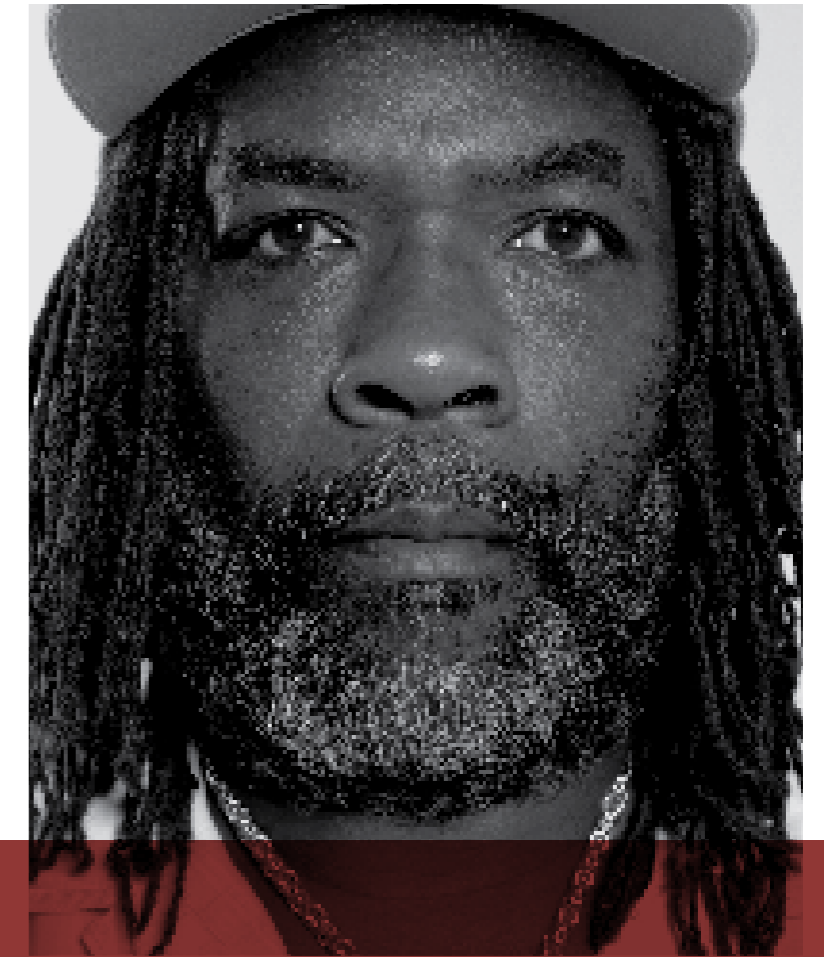
A way forward: recommendations

Prostate cancer in black African-Caribbean men is a clear area of health inequality; black men have a higher risk of prostate cancer, they present with it at a younger age and are more likely to die from prostate cancer than white men. This health inequality not only affects the men, but their families, friends and communities.

The evidence in this report demonstrates that action is needed to improve the outcomes of black men with prostate cancer, to better understand the increased risk, dismantle barriers to accessing health services and address cultural concerns.

Recommendations for national policy-makers

- The National Institute for Health Research (NIHR), the National Cancer Research Institute (NCRI) and partner organisations to fund further research on the experience and outcomes of black men with prostate cancer in England, including a better understanding of the cultural barriers and their support needs.
- The National Cancer Intelligence Network (NCIN) to continue to collect and analyse cancer data on ethnicity. NCIN to produce online evidence-based reports on ethnicity and cancer.
- The new NHS improvement body should identify a lead director on cancer and ethnicity to continue the work of the National Cancer Action Team (NCAT) programme tackling cancer inequalities.
- Public Health England to fund a national campaign to raise awareness of prostate cancer for all men, with emphasis where appropriate on black men, delivered locally in partnership with community groups.
- Public Health England to fund a national campaign to raise awareness of prostate cancer in high risk BME communities. The campaign should be delivered locally to reach BME communities.
- Prison services and mental health services to ensure all black men have access to information about their increased risk of prostate cancer, and access to tests, treatments and a cancer information helpline.
- The Department of Health and prostate cancer charities to fund and support evaluated prostate cancer awareness raising sessions in prisons and mental health facilities for staff and men with an increased risk of prostate cancer.
- The National Institute for Health and Clinical Excellence (NICE) to ensure that future guidelines and quality standard on prostate cancer include a focus on black men and prostate cancer.
- The National Institute for Health and Clinical Excellence (NICE) to ensure that future guidelines and quality standards on prostate cancer include a greater focus on black men and prostate cancer, and the effectiveness of treatments for men of African genetic heritage.
- The national cancer patient survey to further investigate the experiences of men with prostate cancer to gain a better understanding of the support and care they receive, as well as aim to increase responses from BME patients.
- The Department of Health to ensure that equality metrics for the NHS Outcomes Framework and *Improving Outcomes: A Strategy for Cancer* include data and indicators on ethnicity.
- The BME Cancer Alliance '10 Calls for Action', launched in the House of Commons in December 2012, to be a recognised resource to inform policy makers.



Recommendations for local organisations

- Strategic Clinical Networks and commissioners to prioritise prostate cancer services and focus on unwarranted variations in service and outcomes, including those of black men.
- Clinical commissioning groups and local authorities should contract local arrangements to enhance identification and early diagnosis of men who are at higher risk of prostate cancer, including black men
- Health and Well-Being Boards should appoint a BME lead to ensure strategy and interventions tackle health inequalities are delivered.
- Health and Well-Being Boards should ensure that JSNAs review health data on BME groups, including black men with prostate cancer. Where data is not available, measures should be taken to address this.
- Local authorities in their public health remit should provide BME cancer awareness training for GPs and other healthcare professionals to highlight the increased risk of prostate cancer in black African-Caribbean men and other cancers that disproportionately affect BME groups, and the importance of equality data recording.
- Local authorities should fund community outreach workers on BME and cancer issues to raise awareness of prostate cancer and other cancers in local BME communities.
- Commissioners should adopt 'reverse commissioning' and engage with local BME communities and local providers to ensure services are in place to meet local needs.



A concerted approach is needed on the part of national policy-makers and health bodies, as well as local organisations to improve ethnic data collection for all BME communities, and address the challenges and barriers across the prostate cancer care pathway.

Conclusion

The uncomfortable reality of prostate cancer in black men is that they have poorer outcomes than white men, and despite the commitment to reduce cancer inequalities, limited action has been implemented to address this inequality. A concerted approach is needed on the part of national policy-makers and health bodies, as well as local organisations to improve ethnic data collection for all BME communities, and address the challenges and barriers across the prostate cancer care pathway.

The author of this report also calls for a solution to the development of an NHS prostate cancer screening programme in the UK. Black men of African-Caribbean and African descent join with all men to call for UK research bodies to identify a solution as soon as possible, in partnership with international organisations.

The author also asks that BME community groups continue to be supported to deliver cancer awareness raising in black and other BME communities across the country.

Finally, this report ends with a comment from the PROCESS study:

“Our observation that younger black men were at greater relative risk is interesting and potentially important because such men have longer remaining life expectancy than their older counterparts and may have more to benefit from screening and early treatment. A case for screening would be further supported if one believes that black men have a worse prognosis, as suggested from US data... Any decision to introduce population-based screening must have strong evidence that the benefits of screening outweigh the potential adverse effects.”²

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