HEAR ME NOW
ONE YEAR ON

COMMUNITIES’ CALL TO ACTION
TO ADDRESS THE BURDEN OF
PROSTATE CANCER IN BLACK
AFRICAN-CARIBBEAN AND BLACK
AFRICAN MEN

A report by Rose Thompson,
BME Communities, April 2014

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All views expressed in this report are those of the
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About the author

Rose Thompson is Director of BME Cancer Communities, a social enterprise addressing cancer inequalities within black and minority ethnic (BME) and low income communities. Rose is a radiotherapy radiographer, qualified to superintendent grade, with over 26 years’ clinical experience in radiotherapy departments in London and the Midlands, where she was awarded two discretionary points for her work with children and BME communities.

In 2003, after a nine 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 first Black and Minority Ethnic Cancer Information Specialist (2003-2007) and the first 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.

Rose is also Chair of the Nottingham African Caribbean Health Network and on the management team of Cancer Equality, the charity that founded and coordinates Ethnic Minority Cancer Awareness Week. She is a member of the Awareness and Early Detection Work Group that contributed to the development of the Cancer Reform Strategy 2008.

Rose, as a recognised expert on BME and cancer, has contributed to numerous ground-breaking cancer initiatives in the UK to reduce cancer inequalities.

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 all the people who have contributed to this report by sharing their expertise, experiences and attending the local Hear Me Now meetings.

A special thank you must go to Frank Chinegwundoh, Consultant Urologist Surgeon and Chair of Cancer Black Care and Vivienne Lyfar-Cissé for their invaluable contributions to the report.

I am also indebted to community leaders from diverse community organisations, in particular the Association of Prostate Awareness, Black Health Initiative and the Friends and Bredrins support group for their insightful contributions to this report.

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The facts are that black men are more than twice as likely as white men to develop prostate cancer.
It is over a year since I launched the report *Hear Me Now: The uncomfortable reality of prostate cancer in black African-Caribbean men* in Parliament. Prostate cancer remains the most common cancer in men. It is encouraging to hear that, despite the high prevalence, most men will survive prostate cancer and go on to lead fulfilling lives. However, the facts are that black men are more than twice as likely as white men to develop prostate cancer, and they are also more likely to have prostate cancer at a younger age. All men with close relatives who have been diagnosed with prostate cancer are also at higher risk of the disease. Black men are twice as likely to die of prostate cancer than white men, and prostate cancer accounts for double the proportion of deaths under the age of 75 among black men, than among men in England overall. The *Hear Me Now* programme has been and continues to be determined to address the burden of prostate cancer among men at higher risk, such as black African-Caribbean and black African men.

Over the past year, a series of *Hear Me Now* local roundtable meetings were held in London, Leeds, Nottingham and Birmingham. The meetings brought together community and support organisations representing black men with leading experts in prostate cancer, from clinicians and commissioners to Councillors, patients and carers. In addition to assessing the work already undertaken in prostate cancer locally, these meetings developed strategies to address the issues around the lack of awareness and late diagnosis of prostate cancer among black African-Caribbean and black African men.

In order to save lives and improve outcomes, it is crucial that men at higher risk are identified earlier, and that the challenges outlined to address this in the second *Hear Me Now* report are tackled without delay.

At a national level, there must be concerted efforts to identify prostate cancer as early as possible in higher risk groups. Data on ethnicity also needs to be improved, so that cancer inequalities can be effectively tackled and progress measured.

Locally, there must be joined-up working not only between local authorities, Clinical Commissioning Groups, the health service and the voluntary sector, but also in partnership with BME community organisations, which must be supported to increase awareness of prostate cancer in their local populations. In parallel, it is essential that health professionals are aware of which patients are at higher risk of prostate cancer, and are prepared to discuss informed choice PSA testing, especially with men at higher risk.

My thanks go to Rose Thompson for this important report, and for the excellent work that she and others do to help black and minority ethnic communities. I would also like to thank Janssen for their support for this project.

David Lammy
MP for Tottenham
Sean Duffy
National Clinical Director for Cancer, NHS England:

“The ‘Hear Me Now, One Year On’ report tells an inspiring story of communities coming together to take action to address the health inequality faced by black African-Caribbean and black African men with prostate cancer.

“Black men are twice as likely to develop prostate cancer than their white counterparts and are more likely to have the disease at a younger age. I support this report’s ambition to raise awareness of black African-Caribbean and black African men’s higher risk of prostate cancer and improve early diagnosis rates.

“The report’s recommendations represent an insightful set of enablers that if acted upon, would support better collaboration between Health and Wellbeing Boards, Clinical Commissioning Groups, providers and community organisations and help them to achieve better outcomes for men at a higher risk of prostate cancer.”

Duncan Selbie
Chief Executive, Public Health England:

“We welcome the ‘Hear Me Now, One Year On’ report, which shares key learnings following local engagement to improve awareness and diagnosis levels of prostate cancer in the male black African-Caribbean and black African population.

“Figures show that black men have over double the risk of developing prostate cancer, and are twice as likely to die from prostate cancer compared to their white counterparts. These are shocking and worrying statistics, and Public Health England is pleased to support this significant report, which raises awareness of this particular form of cancer among the black African-Caribbean and black African community.

“It is important that men, from all communities, are aware of symptoms that are associated with prostate cancer. These include, the need to urinate often, especially at night, and straining to urinate or taking a long time to finish. Our message is: Do not delay, if you are experiencing any symptoms or suffering from any discomfort, do go and see your GP.”
Bob told attendees at the Hear Me Now meeting in Newham, East London, how he first visited his GP ten years ago after noticing that his urinary flow had become slow, followed by an increased frequency in the need to urinate. Despite Bob asking for a PSA test, his doctor declined the request as he did not agree that a test was needed. Bob continued to experience the same symptoms and three years later, he visited his GP again, who once more did not put Bob forward for a PSA test.

Bob then went to hospital, where he undertook several tests and was prescribed tablets. After three years, his quality of life had still not improved, so he decided to return to hospital. He had a prostate biopsy which diagnosed prostate cancer and showed that he required further treatment. He was given a choice of radical surgery or radiotherapy. Bob opted for surgery, which he had in early 2006.

After surgery, Bob’s quality of life improved 100 per cent. He was given a PSA test every six months for a period of two years, and annually after that. However, the test results were not communicated to Bob by his GP; Bob assumed that his doctor would tell him if his PSA levels had gone up. It was only because his medical notes went missing that Bob ended up finding out that his PSA levels were higher than they should have been after radical surgery.

At the time of writing, after having seen a specialist Bob had completed a seven-week course of radiotherapy and was due to have another PSA test in six months’ time.
Executive Summary

Since the launch of the report, *Hear Me Now: The uncomfortable reality of prostate cancer in black African-Caribbean men*, a series of roundtable meetings were held in London, Leeds, Nottingham and Birmingham as part of the *Hear Me Now* programme. The meetings highlighted, and aimed to address, issues of lack of awareness and late diagnosis of prostate cancer in the male black African-Caribbean and black African population.

Addressing these issues is highly relevant for the Coalition Government’s 2010 cancer strategy, *Improving Outcomes: A Strategy for Cancer*, which set out the aim of saving an additional 5,000 lives from cancer every year by 2014/15, whilst also narrowing the inequalities gap in cancer. Key policy drivers to reduce inequalities between patients also exist in the form of the Equality Act 2010 and the Health and Social Care Act 2012 respectively. In addition, the All Party Parliamentary Group (APPG) on Cancer’s 2013 report, *Cancer across the Domains*, calls for improvements in cancer survival rates. Meanwhile, the Black Minority Ethnic (BME) Cancer Patient Information Survey report, which was launched in Parliament in February 2014, indicates that some aspects of BME cancer patient experience could be improved.

The first UK studies, which focused on London and Bristol, demonstrated black men’s three-fold increased risk of prostate cancer, there was little information around black men’s prostate cancer death rates.

More recent data looking at the national picture shows that black men in England are currently more than twice as likely to develop prostate cancer than white men, and they are more likely to have prostate cancer earlier than white men. Men with a family history of prostate cancer also have a higher risk of developing the disease. Black men are twice as likely to die of prostate cancer than white men, and prostate cancer accounts for double the proportion of premature deaths (under the age of 75) among black men, than among men in England overall.

Despite this increased risk of prostate cancer, delegates at the *Hear Me Now* local meetings heard how some black African-Caribbean and black African men in their 50s who made appointments with their GPs to discuss prostate cancer and their right to an informed choice PSA blood test were denied the test. The tests were denied based on evidence that should not have been applied to black men, or other men with an increased risk due to a family history.

Black men repeatedly reported at the *Hear Me Now* meetings and in contact with BME Cancer Communities and other BME organisations that they were informed by their GPs that they were too young to develop prostate cancer. The primary reason for not undertaking a blood test appeared to be lack of awareness about black men’s increased risk of prostate cancer and its occurrence in younger men. General cancer awareness also appeared to be lacking amongst some GPs, as prostate cancer was also frequently not suspected due to lack of signs and symptoms. It is well documented that early prostate cancer may not have symptoms.

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*a British African Caribbean people are residents of the United Kingdom who are of West Indian background and whose ancestors were primarily indigenous to Africa. As immigration to the United Kingdom from Africa increased in the 1990s, the term has sometimes been used to include UK residents solely of black African origin, or as a term to define all Black British residents, though the phrase “African and Caribbean” has more often been used to cover such a broader grouping. This report focuses on existing evidence relating to black African-Caribbean and black African men.

*b In the NHS in England, men aged 50+ can have a PSA test provided they have discussed the pros and cons with their GP.*
“Friends and Bredrins Support group is brilliant. This is what people really need. Even when I was in hospital they were there for me.”

Derrick Powell, member of Friends and Bredrins, Nottingham
Furthermore, there appeared to be a difference of opinion amongst some GPs about PSA threshold levels to trigger a referral. Some of the men reported significantly higher levels without a referral – despite the NHS Prostate Cancer Risk Management Programme (PCRMP) indicating when a referral should be made after a PSA test result.10

It is important for there to be informed choice PSA testing. Health service and local authority professional representatives who attended the Hear Me Now meetings indicated that there is a need to support health professionals, including GPs and other front line health service workers, with an awareness-raising information programme about prostate cancer and its increased risk in black men. Professionals in attendance were keen to engage with black men in the community and black community organisations.

In addition to the need for increased understanding of prostate cancer testing among health professionals, it was also seen as important to raise awareness in higher risk communities to encourage and empower men to ask their GPs for tests, including by harnessing the persuasive power of family members.

Crucially, good data collection by ethnicity is required for NHS England, Clinical Commissioning Groups (CCGs) and local authorities not only to plan and commission services to meet the needs of people with prostate cancer, but also to understand and reduce differences and inequalities between patients. However, data presented at the Hear Me Now local meetings showed that ethnicity is currently recorded more in death than in life.8 Currently, prostate cancer accounts for three in five of the cancer cases in England which have no known ethnicity.8

The Hear Me Now meetings emphasised that in order to commission services that meet the health needs of local communities, it is important not only to have meaningful engagement with the local community, but also for local communities to be approached in a way that respects their diverse skills and expertise. Community organisations were seen as having a vital voluntary role in engaging with their local populations, but partners needed to be aware of costs to these organisations and factor in adequate funding from the outset.

The meetings also underscored the importance of partnership working in the new health and wellbeing landscape, given that a broader range of organisations are now involved in preventing cancer and in treating and supporting people through cancer. It is essential for there to be effective partnership between all relevant stakeholders, so that BME patients have equality of access to appropriate emotional and practical support.

This report shares the experiences of the Hear Me Now local meetings, collates the evidence and makes a number of recommendations for action by national policy-makers and local organisations. The recommendations aim to ensure that men at higher risk of prostate cancer, including black African-Caribbean and black African men, and men with a family history of prostate cancer, can be identified early and treated effectively.

“A huge thank you to the Friends and Bredrins group for allowing me to attend the February meeting in Nottingham. My experience is one which will stay with me for the rest of my life. It was amazing to meet such a strong and inspiring group of men who despite their experience of cancer still remain energised, full of hope and optimism.

“Listening to their personal experiences has provided me with so much knowledge and insight into how prostate cancer affects black men. I learned more about prostate cancer in those two hours than I have ever done by reading books and articles. I am truly grateful for all the group members for making me feel comfortable and part of the group. Their complete openness, honesty and sincerity were valuable in allowing me to learn more about prostate cancer but more importantly about them as people. The members are complete legends.”

Jawad Mahboob, Outreach Worker, BHA, Manchester
This report shows that the experience of prostate cancer in black African-Caribbean and black African men is a clear inequality. Black men in England have over double the risk of getting prostate cancer, compared to white men, and they are also more likely to have prostate cancer at an earlier age. Black men have double the risk of dying from prostate cancer than white men, and prostate cancer accounts for double the proportion of premature deaths (under the age of 75) among black men than among men in England overall. It is also known that men with a family history of prostate cancer have a higher risk of developing the disease.

The evidence outlined in this report demonstrates that a concerted effort is needed to ensure that those at higher risk of prostate cancer can be identified early and treated effectively, in order to save lives and maximise the effectiveness and cost-effectiveness of health services.
Recommendations for national policy-makers

NHS Outcomes Framework

The Secretary of State for Health to include prostate cancer in Section 1.4iii and 1.4iv of the NHS Outcomes Framework. In addition CCGs with significant black African-Caribbean and black African populations should report annually to NHS England on prostate cancer outcomes for black African-Caribbean and black African men, in line with the statutory duty on the Secretary of State to have regard to the need to reduce health inequalities.

Prostate cancer screening

In 2014 NHS Cancer Screening Programmes - part of Public Health England – are due to evaluate the decision not to introduce a prostate cancer screening programme. Given the increased risk, higher mortality rates and earlier onset of prostate cancer in black African-Caribbean and black African men we recommend:


— The PCRMP should create Patient Information Sheets specifically tailored for black African-Caribbean and black African men, which outline their increased risk of prostate cancer and address some of the cultural barriers to testing and access to care. The leaflet should be designed to be distributed by community organisations as well as primary care staff.

— Every GP should hold a register of black African-Caribbean and black African men aged over 45 and send them the tailored Patient Information Leaflet to encourage them to come forward for an informed choice PSA test.

— GPs in areas with a significant black African-Caribbean and black African population should use the register to record PSA data for black African-Caribbean and black African men. This should be part of a ‘Know your numbers’ pilot campaign, targeting areas where there is a high black African-Caribbean and black African population.

— GPs’ additional administrative costs to hold this register and distribute the leaflet should be covered by locally enhanced service funding.

— Where men have been diagnosed with prostate cancer, the programme should include notification of their first degree male relatives - including sharing their family member’s age at diagnosis.

— PCRMP should be refreshed in order to raise health and social care professionals’ awareness regarding the importance of early detection through current prostate cancer diagnostic tests for men with an increased risk of prostate cancer, such as black African-Caribbean and black African men. These men are more likely to be younger than expected at diagnosis and therefore are more likely to be living with prostate cancer for a longer period than their white counterparts.
| NICE Quality Standard on prostate cancer | The National Institute for Health and Care Excellence (NICE) to ensure that their upcoming Quality Standard on prostate cancer includes a Quality Statement on the increased risk of prostate cancer to black African-Caribbean and black African men. NICE should also review the evidence for reducing the recommended age for an informed choice PSA test for black African-Caribbean and black African men to 45, as part of the Quality Statement. |
| Community engagement | Public Health England to work in partnership with the leading cancer charities to set up an advisory board to develop best practice guidance on how CCGs and local authorities should work with community-level organisations to tackle the health inequality faced by black African-Caribbean and black African men with prostate cancer. |
| Be Clear on Cancer campaign | Public Health England’s Be Clear on Cancer campaign should establish local pilots to educate GPs and other primary care professionals about the appropriate diagnostic tools for men (particularly black African-Caribbean and black African men), in order to reduce the large amount (30%) of newly diagnosed prostate cancers being identified at an advanced stage. Be Clear on Cancer should also consider a broader public-facing prostate cancer health campaign. |
| JSNAs and Health and Wellbeing Strategies | Public Health England to work with local authorities with significant black African-Caribbean and black African populations to ensure that Joint Strategic Needs Assessments (JSNAs) appropriately review the needs of black African-Caribbean and black African men accessing health services. Where concerns around access for high risk groups (such as black African-Caribbean and black African men) are identified, this should be addressed in the local Health and Wellbeing Strategies, and local commissioners should endeavour to establish other evidence-based access points. The most prominent example is the Newham Community Prostate Clinic, where 50% of the men who visited the Newham clinic said that they would not visit a GP. |
| National Prostate Cancer Audit | It is welcomed that the National Prostate Cancer Audit includes ethnicity in its specification, but the Audit should also facilitate the comparison - by ethnic groups - of PSA score at presentation and cancer stage, grade and Gleason score at diagnosis. |
| Cancer Patient Experience Survey | NHS England to ensure that the Cancer Patient Experience Survey aims to increase responses from BME groups, and adopt the recommendations from the 2014 national survey of BME Cancer Experience. |
| NHS Health Check | Public Health England should work with local authorities and community organisations that engage and involve black African-Caribbean and black African men, to pilot informed choice PSA testing as part of the NHS Health Check for men aged 45 upwards in areas with a significant population of black African-Caribbean and black African men, and if successful consider implementing for all men. |
| Research | Cancer research funders including the National Cancer Research Institute, National Awareness and Early Diagnosis Initiative, Cancer Research UK and Movember (via the UK’s identified funding benefactor – Prostate Cancer UK) should aim to fund more research on access to prostate cancer diagnostic services, socio-economic deprivation and lifestyle, in relation to prostate cancer and ethnicity, and up-to-date evidence on prostate cancer and ethnicity should be accessible via the National Cancer Intelligence Network website. |
Recommendations for regional and local organisations

**Recognising prostate cancer as a priority**
- NHS England regional teams and Health and Wellbeing Boards should identify prostate cancer as a priority, particularly for men at higher risk, such as black African-Caribbean and black African men, and men with a family history of prostate cancer.
- Local authorities with significant black African-Caribbean and black African populations should ensure that prostate cancer is recognised as a priority in JSNAs and Health and Wellbeing Strategies.

**Prostate cancer testing**
- Local authorities with significant black African-Caribbean and black African populations should include informed choice PSA testing as part of the NHS Health Check. NICE recommendations for local authorities to prevent chronic conditions in BME groups provide a precedent for targeting communities at higher risk of developing a disease.
- NHS England regional teams should work with CCGs to ensure that clinicians Make Every Contact Count by raising the issue of prostate cancer whenever they have interaction with high risk groups, such as black African-Caribbean and black African men over the age of 45, or 40 if there is a family history of prostate cancer.

**Community engagement**
- As part of their public health remit, local authorities should provide sustainable financial support to community organisations to raise awareness of prostate cancer in local BME communities, in particular during Ethnic Minority Cancer Awareness Week.
- NHS England regional teams should work with CCGs and the BME voluntary sector to promote community engagement as part of clinicians’ contracted work, and ensure that health professionals are engaging with BME and community organisations, who are the experts on community engagement and involvement. In particular, CCGs should look at commissioning secondary care to undertake work such as early detection initiatives in the community.

**Data on prostate cancer**
- Where local health data on BME groups is not available, local authorities and the NHS should adopt ‘reverse commissioning’, in order to generate evidence based on service utilisation and ensure that services are in place to meet local needs.

**Quality of life**
- CCGs should ensure that therapeutic remedies, such as counselling, are offered when men are told they have cancer, to enhance patients’ quality of survival. In addition, men who have a family history of prostate cancer should be signposted to genetic counselling services.
It is important that men, from all communities, are aware of symptoms that are associated with prostate cancer.
Introduction

According to Cancer Research UK figures released in November 2013, prostate cancer death rates in the UK have fallen by a fifth since the early 1990s. This is positive news. However, as Cancer Research UK also notes, “more work needs to be done to reduce the number of men dying from this disease even further.”

Ethnic data monitoring in the NHS was woefully inadequate in the early 1990s and whilst improvements have been made, lack of data delayed the first validated report on ethnicity and cancer, *Cancer Incidence and Survival: By Major Ethnic Group*. When the 2009 report was launched and made available via the National Cancer Intelligence Network (NCIN) website, 37% of men with prostate cancer had no ethnic identification.

Robust UK prostate cancer incidence rate data for black men was not specifically available until the North East London study led by Consultant Urological Surgeon, Dr Frank Chinegwundoh. The study paved the way for the larger PROCESS cohort study in London and Bristol. However, prostate cancer death rates for black men were not readily available until a 2012 NCIN report, Mortality from Prostate Cancer, which included black men’s increased incidence and death rates.

As described in the 2013 report, *Hear Me Now: The uncomfortable reality of prostate cancer in black African-Caribbean men*, black men’s prostate cancer death rates were 30% higher than white men’s.

At the Nottingham *Hear Me Now* meeting in October 2013, Dr Luke Hounsome, Principal Cancer Intelligence Analyst at Public Health England, presented more recent national evidence that black men’s death rate from prostate cancer was double that of white men.

We can therefore assume that the positive news on prostate cancer death rates in November 2013 was not inclusive of black men’s experience. In fact the media coverage led to some confusion in the black community, where there is increasing anecdotal and now validated evidence, as noted above, to suggest the contrary.

The Coalition Government’s 2010 cancer strategy, *Improving Outcomes: A Strategy for Cancer*, outlined the aim of saving an additional 5,000 lives from cancer every year by 2014/15, whilst also narrowing the inequalities gap in cancer. In addition, the Equality Act 2010 and the Health and Social Care Act 2012 are key policy drivers to advance equality and to reduce inequalities between patients respectively. Meanwhile, in December 2013 the All Party Parliamentary Group (APPG) on Cancer published its report Cancer across the Domains, which highlights the need for improvements in cancer survival rates.

“There used to be a funeral catered for about once a week at our local African Caribbean community centre in Manchester, but now there are about three a week. With black men you often don’t know they had prostate cancer until the funeral. Cancer seems to be increasing quickly in the black community and we are now burying younger people in their 40s and 50s.”

Deanne Heron, author of *Pardner Money Stories* and radio presenter.
Further to the publication in February 2013 of *Hear Me Now: the uncomfortable reality of prostate cancer in black African-Caribbean men*, four *Hear Me Now* meetings were held during Autumn/Winter 2013 in Birmingham, Leeds, London and Nottingham, all of which have a significant black population. The *Hear Me Now* programme is led by a steering group consisting of BME Cancer Communities, Cancer Black Care and the NHS BME Network. It is sponsored and facilitated by Janssen.

The meetings brought together leading experts in prostate cancer services, such as cancer charities, black African-Caribbean and black African community organisations and prostate cancer patient groups, local authority representatives (public health directors and Councillors), CCG representatives and NHS health professionals, including consultants and nurses from the local urology and oncology departments. The objective was to assess work already undertaken locally in prostate cancer and jointly develop strategies that would address the issues around lack of awareness of the condition and late diagnosis. At each of the meetings, a local action plan was agreed with the aim of helping to improve life expectancy and address the burden of prostate cancer in the local male black African-Caribbean and black African population.

This report sets out the findings from the local meetings, in addition to evidence from research and case studies demonstrating that prostate cancer in men at higher risk, such as black African-Caribbean and black African men, and men with a family history of prostate cancer, remains a significant health inequality in England. The report also shows that data on prostate cancer and ethnicity needs to be significantly improved in order to have visibility of, and to help narrow, the inequality gap.

The report outlines the need to increase awareness of informed choice PSA testing especially with regard to high-risk groups, both among BME communities and health professionals across the prostate cancer care pathway. It also examines the important role of community-level organisations and of a partnership approach in tackling prostate cancer. The report makes a number of recommendations to address prostate cancer inequalities in men at higher risk of the disease.

*more work needs to be done to reduce the number of men dying from this disease*
Case Studies

A family history of prostate cancer

Pastor George Crawford’s father died of prostate cancer in Jamaica at the age of 86, and Pastor George’s older brother died of prostate cancer in his 60s. Pastor George, who attended the Hear Me Now meeting in Leeds, and his other four brothers have all been diagnosed with prostate cancer.

Pastor George had no symptoms of prostate cancer, but visited his GP to request a test at the insistence of his sister, a nurse in Jamaica. George’s GP did not hesitate, and his PSA test was carried out at Leeds General Infirmary. He was diagnosed with prostate cancer and was treated with radiotherapy.

Pastor George is now fit and active and attends regular check-ups. Pastor George says that through being a BHI Health Ambassador he has seen many people suffer before dying from prostate cancer as well as being fortunate to have been able to inform and educate his peers on prostate cancer, dispelling myths and providing factual information on this health issue. He emphasises the need for culturally appropriate information, help and support to be provided as this is necessary to educate men most at risk, especially black African and African-Caribbean men.

A dual heritage man’s story

Graham Forde is of African-Caribbean/English dual heritage. He lives in Nottingham. Graham’s father, who came to the UK from Barbados in the late 1940s, had a lot of medical issues with his health throughout his life. This made Graham aware that he needed to make sure that he was ok and have check-ups with his GP if he was aware of any irregularities with his health.

When Graham reached the age of 50, he started to take more notice of what his body was telling him. Through listening to the local community radio, which covered lots of issues on health in the African-Caribbean and wider community, Graham had also become aware that, based on initial studies, African-Caribbean men were three times more likely to get prostate cancer than some other male ethnic groups.

At the age of 58, Graham decided that he should get tested for prostate cancer. He went to his GP and asked for a test. The GP asked Graham why he wanted a test, and Graham replied that it was because of his age. Graham’s GP said that they did not do the test unless there was a problem that might indicate that the test was needed. He left the GP surgery feeling a little disappointed.

Graham talked to a presenter at the community radio station about his experience, who told him that he should go back to the doctors and demand that he be tested, stating that because of his heritage he was more likely to get prostate cancer. Graham went back to his GP and saw a different doctor in the practice. He asked for the test again, and this time he was offered the test without having to insist. A blood sample was taken and sent for testing, and the results came back negative.

Graham’s perception is that it seems in some GP practices that it can be ‘luck of the draw’, as how likely you are to be offered tests depends on which doctor you see.
Prostate cancer and diagnosis

Prostate cancer is the most common cancer diagnosed in men in the UK, accounting for a quarter of all cancer cases in men. It is also the second most common cause of death from cancer among UK men after lung cancer.17

The prostate gland is a small gland that is found at the base of men’s bladders, surrounding the urethra. It is about the size and shape of a walnut.6 Prostate cancer occurs when some of the cells in the prostate gland reproduce far more rapidly than normal, causing a tumour.18

Black men have a greater risk of developing prostate cancer than white men.8 Men with a family history of prostate cancer are also at higher risk. Men with an affected father or brother are generally two to three times more likely than average to develop prostate cancer.9 If more than one first-degree relative (e.g. father, brother) is affected, the risk is even higher.3

Prostate cancer: the cancer is inside the prostate gland.21

Prostate-specific antigen (PSA) is a protein which is produced by cells in the prostate gland. A raised or rising level of PSA can indicate that there might be a problem with the prostate, although it does not necessarily mean that this is due to cancer. PSA is measured through a blood test, and the PSA test is one of a number of tests that can be used to help diagnose prostate cancer. It is currently an important test which triggers referral to secondary care urology services, which is important for diagnosing early stage prostate cancer showing no symptoms. Men in England over the age of 50 are entitled to have a PSA test by the NHS, provided that they make an informed choice, e.g. they have discussed the pros and cons with their GP.19

Black men are more likely to have prostate cancer at an earlier age, even in their 40s.8 The NHS Prostate Cancer Risk Management Programme indicates when a referral (i.e. to secondary care urology services) should be made after a PSA test result.6 It is recommended to these guidelines can therefore have serious consequences. In addition, given the risk of prostate cancer at an earlier age, black African-American men and black African men aged over 45 need to be able to have an informed choice PSA test. In the USA, a target screening age of 45 is recommended for African-American men and men with a first-degree relative diagnosed with prostate cancer at an early age, and for men aged 40 whose family history puts them at even higher risk of developing the disease.20

Stage 1

The cancer is very small and confined to within the prostate gland.

Stage 2

The cancer is still inside the prostate gland, but can be felt as a hard lump during a rectal examination.22

Stage 3

Locally advanced prostate cancer: the cancer has spread outside the prostate gland, and may have grown into the tubes that carry semen. It is also frequently asymptomatic (showing no symptoms).10

Stage 4

Metastatic (advanced) prostate cancer: the cancer has spread from the prostate gland to nearby parts of the body such as the bladder or rectum, or further for example to the liver or bones.22

Current referral guidance: “The serum PSA level alone should not automatically lead to a prostate biopsy. Other factors that should be considered in conjunction with the PSA level are prostate size, DRE findings, age, ethnicity, co-morbidities, history of any previous negative biopsy and any previous PSA history. The patient should be involved in any decision about referral to another healthcare provider.” (NHS Cancer Screening Programmes. Prostate Cancer Risk Management Programme information for primary care. PSA testing in asymptomatic men. Evidence document. January 2010.)

Findings from study report by Genetic Alliance UK and the University of Nottingham12
One-year and five-year relative cancer survival rates relate to the percentage of people who will be alive after one and five years (whilst mortality rates mean the percentage of people in a given population who have died from a particular cause). Data presented at the local Hear Me Now meetings indicated that survival rates vary across England, as shown by the examples in the tables below.

Furthermore, of the 9% of men who are diagnosed with prostate cancer through emergency presentation in England, one-year survival is 54%. Evidence shows that prostate cancer survival is related to stage at diagnosis. As outlined in the table below, at one year from diagnosis, the difference in survival between prostate cancer that is localised (Stage 1 or Stage 2) at diagnosis and prostate cancer that is advanced at diagnosis is about 20%.

This means that the proportion of men diagnosed with localised prostate cancer that are expected to survive for one year is about 20% higher than the proportion of men diagnosed with advanced prostate cancer that are expected to survive for one year. At five years, the difference in survival is about 55%, and it is nearly 80% at ten years. Yet in its 2013 report Cancer across the Domains, the All Party Parliamentary Group (APPG) on Cancer drew attention to the problem that, “Too many people are still being diagnosed in the advanced stages of cancer.”

With 30% of prostate cancer patients presenting with advanced prostate cancer, much more needs to be done nationally and locally to lower the proportion of men presenting late. Shifting the curve to early detection and earlier diagnosis by increasing awareness of prostate cancer, running early diagnosis initiatives and improving data collection would not only benefit cancer patients and their families, but also national and local stakeholders involved in commissioning and providing prostate cancer-related services. It is also highly relevant for the NHS Outcomes Framework Domain 1 indicator on ‘Under 75 mortality rate from cancer’, which includes one-year and five-year survival from all cancers.

In addition, the CCG Outcomes Indicator Set 2014/15 includes improvement areas on ‘Under 75 mortality from cancer’, ‘One year survival from all cancers’, ‘Cancer: early detection’, ‘Cancer: diagnosis via emergency routes’ and ‘Cancer: record of stage at diagnosis’. The APPG on Cancer notes that if CCGs focus on one-year and five-year survival rates, this should promote earlier diagnosis, because late diagnosis results in poor survival rates.

### Table 1
#### One-year relative survival for prostate cancer

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>England average</td>
<td>95%</td>
</tr>
<tr>
<td>Newham</td>
<td>90%</td>
</tr>
</tbody>
</table>

### Table 2
#### Five-year relative survival for prostate cancer

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>England average</td>
<td>84%</td>
</tr>
<tr>
<td>Nottingham City</td>
<td>62%</td>
</tr>
</tbody>
</table>

### Table 3
#### Difference in survival between localised and advanced cancer at diagnosis

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>At one year from diagnosis</td>
<td>about 20%</td>
</tr>
<tr>
<td>At five years from diagnosis</td>
<td>about 55%</td>
</tr>
<tr>
<td>At ten years from diagnosis</td>
<td>nearly 80%</td>
</tr>
</tbody>
</table>

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“Technological advances in radiotherapy software and hardware now enable us to deliver radiation very precisely and reduce side effects significantly.”

Dr Santhanam Sundar, Consultant Clinical Oncologist

“By concentrating on increasing early stage at presentation and reducing the emergency route for cancer diagnosis, CCGs and providers can work collaboratively to achieve the outcomes we desire.”

Sean Duffy, NHS England National Clinical Director for Cancer

“The importance of earlier diagnosis cannot be overstated. It is truly cancer’s ‘Magic Key’, and it is essential the NHS ups its game in this area, both at a local and national level. The local NHS being monitored on its record by the one-year cancer survival rate indicator is a key weapon in our armoury.”

John Baron MP, Chair, All Party Parliamentary Group on Cancer

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*“Relative survival takes into account the fact that the person may have died even if they did not have cancer; it is relative to the rest of the population.” (Cancer Research UK Glossary)*
Bishop Melvin Brooks is the Senior Pastor of New Jerusalem Apostolic Church and the Presiding Bishop of Jabula Europe and Asia. He attended the *Hear Me Now* meeting in Birmingham.

Bishop Brooks saw his GP in March 2006, after experiencing a need to go to the bathroom more frequently. The GP recommended some tablets that Bishop Brooks could buy from a health food shop. However, when he went to buy the tablets, the shop assistant told him that they were for prostate cancer. This was the first time anyone had mentioned prostate cancer to Bishop Brooks.

Bishop Brooks returned to his GP to ask what was happening, and the GP said that he did not think anything was wrong, but that maybe Bishop Brooks had an irritable bladder or possibly an enlarged prostate. Bishop Brooks was eventually given a PSA test, at which point his GP said that his prostate was “a bit large” and decided that he should have a biopsy.

The doctor who performed the biopsy said immediately afterwards that he could not see anything for Bishop Brooks to worry about. However, two days later Bishop Brooks was in acute pain, which lasted for nine days and caused sleepless nights. During this time he was in and out of A&E, on the phone to his GP and prescribed numerous painkillers, however nothing worked.

On the first Friday in May 2006, Bishop Brooks was still in agonising pain and demanded to speak to his consultant, who thought that he might be experiencing urinary retention. As soon as he arrived in hospital, a catheter was inserted and eight pints of urine were released from his bladder.

At that point, Bishop Brooks’ kidneys were failing due to urinary retention. The doctor said that the kidney pain he had experienced was the closest a man can come to experiencing the pain of childbirth.

After having further tests, Bishop Brooks was lying in a hospital bed when a nurse shouted across the ward: “Melvin, your tests came back and you’ve got prostate cancer.” After speaking with his consultant, Bishop Brooks opted for surgery. The same nurse told him: “Of course, you know you could be incontinent and impotent for the rest of your life.”

Since having surgery, Bishop Brooks has had no further problems, and his message is that unless you are persistent and bold, you won’t make progress. “Don’t be afraid – go and have a test and go to your doctor regularly,” he says.
Ethnic health inequalities

Evidence presented at the Hear Me Now meetings in Birmingham, Leeds, London and Nottingham showed that black men in England are more than twice as likely to get prostate cancer than white men. Research indicates that compared to white men, black men do not have a differing risk of getting cancer generally, which makes the prostate cancer differences by ethnicity particularly notable.

The higher incidence of prostate cancer in black African-Caribbean and black African men is likely to be due to genetic heritage or family history, not just geographic location. Cancer Research UK has stated that, “The risk of developing prostate cancer is high in black Caribbean and black African men and low in Asian populations, suggesting important genetic determinants of risk also exist.” However, in BME communities, a family history of prostate cancer is often unknown due to separation by migration. It should be noted that the risk of developing prostate cancer may also be due to environmental factors; for example, it has been noted that diet and lifestyle may play a role in protecting against prostate cancer.

Addressing ethnic health inequalities is crucial for the delivery of “high quality care for all”. If patients are to be treated equally, it is important to understand what needs to be done differently for them, and not lose sight of ethnic health inequalities in discussions around health inequalities more generally. Ethnic health inequalities also need to be considered in groups of people who are easy to ignore, such as people with mental health conditions and the prison population.

Inequality: incidence of prostate cancer

Black men in England have over double the risk of getting prostate cancer compared to white men. Prostate cancer accounts for:

- 26% of new cases of cancer in men in England overall
- 42% of cancers known to be in black men
- 18% of cancers known to be in South Asian men.

There should be no complacency about lower incidence in other ethnic groups and in mixed populations, however. For example, anecdotal evidence indicates that some consultants are concerned about the aggressiveness of prostate cancer in some South Asian men.

Data presented at the Hear Me Now local meetings indicated that there are local variations in prostate cancer incidence in black men. In Birmingham, for example, prostate cancer accounts for 50% of new cases of cancer in black men.

Black men are also more likely to have prostate cancer at an earlier age, even in their 40s. In its information on prostate cancer risk factors, Cancer Research UK refers to research showing that, “The risk increase associated with black ethnicity is higher at younger ages,” and black men may be diagnosed on average three–five years younger than white men, although firm conclusions about differences in the average age at diagnosis between ethnic groups are hampered by differences in the underlying population age distribution within these groups.

Cancer Research UK. Prostate cancer risk factors.

"Prostate cancer is relatively uncommon in South Asian men but clinical experience indicates that the cancer is very aggressive in some of those who are unfortunate enough to develop the cancer.”

Dr Santhanam Sundar, Consultant Clinical Oncologist

References:
1. The risk increase associated with black ethnicity is higher at younger ages, a cohort study shows, and black men may be diagnosed on average three–five years younger than white men, although firm conclusions about differences in the average age at diagnosis between ethnic groups are hampered by differences in the underlying population age distribution within these groups. (Cancer Research UK. Prostate cancer risk factors.)
Inequality: prostate cancer mortality

Black men have double the risk of dying from prostate cancer compared to white men in England; data suggests that this may be largely due to the higher incidence of prostate cancer among black men. Among men in England overall, prostate cancer accounts for 12% of cancer deaths and 4% of all deaths, but 22% of cancer deaths and 8% of all deaths in black men. Data indicates that local variations exist in prostate cancer mortality, as shown by the example in the table 4.

Furthermore, prostate cancer accounts for double the proportion of premature deaths (deaths in those aged under 75) among black men than among men in England overall, as the table below shows. This is extremely relevant for the indicator on ‘Under 75 mortality rate from cancer’ under Domain 1 of the NHS Outcomes Framework, ‘Preventing people from dying prematurely’. Addressing inequalities in premature deaths is also important for the Coalition Government’s aim of saving an additional 5,000 lives from cancer every year by 2014/15.

Data from the Hear Me Now local meetings indicated that premature mortality from prostate cancer is much higher than average among black men in some areas, as illustrated in the table 6.

In the context of the Government’s aim to increase cancer survival rates and save an additional 5,000 people per year by 2014/15, the All Party Parliamentary Group on Cancer has called for CCGs to be held to account for improving survival rates in their area.

Table 4
Prostate cancer deaths, Nottingham City

<table>
<thead>
<tr>
<th></th>
<th>Men in Nottingham City overall</th>
<th>Black men in Nottingham City</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths from prostate cancer as a % of cancer deaths</td>
<td>11%</td>
<td>31%</td>
</tr>
<tr>
<td>Deaths from prostate cancer as a % of all deaths</td>
<td>4%</td>
<td>12%</td>
</tr>
</tbody>
</table>

Table 5
Premature deaths from prostate cancer, England

<table>
<thead>
<tr>
<th></th>
<th>Men in England overall</th>
<th>Black men in England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature deaths from prostate cancer as a % of premature cancer deaths</td>
<td>7%</td>
<td>15%</td>
</tr>
<tr>
<td>Premature deaths from prostate cancer as a % of all premature deaths</td>
<td>3%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Table 6
Premature deaths from prostate cancer, Newham and Birmingham

<table>
<thead>
<tr>
<th></th>
<th>Newham</th>
<th>Birmingham</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature deaths from prostate cancer as a % of premature cancer deaths – among men overall</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Premature deaths from prostate cancer as a % of premature cancer deaths – among black men</td>
<td>20%</td>
<td>17%</td>
</tr>
</tbody>
</table>
Inequality: survivorship

The series of Hear Me Now local meetings also highlighted the need for attention to be given to the quality of survival for BME people with cancer, many of whom also have co-morbidities (other health conditions) such as diabetes, according to anecdotal evidence from the meetings. The results of the 2010, 2012 and 2013 Cancer Patient Experience Surveys showed that BME groups are less positive than white groups.34

In addition, anecdotal evidence indicates that there are currently concerns about cuts to NHS language services. French-African and Portuguese are important languages for black African men in the UK, in addition to languages spoken in diverse African countries. Whilst a significant number of African men speak English, there may be a need in some cases for cancer-related words to be interpreted; this is particularly important in secondary care, where full information about treatment options is essential.

The BME Cancer Patient Information Survey report notes that “1 in 10 (9%) of patients required an interpreter at some point during their cancer journey”, but in 2 in 5 of those cases an interpreter was not offered by the NHS.5 The National BME Cancer Alliance has stated that “Healthcare providers must have access to interpreters trained in medical terminology so that they are able to communicate accurately with cancer patients in the language of their choice.”35

“People whose first language is not English have the right to receive the same high standard of health care as English speakers. There is increasing evidence that more staff are using their limited language skills, family and friends are being asked to accompany patients and even children asked to interpret for their parents. This is not acceptable, on so many levels.”

Dawn Bowes
Language is Everything, who have experience of providing telephone interpreting services to Macmillan Cancer Support
In order to gain further understanding of how prostate cancer in BME groups – and cancer generally – is being prioritised at a local level, this report examined the Joint Strategic Needs Assessments (JSNAs) for each of the areas where the Hear Me Now meetings were held, as well as Manchester, where there is also a significant black population. However, it is also important that the health needs of “minorities within minorities” are adequately met. For example, some minorities may be less visible in rural areas, but JSNAs – and CCGs – need to recognise their presence and their health needs, which if ignored will become more costly later on. JSNAs gather evidence on the health and wellbeing needs of the local population. The development of JSNAs is led by local authorities, who now have responsibility for public health. JSNAs also inform the development of Joint Health and Wellbeing Strategies by Health and Wellbeing Boards, which set out how partners including local authorities and the NHS aim to meet local health and wellbeing needs. This report also examined the Joint Health and Wellbeing Strategies from each of the five areas, to provide a snapshot of whether cancer and prostate cancer-related needs are being reflected in the strategies.

### Table 7: Assessment of JSNAs against criteria

<table>
<thead>
<tr>
<th>JSNA location (year of publication)</th>
<th>Proportion of black population</th>
<th>Highlights cancer in health priorities</th>
<th>Connects cancer and ethnicity</th>
<th>Indicates prostate cancer as an area of need</th>
<th>Links prostate cancer &amp; ethnicity</th>
<th>Calls for further action on prostate cancer in BME men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birmingham24 (2012)</td>
<td>7%</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes “More research on cancers by ethnic group is required”</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Leeds25 (2012)</td>
<td>1.3% Black African</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes Recommendations improving BME access and experience of services</td>
</tr>
<tr>
<td></td>
<td>1% Black or Black Caribbean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.2% Other Black</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manchester26 (2012)</td>
<td>8.6%27</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Newham28 (2012)</td>
<td>6.6% Black Caribbean</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>15.9% Black African</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.1% Black Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nottingham City29 (2010-13)</td>
<td>4% Black Caribbean</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Call to improve understanding of poor survival for prostate cancer in Nottingham</td>
</tr>
<tr>
<td></td>
<td>3.2% Black African</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

In summary, it is clear that cancer is a health priority in all five JSNAs. However, despite most linking cancer, and specifically prostate cancer, with ethnicity as an issue, only two of the JSNAs recommend action related to prostate cancer in BME men.

Meanwhile, none of the Joint Health and Wellbeing Strategies for these five areas connect cancer and ethnicity, and none mention prostate cancer. However, the Leeds strategy includes a priority to “Ensure people have equitable access to screening and prevention services to reduce premature mortality.” The Newham strategy states that “certain groups may be more likely to be at risk of particular conditions”, and mentions removing “the barriers that stop people seeking help or that create delays in diagnosis and treatment.” However, this snapshot of JSNAs and Joint Health and Wellbeing Strategies indicates that there is a clear need for local prioritisation of prostate cancer in higher-risk groups such as black African-Caribbean and black African men, and men with a family history of prostate cancer. Public Health England has a role to play in ensuring that the health needs of men at higher risk of prostate cancer are appropriately reviewed at local level. Given that JSNA decisions are based on data, shortcomings in prostate cancer and ethnicity data are an issue. The required data improvements and the approaches that should be taken in the meantime are set out later in this report.

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N.B. it was not possible to compare JSNAs from the same year. It is recognised that the NHS reforms will have led to some areas being behind in updating their JSNAs.
Increasing understanding of prostate cancer testing

The Hear Me Now meetings held in Birmingham, Leeds, London and Nottingham highlighted the need to raise awareness of informed choice PSA (prostate-specific antigen) testing including with regard to high-risk groups, among GPs and all other healthcare professionals in the prostate cancer care pathway. It was also considered important to raise awareness in high-risk communities by empowering patients to ask their GPs for tests.

The PSA test is one of a number of tests that can be used to help diagnose prostate cancer. It is currently an important test that triggers referral to secondary care urology services, which is important for diagnosing early stage prostate cancer showing no symptoms.

Ensuring that men at higher risk, such as black African-Caribbean and black African men, and men with a family history of prostate cancer have appropriate access to informed choice PSA testing is highly relevant for Domain 1 of the NHS Outcomes Framework (‘Preventing people dying prematurely’). The new Health and Social Care Act 2012 allocated local authorities and CCGs the responsibility for improving the health of people in their locality, and this provides an opportunity for local initiatives that have regard for high-risk groups, such as raising awareness about prostate cancer testing.

There is a need to raise awareness of informed choice prostate-specific antigen testing
Increased understanding of BME communities’ perspective

Attendees at the *Hear Me Now* meetings saw GPs as ideally placed to diagnose prostate cancer early. As the All Party Parliamentary Group (APPG) on Cancer has explained, GPs are the ‘public face’ of primary care, so they are often a patient’s first point of contact. However, research has shown that prior to cancer diagnosis ethnic minority groups are “more likely to have consulted their GPs three or more times before hospital referral.” Although black men in England are more than twice as likely to have prostate cancer than white men, the *Hear Me Now* local meetings indicated that some GPs and health professionals along the prostate cancer care pathway were unaware of the prostate cancer risk factors for black African-Caribbean and black African men.

<table>
<thead>
<tr>
<th>Age</th>
<th>PSA referral value (ng/ml)</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-59</td>
<td>≥ 3.0</td>
</tr>
<tr>
<td>60-69</td>
<td>≥ 4.0</td>
</tr>
<tr>
<td>70 and over</td>
<td>≥ 5.0</td>
</tr>
</tbody>
</table>

Delegates at the meetings heard that some black African-Caribbean and black African men aged over 50 have been refused or deterred from having tests by their GPs because prostate cancer was not suspected, as illustrated by some of the case studies in this report. This is despite the PCRM providing information including the increased risk of prostate cancer in men of black Caribbean and black African origin and the fact that early stage prostate cancer is usually asymptomatic (showing no symptoms). In April 2012, then Health Minister Paul Burstow said, “We know that some GPs are still unsure of the [Prostate Cancer Risk Management] programme and its objectives.”

In its 2013 report Cancer across the Domains, the APPG on Cancer noted that, “GPs need more support to help them identify cancer signs and symptoms, which would lead to earlier diagnoses.” This observation is particularly relevant to the need to increase awareness of informed choice PSA testing including with regard to high-risk groups, among GPs and other health professionals in the prostate cancer care pathway, to ensure that prostate cancer is diagnosed as early as possible. It is important that information given to patients about how the test works is clear, and that test results are properly interpreted and personalised to the individual. It also needs to be ensured that patient choice is central in deciding whether or not to have an informed choice PSA test, as per the PCRM recommendation that, “The patient’s personal preferences should be an important factor in the decision.”
Increasing community awareness

In addition to the need to raise awareness of informed choice prostate cancer PSA testing among GPs and other health professionals, the *Hear Me Now* local meetings also identified the potential for developing early detection programmes from the “bottom up”, through raising awareness in higher risk communities to encourage and empower men to ask their GPs for tests.

It was indicated at a *Hear Me Now* local meeting that such an approach would benefit GPs, who would find it helpful for people to be informed before they attend appointments. It is recognised that GPs are currently under increased pressure, due to the changes made to the way services are commissioned caused by the recent NHS reforms. GP practices based in inner city socio-economically deprived areas – where BME communities tend to be over-represented⁴⁹,⁵⁰ – may also be more likely to be caring for larger populations with poorer health outcomes⁵¹,⁵².

The Association for Prostate Awareness (APA), a voluntary African-Caribbean association based in East London, has run events to inform men (and women) about PSA testing. Anecdotal evidence from men who have attended these sessions indicates that their knowledge was improved. For example, one man saw his GP because he had a family history of prostate cancer and had begun to have symptoms. His PSA level was low, but he was able to have a conversation with his doctor about when to be tested again. Furthermore, because he had the knowledge of what could cause false PSA test results and when his PSA level rose he knew this should be taken seriously.

It is vital to raise awareness among both health professionals and communities of the importance of informed choice PSA testing in high-risk groups, if the proportion of prostate cancer patients presenting with advanced prostate cancer (30%) is to be reduced.⁶ It is well documented that raising awareness initially increases incidence rates. For example, the National Awareness and Early Diagnosis Initiative (NAEDI) lung cancer awareness project led to a 10% increase in patients diagnosed with lung cancer and more patients diagnosed at an early stage.⁵¹

However, delegates at the *Hear Me Now* local meetings emphasised that awareness raising initiatives should not just target men, but also family members in the community, in order to harness the persuasive power of families. In particular, the meetings highlighted the importance of family members in encouraging husbands, partners and other male relatives to be tested. An outreach project in a school in Newham, East London, was highlighted as an example of good practice – the project aimed to promote breast cancer awareness among Asian women and girls, including by reaching mothers through their daughters.⁵⁶

By the end of the project, 29.2% of mothers could name five or more symptoms of breast cancer unprompted, compared to 1% at the start of the project.⁶¹

“NICE Guidelines require GPs to speak to patients about the benefits and implications of PSA testing prior to being tested,” said Dr Philip Abiola, an East London GP and CCG Cancer Lead for Newham.

“To maximise GP appointment time, pre-informing the community so that they were knowledgeable about the realities of PSA testing could make it more efficient for GPs to be able to offer the test.”

“The ability to more accurately diagnose prostate cancer, and being able to do this earlier, would allow aggressive disease to be treated sooner and its progression to be better controlled. Despite its limitations, the PSA test continues to be the mainstay approach for ‘flagging’ up the potential presence of prostate cancer and there is currently no other option but to routinely use the PSA test and perform a DRE (digital rectal examination) in patients who are regarded as being at higher risk for having prostate cancer than the general public. Ongoing studies might lead to the development of better alternatives to this test in the future.”

Professor A. Graham Pockley, Associate Director, John van Geest Cancer Research Centre, Nottingham Trent University
Targeting black African-Caribbean men

Local GP Dr Steve Knights from the Windmill Practice in Nottingham, successfully targeted at-risk black African-Caribbean men for prostate cancer testing.

In October 2012, a practice meeting was held to clarify the ethnic group codes and age groups to be targeted, and how often screening with PSA testing should take place. A health promotion specialist advised on the best patient information leaflets to use.

The practice then ran searches of computer records for the target group of men and patients without recent screening tests were invited to an appointment with Dr Knights to discuss the benefits and implications of screening. Those who accepted screening had a PSA test arranged and saw Dr Knights for the results. Most patients were happy to be tested.

The practice will be producing a register from the target group and updating it annually. Dr Margaret Abbott picked up the work after Dr Knight’s retirement.

Dr Safiy Karim, the CCG Clinical Lead on Cancer, informed the Nottingham Hear Me Now meeting that 18 GP practices were carrying out similar prostate cancer audits.
Improving prostate cancer data

As this report has demonstrated, black men in England are more than twice as likely to have prostate cancer, and they are more likely to have prostate cancer earlier than white men. Prostate cancer accounts for a higher proportion of cancers known to be in black men than in men in England overall, and black men are twice as likely to die of prostate cancer than white men. These are important statistics, but the *Hear Me Now* local meetings held during Autumn/Winter 2013 revealed that there is still a long way to go in improving NHS data collection by ethnicity.

Prostate cancer and ethnicity data

Data presented at the *Hear Me Now* local meetings clearly showed that ethnicity is currently recorded more in death than in life. Between 2008 and 2010, 74% of new cases of prostate cancer in England had a recorded ethnicity compared to 98% of deaths from prostate cancer. Meanwhile, prostate cancer accounts for three in five of the cancer cases in England which have no known ethnicity. Furthermore, there are indications that regional variations exist in rates of data collection by ethnicity, as illustrated by the table below.

Good data collection by ethnicity is essential for NHS England, CCGs and local authorities not only in planning and commissioning services to meet the needs of those affected by prostate cancer, but also in understanding and reducing differences and inequalities between patients. It would also contribute to the Government’s aim of saving an extra 5,000 lives from cancer every year by 2014/15. As noted by the National Cancer Intelligence Network, “The completeness of ethnicity coding is vital to understanding more about the impact of cancer on different ethnic groups.” In its cancer strategy, Improving Outcomes: A Strategy for Cancer, the Coalition Government also stated that, “It will be impossible to tackle inequalities effectively without the appropriate data to inform activity and scrutinise progress.”

<table>
<thead>
<tr>
<th></th>
<th>Percentage of new cases of prostate cancer with a recorded ethnicity 2008-10 (percentage of which were white)</th>
<th>Percentage of deaths from prostate cancer with a recorded ethnicity 2008-10 (percentage of which were white)</th>
<th>Prostate cancer cases as proportion of cancers with no known ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>74% (94%)</td>
<td>98% (99%)</td>
<td>3 in 5</td>
</tr>
<tr>
<td>Birmingham</td>
<td>76% (79%)</td>
<td>98% (85%)</td>
<td>More than 1 in 3</td>
</tr>
<tr>
<td>Leeds</td>
<td>84% (96%)</td>
<td>96% (96%)</td>
<td>1 in 6</td>
</tr>
<tr>
<td>Newham</td>
<td>81% (49%)</td>
<td>99% (53%)</td>
<td>1 in 3</td>
</tr>
<tr>
<td>Nottingham City</td>
<td>84% (92%)</td>
<td>95% (91%)</td>
<td>1 in 6</td>
</tr>
</tbody>
</table>
**Prostate cancer staging data**

In addition to improving data collection on new cases of prostate cancer, the *Hear Me Now* local meetings also highlighted the need for better staging data. The stage of a cancer indicates the extent to which the cancer has spread in the body, or in other words how advanced the cancer is, and this is an important factor in the outcome for the patient. It is therefore crucial that prostate cancer is diagnosed at the earliest stage possible, in order to maximise treatment options and improve survival.

Whilst there are indications that the stage at presentation of prostate cancer is similar between ethnic groups, at least one review has noted “A greater incidence of advanced-stage diagnoses of ... prostate cancers among ethnic minority groups compared to the majority”. However, staging data is only available for 26% of newly diagnosed prostate cancers. It is vital that improvements are made in the collection of staging data, in order to facilitate better understanding of inequalities in cancer at national and local levels.

In 2011, the Department of Health “acknowledged that the paucity of data in most regions about the stage that a patient’s cancer has reached at the time of diagnosis was an extremely important issue and resolving it was key to making better use of resources and improving outcomes.” In December 2013, the Department of Health, Public Health England and NHS England published the Third Annual Report of Improving Outcomes: A Strategy for Cancer, which noted that, “for some indicators such as ethnicity and staging, data completeness is improving although further and faster progress is urged.” The CCG Outcomes Indicator Set 2014/15 includes an improvement area on ‘Cancer: record of stage at diagnosis’.

**Gleason scores**

At the same time, the *Hear Me Now* local meetings identified the need for better data on Gleason scores, which are also important indicators for patient outcomes. The Gleason score, or grade, relates to the aggressiveness of the prostate cancer. The Prostate Cancer Risk Management Programme lists black-African and black-Caribbean ethnicity as one of the factors associated with high-grade cancer. US research also indicates that African-American men may be more likely to have more aggressive prostate cancer. Better data collection on – and patient understanding of – the Gleason score is required to inform the most appropriate management of the disease.

**Reverse commissioning**

However, whilst improved data collection on prostate cancer is essential moving forward, where there is currently a lack of evidence for commissioning, local authorities and the NHS should make use of existing evidence held by local providers. ‘Reverse commissioning’ has been identified by the Joint Commissioning Panel for Mental Health as an example of values-based commissioning. It works by identifying the needs of BME communities by using existing evidence and data from JSNAs and other sources. At the same time, BME communities are empowered to engage with health professionals. A partnership approach between health professionals and BME service users is then taken in order to improve services to meet service users’ needs. The reverse commissioning approach also includes opportunities to educate health professionals and empower BME service users to improve the experience of the latter.

The NHS BME Network has adopted the reverse commissioning approach in Brighton, where it was identified that a significant amount of BME patients were using HIV and diabetes services. Healthcare professionals in both services were trained to engage with communities, and patients also underwent training to empower them to engage with the health professionals. A focus group was then formed for each of the services, which will identify issues of concern and recommend service improvements.

In Nottingham, the ‘Hearts and Minds’ programme is a successful example of reverse commissioning. Funded by the British Heart Foundation and led by Bright Ideas Nottingham and the African Caribbean Health Network, the aim of the programme was to communicate that heart disease is treatable and preventable. It was aimed primarily, but not exclusively, at the African-Caribbean community, which has a higher risk of high blood pressure and diabetes. BME community organisations wrote and costed the proposal in line with the community’s needs. The programme ran for one year and achieved a number of successful outcomes, such as high attendance from the target community at physical activity classes.
Case Study
A daughter’s story

For approximately nine months, my father started experiencing excruciating pain in his lower back. My father visited his GP on many occasions and each time they said it was arthritis. My father was repeatedly prescribed pain killers, which did not help alleviate the pain. He tried everything, acupuncture, laying on the floor on his back, hot water bottles – anything that would allow him to be pain free, albeit for a brief period.

Unable to resolve the situation, my father and siblings insisted that the GP look further into the matter and make a referral. My father was finally referred to hospital, where at last they were able to diagnose prostate cancer.

It was at the advanced stage – metastatic – and although treatable, was not curable. It was and is frustrating to know that due to the GP not considering the possibility of prostate cancer, my father had to experience the pain for longer than necessary. Surely GPs have an elimination process that they go through, especially for conditions that are more prominent in certain communities.

Marcella Turner, BHA, Manchester
The vital role of community-level organisations

There is evidence to suggest that there is generally lower awareness of cancer in BME groups than amongst white men and women,\textsuperscript{64} whilst anecdotal evidence from the \textit{Hear Me Now} local meetings indicated that engagement between BME communities and health professionals needs to be improved. Against this backdrop, the \textit{Hear Me Now} local meetings in Birmingham, Leeds, London and Nottingham emphasised the key role of BME and other community organisations in facilitating engagement on prostate cancer with local populations.

The importance of community organisations in facilitating engagement

It is recognised that cancer-related initiatives, such as awareness campaigns and screening campaigns targeted at BME communities.\textsuperscript{35} They noted that “it is well established that people from BME communities can delay going to see a healthcare professional about signs and symptoms for some cancers.”\textsuperscript{64}

Community organisations have a crucial role to play in facilitating engagement on prostate cancer with their local populations. The Department of Health has referred to the role of such organisations with regard to living with and beyond cancer, for example, noting that “voluntary sector ‘buddying’ schemes and community outreach were regarded as particularly important to connect with BME communities and for those communities to connect to services.”\textsuperscript{65}

In South London, for example, a pilot initiative undertaken by two BME community organisations, which aimed to increase the uptake of breast cancer screening among African-Caribbean women, was reported as achieving an unprecedented level of success.\textsuperscript{68}

The \textit{Hear Me Now} local meetings indicated that in order to commission services that meet the health needs of local communities – and to prioritise investment accordingly – it is important to have meaningful engagement with the local community and encourage community groups. It is also vital for local communities to be approached in a way that respects their diverse skills and expertise. In faith communities, for example, this engagement could be through mosques, churches or temples. Engagement could also be through social business places, such as barber shops. The involvement of people who know a community’s language and culture was seen as critical to such engagement.

This view is supported by the National BME Cancer Alliance, which explains that “Community groups are often best equipped to understand the specific needs of those within their communities and how those affected by cancer can be supported to live full and healthy lives.”\textsuperscript{35}

Heather Nelson, CEO of the Black Health Initiative (BHI), a community engagement organisation based in Leeds, confirms that when engaging with BME men on prostate cancer, responses are more effective when the men are reached via their own community groups initially. NHS England has also identified working with local voluntary and community networks as a way to reach more diverse communities.\textsuperscript{67}

The \textit{Hear Me Now} local meetings also highlighted the importance of reaching out to communities in community settings, and not expecting communities to come to clinicians or attend healthcare discussions in “traditional” settings, where they may already feel disenfranchised.
Dr Frank Chinegwundoh MBE, Consultant Urological Surgeon at Barts Health NHS Trust, led a community-based prostate drop-in clinic in Newham, East London. The aims of the clinic included promoting prostate health and awareness of prostate cancer in local men and in particular, but not exclusively, black African-Caribbean men and men depicted as ‘hard to reach’.

Dr Chinegwundoh found that communication through the community, for example through churches, helped attract men to the Newham clinic, which they could attend without going through their GP. The Association of Prostate Awareness (APA), a voluntary organisation based in East London, also played a crucial role in raising awareness of the clinic.

The clinic de-stigmatised attendance by being held in a multi-purpose community centre, the Newham African-Caribbean Resource Centre, and it succeeded in shifting the curve away from presentation with advanced cancer to earlier diagnosis.

In total, 322 men had a consultation at the clinic. 59 men were referred to secondary care and nine men – who said that they would not have gone to their GP – were diagnosed with prostate cancer. Seven of the men had early stage cancer, whilst none had metastatic (advanced) cancer. In addition, three men were diagnosed with other serious conditions.

The clinic model proved to be cost-effective, with a £77.41 cost per consultation if target numbers had been met, compared with the cost of £36 for a GP visit. The cost per case of serious disease diagnosed, including prostate cancer, was £7,586.

In December 2012, the clinic won a Quality in Care, Excellence in Oncology award in the ‘Helping People Live Longer’ category, and was highly commended in the ‘Patient Experience’ category. In October 2013 the clinic also won the ‘Understanding and Engaging With Communities’ award at the annual Civil Service Diversity and Equality Awards.
It is crucial for other stakeholders, including local authorities, CCGs and local NHS services, to work with community organisations, not least because the commissioning process is driven by local needs. In order to identify local needs, collaborative working with community partners and meaningful engagement with the public and patients are needed, along with an understanding of what partnership means. Additionally, as the BHI has found, “Partnership working between statutory service providers and a community engagement organisation ensures that the message you want to disseminate is carried out in the way which will be received by the target group/community.”

From the perspective of the Assistant Director of Equality and HR at Birmingham City Council at the time of writing, “Community engagement is important. Done properly it means we can achieve the best possible health outcomes with our available funds. It means we can improve the quality, the efficiency and effectiveness of health services and secure improved health and wellbeing.” Meanwhile, the National BME Cancer Alliance has called for the local NHS to have strong links with community organisations that work with cancer patients, noting that, “This could include NHS commissioners setting service level agreements involving voluntary organisations, or cancer centres funding community outreach workers.”

Anecdotal evidence from community-level organisations indicates that there is growing reliance on such organisations from statutory bodies and larger third sector organisations. Community organisations can play a vital role in engaging with their local populations, but partners need to be aware of the true costs to community organisations and factor in adequate funding from the outset. For example, commissioning should include a realistic cost for BME community input, which is often expected to be voluntary. Budgetary challenges should not mean that statutory bodies such as local authorities, CCGs and/or larger third sector organisations expect voluntary organisations to undertake their duties free of charge. Public Health England has a role to play in assisting CCGs and local authorities to work with community-level organisations.

**Black Health Initiative (BHI) – Men’s MOT**

BHI, a Leeds-based community engagement organisation, introduced a ‘Men’s Health and Wellbeing MOT’, a Macmillan-sponsored men’s health clinic which was run quarterly until funding ended.

Heather Nelson, BHI’s CEO, notes that it was important that the clinics were held in community venues. In her experience, black African-Caribbean and black African men do not think that events in a clinical setting are for them, nor do they feel included once they access the service.

Medical professionals, such as urology nurses, were in attendance at the clinics. Clinicians invited to participate in the clinics reported that they had never had so many men coming to their clinic, and that they had found it worthwhile and cost-effective to come into the community.

Over 100 men attended the four Men’s MOT sessions, and 27 of the male attendees were subsequently diagnosed with prostate cancer. Through pre- and post-event questionnaires, BHI found that the clinics resulted in a 100% increase in prostate cancer awareness and increased awareness of prostate health. An increased uptake of mainstream services and a reduction in non-attendance at clinical appointments (DNAs, or ‘did not attends’) were also observed through completion of monitoring by service providers.

From BHI’s work on the Men’s MOT, the support group Brothaz was formed, which now has trained ‘buddying and befrienders’.
Ensuring a partnership approach

Further to the Health and Social Care Act 2012, a broader range of organisations are involved in preventing cancer and in treating and supporting people through cancer. It is therefore vital for there to be effective partnership between all relevant stakeholders involved in providing prostate cancer-related services, in order for patients to have the maximum support. The Hear Me Now local meetings in Birmingham, Leeds, London and Nottingham all underscored the importance of partnership working in the health and wellbeing landscape, for example between local authorities, CCGs, the health service, community groups and the voluntary sector.

Desmond Jaddoo, founder of the Birmingham Empowerment Forum, explains that “Prostate cancer is plaguing the African and Caribbean community, highlighting the clear need for positive action and joined up inter-agency thinking between the local authority, clinicians and importantly the community in tackling this dangerous health inequality.” Strategic Clinical Networks have the potential to play an important role in bringing together service users, commissioners and providers of prostate cancer services.

The Hear Me Now local meetings highlighted the need for partnership with communities, for example working with community partners to commission services that optimise health gains and reductions in health inequalities. It was seen as important for the community’s voice to be heard in the right places, such as through BME representation on Health and Wellbeing Boards. The Department of Health has noted that “Working with partners will support Health and Wellbeing Boards to develop a detailed and sophisticated picture of the needs and assets in the area. It will provide a route for Health and Wellbeing Boards to hear from some seldom heard groups either indirectly via representative organisations, or directly by partners facilitating direct engagement activities.”

The meetings also indicated that Third Sector (charities, voluntary and community organisations and social enterprises) involvement in partnerships is essential to reach black African-Caribbean and black African men. Both smaller voluntary sector organisations and larger charities have a key role to play, for example in working together with local authorities, whose role includes narrowing inequalities in public health. Similarly, many responses to the government consultation on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies guidance “commented that good partnership working has supported or would support the development of an understanding of local health inequalities – especially in joint working with local voluntary sector organisations to provide better information on vulnerable and seldom heard groups.”

At the same time, the meetings also pointed to good integration of services being critical in enabling diagnosis and treatment of prostate cancer at an early stage. For example, a unified approach between GPs and community workers could help to maintain levels of prostate cancer testing uptake and encourage engagement.

At the Hear Me Now local meeting in London, the Newham men’s community prostate clinic featured in the previous section of this report was highlighted as an example of good practice in terms of integration. From the CCG’s perspective, the flow between the clinic, GPs and secondary care was reported to have been seamless. However, with initiatives such as the Newham clinic it is important that the risk is shared between partners, not least to maximise cost-effectiveness. The biggest cost for the Newham clinic was paying nurse specialists at an agency rate, as the nurses’ time was not provided by the local NHS Trust. With the clinic used as a triage point, there would be more hospital referrals as a result – of the 322 men seen by the clinic, there were 59 referrals to secondary care – making such initiatives worthwhile for Trusts. Prostate cancer nurse specialists would be ideally placed to work in community clinics alongside qualified BME health professionals.
Conclusion

Significant progress is required to tackle inequalities in prostate cancer care in men at higher risk, including black African-Caribbean and black African men, and men with a family history of prostate cancer.

In order to improve data collection on ethnicity and ensure that prostate cancer is diagnosed early in high-risk groups, it is essential to have a joined-up approach between policy-makers and health bodies at a national level. Prostate cancer should be included in the NHS Outcomes Framework, together with national-level action to ensure the early detection of prostate cancer in men at higher risk.

At a local level, it is important for local authorities, CCGs, the health service, the voluntary sector and, importantly, BME and other community groups to work together. Crucially, in areas with significant black African-Caribbean and black African populations, Joint Strategic Needs Assessments (JSNAs) should prioritise prostate cancer in higher-risk groups such as black African-Caribbean and black African men, and men with a family history of prostate cancer.

If we all play our part and work together, we can build local partnerships that span across disease areas, make better use of resources and most importantly we can improve the outcomes and lives of all men and their families across the country.
Appendix 1

Action Plans from Hear Me Now meetings

The tables on this page outline the local action plans agreed at the Hear Me Now meetings in London, Nottingham, Leeds and Birmingham.

Hear Me Now London
Wednesday 25th September 2013
East Ham Town Hall, London

Action

The CCG Chairs and Chair of the Health and Social Care Scrutiny Commission will add prostate cancer in African-Caribbean men to the next Health and Wellbeing Board meeting agenda and the next CCG Board meeting agenda with a view to this being named as a specific priority in Newham.

Action group to take forward the reinstatement of the community drop-in prostate clinic by March 2014.

Get prostate cancer onto the GP educational programme in Newham, with a London Cancer event to be run around this.

Discuss additional research using Newham-specific Olympic legacy funding.

Hold an event to raise awareness of prostate cancer among the BME community in Newham. London Cancer will provide administrative support for this. CCG will also provide administrative support.

Hear Me Now Nottingham
Tuesday 15th October 2013
Albert Hall Conference Centre, Nottingham

Action

Inform Public Health, Nottinghamshire County & Nottingham City, Health portfolio lead at Nottingham City Council and the Commissioning Executive Group that the Task and Finish group is being formed.

Ensure patient representation in the Task and Finish group, particularly of BME men who have had prostate cancer.

Ensure county representation of Clinical Commissioning Groups (CCGs) in the Task and Finish group.

Objectives and actions for the Task and Finish group should include:

— Better engagement with the community and how to take this forward.
— More investment in urology clinics so outreach nurses can get out into the community. Alison Challenger highlighted that Lynne McNiven is now overseeing the Change Makers project and suggested inviting her to future groups about how Change Makers can become involved with this.
— Exploring the Newham pilot as a potential model for a local pilot.
— Collectively managing input and engagement with media and across organisations. Existing expertise to be used.
— Nottingham to become a “lead city” in tackling this health inequality.
— Support the Task and Finish group to move forward.

Hear Me Now Leeds
Wednesday 30th October 2013
Leeds Town Hall, Leeds

Action

Representatives from the meeting to work together to meet with CCG and local public health leads, to obtain some firm commitments from the CCG and local public health lead to address the meeting findings, including the reinstatement of funding for Health MOTs in Leeds.

Compile a dossier from the evidence presented at the Leeds Hear Me Now meeting ahead of the above meeting with GPs and CCGs.

Implement a research-based approach to addressing the need for earlier diagnosis of prostate cancer in black African-Caribbean men in Leeds, based around the knowledge base and practices of men and GPs.

Take a baseline read of community and clinician awareness.

Roll out a targeted awareness campaign, and for this to be delivered from a CCG partnership with community groups which will include commissioning them for their involvement.

Evaluate the impact of the campaign.
How local community organisations could engage and support improved awareness and early diagnosis initiatives.

- Community champions to raise awareness of prostate cancer and screening - these champions need to be people who are respected and can talk openly about symptoms.
- Educate wider communities by educating people with influence, such as faith leaders.
- Recognise the important role of Health and Wellbeing Boards, and the importance of getting prostate cancer issues captured in the Board’s action plan.
- Increased knowledge may be required about how to access funding for community initiatives.
- Introduce partnership initiatives between the NHS (e.g. urology teams) and the community. Prostate Cancer UK could provide support in the form of training and leaflets.
- Examine how anecdotal data on prostate cancer, e.g. from churches, is being used. How is it fed back to commissioners to get the targeted services that are needed?
- Efforts should be made to change men’s mindsets with regard to prostate cancer and testing. Issues such as pride and men not taking ownership of their health were seen as cultural issues, and issues around masculinity also need to be examined.
- Capitalise on opportunities such as Black History Month to raise awareness of prostate cancer.
- Care should be taken with the language that is used around prostate cancer, as it can confuse and alienate people.
- Prostate awareness should be couched in a global health MOT.
- Develop and use key messages on prostate cancer for use with black men over 40 and their wives. The need to educate women to educate their male relatives was seen as important.
- Develop and use a simple message on prostate cancer/testing, possibly with diagrams.
- Utilise a variety of ways to conduct outreach on prostate cancer, e.g. in community centres and through posters and leaflets.
- Examine the diabetes-related ‘barbershop campaign’ model as an example of going out into the community.
- Consider how the next generation is being influenced, i.e. through engagement with young black men on prostate cancer.

How Healthcare professionals could improve engagement with black African-Caribbean men to raise awareness and increase early diagnosis initiatives.

- Make the case for introducing a targeted screening programme for prostate cancer.
- There should be more GP education to increase understanding of prostate cancer and testing, so that GPs do not present a barrier when men go forward for testing. It is important to convince GPs to get more men tested, particularly black African-Caribbean men, for prostate cancer so they are diagnosed at an earlier rather than advanced stage of the disease.
- Make every contact count (MECC) - clinicians raise issues such as weight and smoking whenever they have contact with patients. A representative from Queen Elizabeth Hospital volunteered to explore the possibility of including a prompt for clinicians in the hospital’s electronic system, so that a prostate cancer test could be offered to patients who are male, African-Caribbean and over 40.
- There should be resources on prostate cancer in GP surgeries as well as in communities.
- Introduce partnership initiatives between the NHS (e.g. urology teams) and the community. Prostate Cancer UK could provide support in the form of training and leaflets.
- Different African languages should be taken into account.
- Ensure that therapeutic remedies, such as counselling, are offered when men are told they have cancer, in order to convey the message that there is life after diagnosis.
- Ensure there are community outreach programmes in place for those communities and groups who are less likely to proactively come forward for prostate cancer screening.
- Care should be taken with the language that is used around prostate cancer, as it can confuse and alienate people.
- Prostate awareness should be couched in a global health MOT.
- Develop and use key messages on prostate cancer for use with black men over 40 and their wives.
- Develop and use a simple message on prostate cancer/testing, possibly with diagrams.
- Utilise a variety of ways to conduct outreach on prostate cancer, e.g. in community centres and through posters and leaflets.
- Examine the diabetes-related ‘barbershop campaign’ model as an example of going out into the community.
- Hold health hubs in communities, e.g. in the central mosque in Birmingham, which has 10,000 visitors per week.
Appendix 2

Hear Me Now meeting attendees

Hear Me Now London
Wednesday 25th September 2013
East Ham Town Hall, London

Chair
Professor Kathy Pritchard-Jones
Chief Medical Officer, London Cancer

Dave Beesley
Chair, Oxford Prostate Cancer Support

Rajiv Bhattacharjee
Macmillan Involvement Co-Ordinator (London), Macmillan Cancer Support

Laura Boyd
NHS England (London Region)

George Clerk
London Minority Ethnic Elders Project, Age UK, London and Greater London Forum for Older People

Nick Hodgkiss
Project Manager, Primary & Community Care Engagement, London

Darren Morgan
Information and Signposting Manager, Healthwatch Newham

Shehla Javed
NHS England

Lyn Paulo
NHS England

Dr Ashwin Shah
Deputy Chair, Newham CCG

Vasco Stevenson
Trustee, Association of Prostate Awareness

Martin Tod
Chief Executive, Men’s Health Forum

Dr Zuhair Zarifa
Chair, Newham CCG and Deputy Chair, Newham Health and Wellbeing Board and GP at Custom House Teaching & Training Practice

Rose Thompson
Director of BME Cancer Communities (and author of Hear Me Now)

Dr Frank Chinegwundoh MBE
Consultant Urological Surgeon, Barts Health NHS Trust & Executive Chairman of Cancer Black Care

Richard Hope
Patient representative

Councillor Winstan Vaughan
Chair of the Health and Social Care Commission, London Borough of Newham, North East London

Dr Vivienne Lyfar-Cissé
Chair, NHS BME Network

Dr Philip Abiola
CCG Cancer Lead for Newham & GP at Lord Lister Health Centre

Sonia Harding
Chair, Association for Prostate Awareness

Hear Me Now Nottingham
Tuesday 15th October 2013
Albert Hall Conference Centre, Nottingham

Chair
Dr Safiy Karim
GP Cluster Lead (Robin Hood), Nottingham City CCG and GP at Limetree Surgery

Rose Thompson
Director of BME Cancer Communities (and author of Hear Me Now)

Dr Vivienne Lyfar-Cissé
Chair, NHS BME Network

Dr Luke Hounsome
Principal Cancer Intelligence Analyst, Public Health England

Alison Challenger
Consultant in Public Health, Nottingham City Council

Wayne Marston
Patient representative

Councillor Merita Bryan
Lord Mayor of Nottingham, Sheriff of Nottingham

Simon Castle
Assistant Director of Acute Contracts, Productivity and Performance, Nottingham City CCG

Cynthia Colston
Chair, BME Network, Maidstone & Tunbridge Wells NHS Trust

Lloyd Ferron
Community Champion and Complimentary Therapist

Dr Martin Glynn
Centre for Health and Social Care Improvement, University of Wolverhampton

Louise Jackson
Community Support Services Manager, Midlands, Prostate Cancer UK

Karen Morgan
Strategy & Development Manager, Nottingham West CCG

Marva Paterson
Specialist Nurse

Lisa Robinson
Director, Bright Ideas Nottingham

Adele Smith
Assistant Primary Care Development & Service Integration Manager, Nottingham City CCG

Dr Santhanam Sundar
Consultant Clinical Oncologist, Nottingham University Hospitals NHS Trust

Professor Matthew Whitaker
Foundation Professor of History, Arizona State University
Hear Me Now Leeds

Wednesday 30th October 2013
Leeds Town Hall, Leeds

Chair
Professor Alan White
Centre of Men’s Health, Institute of Health & Wellbeing, Leeds Metropolitan University

Heather Nelson
Chief Executive Officer, Black Health Initiative (BHI)

Rose Thompson
Director of BME Cancer Communities (and author of Hear Me Now)

Cynthia Colston
Chair, BME Network, Maidstone & Tunbridge Wells NHS Trust

Dr Luke Hounsome
Principal Cancer Intelligence Analyst, Public Health England

Pastor George Crawford
Patient representative, BHI Health Ambassador

Councillor Lisa Mulherin
Executive Board Member for Health and Wellbeing, Leeds City Council

Lisa White
Clinical Nurse Specialist in Urology Oncology, Leeds Teaching Hospital

Philip “Blacka” Brown
BHI Health Ambassador

William Cross
Consultant Urologist, Leeds Teaching Hospitals Trust

Permjeet Dhoot
Equality and Health Inequalities, NHS England

Steven Edwards
Regional Development Manager, Macmillan Cancer Support

Claude Hendrickson
Chair, Leeds Men’s Health Network

Tom Mansell
Macmillan Project Officer, Leeds Teaching Hospitals NHS Trust

Sharon Moore
Senior Associate Equality and Diversity, NHS Leeds North CCG

Steven Rowntree
Community Support Services Manager, North East, Prostate Cancer UK

Tony Stanley
Director Equality Leads, Leeds Racial Equality Council

Richard Worlock
Equality and Diversity Manager, Leeds Community Healthcare NHS Trust

Ian Yearwood
Vice Chairman, Leeds Prostate Cancer Support Group

Hear Me Now Birmingham

Wednesday 11th December 2013
Birmingham Town Hall, Birmingham

Chair
Desmond Jaddoo
Founder & Organiser of Birmingham Empowerment Forum

Dr Mashuq Ally
Assistant Director, Equalities and Human Resources Equality and Diversity, Birmingham City Council

Councillor John Cotton
Cabinet Member for Social Cohesion and Equalities, Birmingham City Council

Richard Gledhill
Prostate Cancer Charity Nurse Specialist, University Hospitals Birmingham NHS Foundation Trust

Cynthia Dwyer
Patient representative

Rose Thompson
Director of BME Cancer Communities (and author of Hear Me Now)

Dr Vivienne Lyfar-Cissé
Chair, NHS BME Network

Cynthia Colston
Chair, BME Network, Maidstone & Tunbridge Wells NHS Trust

Jane Thakoordin
Community Development Officer, NHS Birmingham CrossCity CCG

Permjeet Dhoot
National Project Coordinator, Equality and Health Inequalities Team, NHS England

Alan Ferguson
Macmillan VBS Project Lead, NHS Birmingham South Central

Councillor Paulette Hamilton
Handsworth Wood Ward, Birmingham City Council

Winston Mosquito
Equality & Community Engagement Officer, Birmingham City Council

Marcia Wynter
Birmingham City Council, Sandwell & West Birmingham Hospitals NHS Trust

Emma Hall
Urology Specialist Nurse, Sandwell & West Birmingham Hospitals NHS Trust

Sharon Leahy
Urology Specialist Nurse, Sandwell & West Birmingham Hospitals NHS Trust

Dr Kate Crocker
GP Facilitator, Macmillan Cancer Support

Louise Jackson-Sanders
Community Support Services Manager, Prostate Cancer UK

Surrinder Bains
John Taylor Hospice CIC

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