



Prostate Cancer in BME Communities

Raising
Awareness
and Improving
Outcomes

A Parliamentary Stakeholder Group
Chaired by Paul Uppal MP



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Foreword

Paul Uppal MP

I am delighted to introduce Prostate Cancer in BME Communities: Raising Awareness and Improving Outcomes, a report which follows a meeting of the Parliamentary Stakeholder Group which I chaired in early autumn 2012.

African-Caribbean men are three times more likely to develop prostate cancer than white men of the same age. There is also evidence to suggest that the BME community more widely suffers from increased health inequalities due to a number of factors. With this in mind, I asked the group to identify how prostate cancer affects men in Black and Minority Ethnic (BME) communities and whether awareness of the disease and access to treatments could be improved for these men.

The members of the group have all proved instrumental in researching, treating and raising awareness of prostate cancer and in this report share their knowledge and examples of best practice in reaching out to the BME community. The group has recommended that the replication and expansion of this excellent work is vital if we are to raise awareness and improve diagnosis and standards of care for men from these communities.

As an MP representing a constituency with a diverse population, and as Vice-Chair of the All-Party Parliamentary Men's Health Group, I am keen to do all I can to help raise awareness of the most common cancer in men and improve patient outcomes, especially in the most at-risk communities. I am therefore grateful for the input of the members of the stakeholder group and for the support of Bristol-Myers Squibb for this project as we strive to ensure prostate cancer remains high on the NHS's agenda.



A handwritten signature in black ink, appearing to read 'P. Uppal'.

Paul Uppal MP

Chair, Prostate Cancer in BME Communities
Parliamentary Stakeholder Group
Vice-Chair, All-Party Parliamentary Group on Men's Health

Introduction

Prostate cancer in BME communities

Prostate cancer is the most common cancer in men in the UK, with the numbers of men being diagnosed each year now exceeding 40,000 for the first time.¹

In 2009, a total of 40,841 men were diagnosed with prostate cancer in the UK² and 10,721 men in the UK died from prostate cancer in 2010.³ This is the equivalent to one man dying from prostate cancer every hour. Increased public awareness will be imperative in the coming years to avoid prostate cancer continuing to be something of a “poor relation” in comparison to the profile of other cancers.

In the UK black men have a higher incidence of prostate cancer than white men, while Asian men have a lower incidence.² Men from Black and Minority Ethnic (BME) communities may also be more likely to experience health inequalities.⁴ With this in mind, a stakeholder group, led by Paul Uppal MP, was established in September 2012 to consider how awareness can be raised and outcomes improved for men with prostate cancer in BME communities. The group brought together clinical experts, patient and professional groups with extensive experience in this area. The initiative was supported by Bristol-Myers Squibb.



The scope

The scope of the stakeholder group’s investigation was to identify the scale of the problem of prostate cancer in BME communities and to explore the initiatives being undertaken to raise awareness. Members of the group were also asked to highlight, from their experiences, best practice case studies across the country, including which prostate cancer awareness programmes have already been undertaken specifically to engage BME communities.

With anecdotal evidence suggesting that patients from the BME community are experiencing poorer standards of care, the group also sought to highlight what barriers currently exist for BME patients in the diagnosis and treatment of prostate cancer and what can be done in the short and long term to improve outcomes for men in these communities.

The report

This report showcases some of the best practice in England and it is hoped that it will be helpful to clinical experts, Clinical Commissioning Groups (CCGs), GPs, specialist nurses, other health professionals, commissioners and policy makers in providing an insight into how prostate cancer is identified and treated in BME communities.

Participants

Paul Uppal MP (Chairman) – Member of Parliament for Wolverhampton South West and Vice-Chair, All-Party Parliamentary Group on Men’s Health

Roger Bacon – Chair, PCaSO Prostate Cancer Network
Miranda Benney – Macmillan Uro-Oncology Cancer Nurse Specialist, Royal United Hospital Bath; Member, British Association of Urological Nurses

Frank Chinegwundoh – Consultant Urologist Surgeon, Barts and the London NHS Trust; Newham University Hospital NHS Trust and Harley Street; Chair, Cancer Black Care

Francis Kaikumba – Chief Executive Officer, African Health Policy Network

John Lehal – Managing Director, Insight Public Affairs

Paula Lloyd Knight – Associate Director of Patient Experience, National Cancer Action Team

Sara Osborne – Head of Policy Development, Cancer Research UK

Dr Heather Payne – Consultant in Clinical Oncology, University College Hospitals, London

Rebecca Porta – Chief Executive, Orchid

Rose Thompson – Director, BME Cancer Communities

Sarah Toule – African Caribbean Policy and Development Manager, Prostate Cancer UK

Helen Tuvey – Lead Mobile Information and Support Specialist, East Midlands and North of England, Macmillan Cancer Support

Martin Whitehead – National Policy Manager, Bristol-Myers Squibb

Contact

For further information about the Prostate Cancer in BME Communities Stakeholder Group, please contact Victoria Parker on 020 7824 1854 or victoria@insightpa.com.

1. Cancer Research UK. Prostate cancer statistics: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/?script=true>

2. National Cancer Intelligence Network and Cancer Research UK (2009). Cancer incidence and survival by major ethnic group, England 2002-2006.

3. Cancer Research UK. Prostate cancer statistics: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/?script=true>

4. National Cancer Intelligence Network and Cancer Research UK (2009). Cancer incidence and survival by major ethnic group, England 2002-2006.

Background

Prostate cancer incidence in BME communities

In comparison to the United States, there has been less research in the United Kingdom into prostate cancer incidence, mortality and outcomes in men from BME communities. However, it has been established that in England Black Caribbean and Black African men have approximately a two to three times higher risk of being diagnosed with prostate cancer than white men.⁵

The 2008 PROCESS cohort study, *Pathways to diagnosis for Black men and White men found to have prostate cancer*, led by Chris Metcalfe, found that Black men also present at an earlier age than white men at first diagnosis – on average 67.9 years compared to 73.3 years. The results of the study suggest that the higher incidence in Black Caribbean and Black African men may be due to greater biological susceptibility to the disease. Anecdotal evidence suggested that black men may delay presentation, yet Chris Metcalfe claimed “if anything the evidence showed black men were presenting sooner...there are very few known risk factors for prostate cancer but it is starting to look like being of black race is a risk factor.”⁶

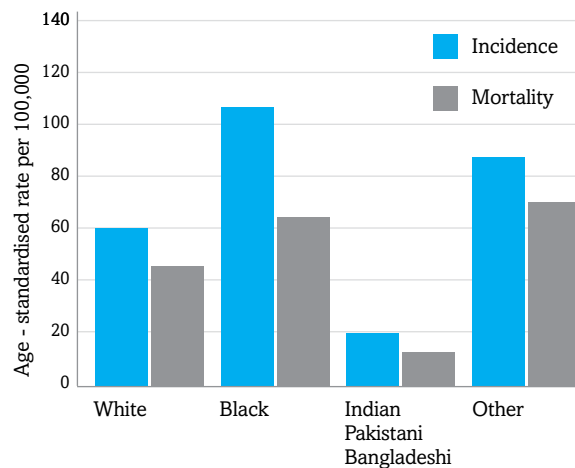
Although evidence shows that Asian men generally have a lower risk of prostate cancer than the national average, migration studies have shown an increase in risk as men move from low-risk to higher risk countries, suggesting that lifestyle factors could play an important role. For example, South Asian men living in the UK have a higher risk of prostate cancer than men living in South Asia, which supports this theory.⁷ However, further research in this area is needed to ascertain the key risk factors for South Asian men; in particular for Indian and Pakistani men who may have a slightly raised risk in this group.

Lower awareness

In the UK awareness of prostate cancer also appears to be lower in parts of the BME community. A 2007 study showed that 37% of black men had heard of prostate cancer compared to 64% of white men.⁸ White men also showed a greater awareness of the signs and symptoms of prostate cancer compared to black men. In addition, “Ethnibus” research by Prostate Cancer UK showed that only 15% of African Caribbean men knew they were at increased risk of developing prostate cancer.⁹

Prostate cancer incidence by ethnic group in England, 2008-10

Despite these evident risk factors in men from BME communities, it was found that ethnic data collection in England is currently patchy and incomplete. Data obtained from the South West Public Health Observatory (SWPHO), the lead registry for Urological cancers, has confirmed the increased risk of prostate cancer in African Caribbean men, which is highlighted in the following graph. The graph shows prostate cancer incidence by ethnic group in England, 2008-10:



Source: South West Public Health Observatory

5. National Cancer Intelligence Network and Cancer Research UK (2009). *Cancer incidence and survival by major ethnic group, England 2002-2006*.

6. *British Journal of Cancer - Pathways to diagnosis for Black men and White men found to have prostate cancer: the PROCESS cohort study*: <http://www.nature.com/bjc/journal/v99/n7/full/6604670a.html>

7. Winter, H., et al., *Cancer incidence in the south Asian population of England (1990-92)*. *Br J Cancer*, 1999. 79(3-4): p. 645-54

8. *Prostate Cancer and Prostatic Diseases – Racial origin is associated with poor awareness of prostate cancer in UK men, but can be increased by simple information* <http://www.nature.com/pcan/journal/v10/n3/full/4500961a.html>

9. *Prostate Cancer UK – response to the call for evidence on cancer equalities from the APPG on cancer* <http://prostatecanceruk.org/media/228142/appgresponse.pdf>

However, when this data is broken down further, it shows that there were 47,028 “unknowns” – that is, men whose ethnicity was not recorded. Recording of ethnicity in England is incomplete for most cancers, and the proportion of cases with unrecorded ethnicity is higher for prostate cancer than most other common cancers.¹⁰ As such, the overall picture is incomplete:

Ethnic group	Recorded incidence	Estimated incidence	Age-standardised rate per 100,000	Rate ratio compared to white population
White	51,643	95,890	60.3	-
Black	1,795	3,337	110.1	1.8
Indian/Pakistani/ Bangladeshi	622	1,156	20.4	0.3
Other	822	1,528	86.9	1.4
Unknown	47,028	-	-	-

Source: South West Public Health Observatory

Standards of care

The National Cancer Equality Initiative’s 2010 report *Reducing cancer inequality, evidence, progress and making it happen*¹¹, highlights that not only are prostate cancer incidence rates higher in BME groups, but that prostate cancer patients as a whole often report a poorer experience of care.

In addition, the 2011/12 Cancer Patient Experience Survey showed results which were more negative from some BME patients in comparison to white patients. Although the survey observed that this was not due to anything specific in terms of the delivery of cancer services, it did acknowledge that “there may be aspects of NHS provision generally which are more heavily criticised by some ethnic minority patients”. The survey also suggested that NHS provision is less appreciated by patients who tend to live in areas where NHS services are worse.

The Cancer Patient Experience Survey also acknowledged that the absolute numbers of ethnic minority respondents to the survey was quite low at around 3.5% of the whole respondent group, substantially less than the proportion estimated to be in the UK population generally by census returns (estimate for 2009: 12% from non-white ethnic groups).¹²

Challenges

Evidence to date shows a link between ethnicity and prostate cancer incidence and awareness. However, it appears that substantial improvements need to be made to ethnic data collection in order to forge a more complete picture across England. The main source of ethnicity data in England is the hospital episode statistics (HES) dataset, which uses self-reported ethnicity at time of hospital admission, and is linked to the national cancer registry data held by the Office for National Statistics. However, this does not extend to patients treated as outpatients or in primary care, which is particularly relevant to prostate cancer, for which many patients are not admitted to hospital. This means the proportion of prostate cancer patients for which the ethnicity is unknown is higher than for other common cancers.¹³ Incomplete data on prostate cancer in BME groups makes it harder for professionals, patient groups and policy makers to evaluate the situation and make improvements where they are needed.

More rigorous ethnic data collection and research will be required if progress is to be made to raise awareness of prostate cancer and improve outcomes. With the NHS undergoing large-scale reform, health professionals, commissioners and policy makers will need robust evidence in order to support new initiatives to tackle prostate cancer in BME communities.

10. National Cancer Intelligence Network and Cancer Research UK (2009). *Cancer incidence and survival by major ethnic group, England 2002-2006*.

11. *Reducing cancer inequality: evidence, progress and making it happen*: http://www.cancerinfo.nhs.uk/images/stories/ncei_report_march_2010.pdf

12. Office for National Statistics (2011). *Population estimates by ethnic group 2002 – 2009*. <http://www.ons.gov.uk/ons/rel/peeg/population-estimates-by-ethnic-group-experimental-current-estimates/population-density-change-and-concentration-in-great-britain.pdf>

13. National Cancer Intelligence Network and Cancer Research UK (2009). *Cancer incidence and survival by major ethnic group, England 2002-2006*.

Discussion overview

The discussion brought together a variety of views and observations on prostate cancer in BME communities. Participants sought to highlight existing problems and the potential solutions that could be explored.

It was agreed that ethnic data collection and research needs to be improved and expanded in order to present a more robust case to policy makers and the health community for increased awareness-raising of prostate cancer in BME communities, and men generally.

Over the course of the group's discussion, several themes emerged which suggested why men from BME communities suffer from lower awareness of the disease. These included cultural differences, relationships with GPs and confusion over PSA testing. Members of the group shared their own experiences of raising awareness of prostate cancer in BME communities and agreed on a series of recommendations which could help take forward the work currently being undertaken by groups and organisations active in prostate cancer.

Data collection and research

The participants agreed that ethnic data collection in the NHS in England is inadequate. Some health professionals might not be aware of the importance of recording ethnicity, which helps to provide a better understanding of disease incidence and variations in care. Ethnic data collection and monitoring is being prioritised by some hospitals but not all, with no link between the best-performing hospitals and areas with a high BME population. It was also noted that encouraging the self-completion of ethnic data forms could more accurately reflect a patient's ethnicity and avoid inaccurate attributions.

The system of recording and monitoring ethnic data in England is arguably too complex. It is currently difficult to link ethnic data from GP practices to hospitals which contributes to missing information, although due to use of hospital episode statistics (HES), the situation in England is improving. In Scotland, NHS Boards have been incentivised to improve ethnic data collection, with the Information Services Division producing a bi-annual report which measures the completeness of ethnic data collection from hospital discharges; and outpatient data across the 14 regional NHS Boards. This approach across England could ensure similar improvements.

Improved ethnic data collection will help health professionals recognise to what extent prostate cancer affects their community, especially in areas with high African-Caribbean populations where risk factors are higher. Robust data and evidence would prompt Clinical Commissioning Groups (CCGs) and Health and Wellbeing Boards (HWBs) to acknowledge the problem and include prostate cancer in local health priorities and Joint Strategic Needs Assessments (JSNAs).

To help improve levels of ethnic data collection, patient cooperation is vital. Health professionals need to convey to patients why they are being asked to provide their ethnicity and what the data will be used for. Some men are wary about being asked their ethnicity so it is important to show them how ethnicity monitoring can help identify trends and risk factors for certain diseases.

Further research is required to understand the extent of the risk factors for men from BME communities. In the UK, there are fewer incentives than in the US for interested parties to take on research projects. Academics and other professionals often do not have the time to write research grant proposals, which are rarely successful. It was agreed that thorough research is essential if progress is to be made in the diagnosis and treatment of prostate cancer; and in ascertaining why some men might be more at risk of developing the disease.

Socioeconomic factors

The group discussed whether there might be a link between poorer prostate cancer outcomes and deprived communities, due to poorer access to services or later diagnosis. Data on prostate cancer in African Caribbean men in the US linked higher incidence of the disease to deprivation. However, it was noted that this could be due to the nature of the US healthcare system, as deprived communities do not have the extensive access to healthcare enjoyed by their better-off counterparts. In contrast, in the UK, it has been reported that prostate cancer incidence is lower in deprived areas due to poorer access to healthcare. This means prostate cancer is less likely to be detected under these circumstances.

With some BME communities existing in deprived areas, the risk of poorer outcomes for these men could be even greater. It was also observed that there are possibly lower awareness levels of prostate cancer in BME communities in the north of England compared to the more affluent south, suggesting a link between socioeconomic status and awareness. Some men from more deprived communities may feel less comfortable visiting their GP, often feeling that practitioners are unwelcoming and unable to understand them.

Employed men on lower incomes may have greater difficulty taking time off for treatment because they are unable to afford time off work. In addition, lower paid workers do not benefit from private health insurance, which provides men with regular health checks which include Prostate-Specific Antigen (PSA) tests.

PSA testing

The PSA test is the primary test used to help identify prostate cancer but it is accepted that it is not always a reliable indicator of whether a man will have prostate cancer. A raised PSA level may be an indicator that a prostate biopsy is required to establish whether cancer is present. As such, there is no national screening programme for prostate cancer due to the flaws of the PSA test. The group discussed the pros and cons of PSA testing, but it was largely agreed that improved access to balanced information for men from BME communities could help improve detection of prostate cancer.

Guidelines set out by the Department of Health's Prostate Cancer Risk Management Programme (PCRMP) state that all men over the age of fifty are entitled to a free PSA test but that a man of any age can request one as long as they have made an informed decision. The aim of the programme is to ensure that men who are concerned about the risk of prostate cancer receive clear and balanced information from their GP about the pros and cons of the PSA test and treatment options for prostate cancer. This will help men decide whether they want the test. However, there was concern that some GPs are not putting these guidelines into practice, which creates additional problems for men who might be too afraid to request the test.

Some GPs are not aware of the PCRMP or are reluctant to provide PSA tests due to their unreliability; it was discussed whether annual PSA testing would encourage men to feel more in control of their prostate health, especially if they were to familiarise themselves with their PSA levels. This was a contentious issue where no broad agreement was reached amongst members of the group. It was suggested that men knowing their PSA numbers could be useful to patients in the way that they might be aware of their blood pressure, cholesterol and blood sugar levels. However, due to the complexity of interpreting the PSA test, not everyone supported this approach.

A number of men are uncomfortable with the idea of the Digital Rectal Examination (DRE), which is another key test used to identify problems with the prostate gland and potentially, cancer. Although patients can request that the DRE is performed by a man or a woman, they are often relieved to hear that the PSA test is simply a blood test and can be performed first. Greater awareness of this might help more men come forward to be tested, as PSA testing takes blood which is considered to be less invasive than the DRE.

Evidence suggests that men have a preference over where they are tested. They are often happier being treated in non-clinical settings and large numbers of men have asked for examinations in the mobile support vans which Macmillan Cancer Support use to raise awareness, although they do not currently provide tests. Awareness of PSA testing could also focus on employers, particularly in larger companies or organisations which may have the resources to provide men's health checks.

Health professionals need to ensure that patients are aware that a PSA number on its own can be meaningless and must be monitored over time in order to evaluate what a normal level might be for the individual. It was argued that this could strengthen the case for increased annual testing in not just the over fifties, but also men in their forties who are more at risk of developing the disease, including African-Caribbean men. However, it is crucial that PSA levels are considered alongside other risk factors and the existence of other signs or symptoms. GPs need to reiterate to their patients that a raised PSA level does not necessarily mean that they are ill and that it can be raised from cycling, sexual activity or even having a DRE examination beforehand.

Due to the complexity of the PSA test, it was agreed that calling for all men of a certain age to receive a PSA test would not be the best step forward. Instead, tailoring approaches to different groups of men and communities could prove more effective. For example, Prostate Cancer UK runs The Testing Choices campaign which enables men to make an informed choice about whether or not they should have the PSA test. The PCRMP is targeted at GPs to ensure that all men are provided with balanced information but it was noted that some GPs either don't know about it or choose not to tell men about it.

It was agreed that PSA should not be included in the Quality Outcomes Framework (QOF) as the test is too unreliable to incentivise GPs to provide it routinely.

Cultural differences

Anecdotal evidence suggests that the mix of different faiths and cultures in BME communities can impact on the diagnosis and treatment of prostate cancer. It is important for primary care services to be aware of their local communities and the diversity of faiths and cultures within them and be trained according to the demographics of the population they serve.

There is some evidence that African Caribbean men are just as likely to be concerned about prostate cancer but are less likely to visit their GP than white men. African men with undocumented migration status might be worried about the negative impact a diagnosis could have on their ability to stay in the UK and access NHS services. There could also be practical barriers preventing men from visiting their GP: some men worry they might not be able to make an appointment or be able to take time off work to get to the surgery.

In some communities, common tests for prostate cancer such as a DRE can be seen as a challenge to men's sexuality, with many men reluctant to take the test. Some treatments for prostate cancer can affect sexual performance and with this in mind, some men may prefer to avoid a prostate cancer diagnosis and related treatment, believing it could threaten their masculinity. Men can be reluctant to trouble their GP, sometimes being unable to assess the severity of any signs or symptoms of prostate cancer and also being afraid of the link between cancer and death.

Faith and cultural beliefs and practices in BME communities can be a positive asset both for patient support and for raising awareness of prostate cancer. Men from these communities tend to have strong support networks around them beyond the support provided by health professionals. They often bring faith or community leaders with them to appointments for examinations and treatment and targeting these individuals can be an excellent way of raising awareness in hard to reach communities.

Crucially, GPs and other health professionals need to be aware of the cultural and language barriers which might dissuade some men from BME communities from making appointments and seeking treatment. Improved training for GPs in areas with higher BME populations could help address this problem.

Snapshot: engaging faith and community leaders

Encouraging testing

Macmillan Cancer Support's mobile information service often targets community leaders to encourage men to get tested for prostate cancer; and Prostate Cancer UK are currently running a pilot in training community leaders in African Caribbean, South Asian and deprived communities.

Raising awareness

The National Cancer Action Team (NCAT) have a cancer and faith programme as part of their Not Too Late campaign which targets Asian, African Caribbean and Irish communities in Nottingham and Tower Hamlets. NCAT has also liaised with the Catholic Church, Council of Gurdwaras and numerous mosques, holding workshops in each faith community and getting local champions on board. It was emphasised that it is important to persuade each community of the importance of raising awareness of prostate cancer.

BME Cancer Communities ran six prostate cancer awareness-raising events in Nottingham in 2008 which reached out to 150 African-Caribbean men in two months.

The role of health professionals

Participants agreed that primary care services need to be more accessible to the most at-risk men so that they aren't afraid to book an appointment with their GP and be open with them. There are variations in the standard of primary care across the country but, where it is needed, GPs could be more proactive by asking men the right questions about their prostate gland and discuss the PSA test with them. If a GP is aware that black men have an increased risk, they should raise this with the patient; and it is crucial that all GPs are aware of this increased risk factor. Given the genetic link, GPs should also ask men if their father or brother had prostate cancer, and be alert to any cultural differences or sensitivities which prevent men from seeking help.

It was felt that the NHS and health professionals need a collective will to improve services. One idea suggested would be for GPs to contact men in their areas and perhaps hold open days and drop-in clinics, such as on Saturdays, to invite men to access information and examinations. In the context of the NHS reforms, Domain 1 of the NHS Outcomes Framework (preventing people from dying prematurely) contains seven indicators on cancer which includes prostate cancer. As a result CCGs will need to ensure people are receiving the best levels of care to deliver improved outcomes. However, the fact that there are no specific indicators on prostate cancer is due to the unreliability of the PSA test, which the Department of Health attributed to the artificial elevation of one-year and five-year cancer survival rates. This reaffirms the need shared by health professionals for better diagnostic testing for prostate cancer.

Another challenge to improving prostate cancer diagnosis could lie in the structure of the new CCGs. Concerns were raised about the potential conflict of interest of those sitting on CCGs as GPs delivering patient care will manage the budget. This could potentially result in a conflict over whether GPs test more men for prostate cancer or hold back due to higher cost of more testing. Some members of the group suggested that some GPs are wary of increased cancer awareness campaigning as this has led to more people asking for tests, which costs money. However, it was also noted that if an early diagnosis saved two lives from metastatic prostate cancer, the money used for this would be far less than the higher costs of treating the advanced disease.

Participants agreed that a fundamental shift is required in Government and the NHS more widely in relation to spending money on screening and early detection of cancer, as it costs more to treat a patient with advanced cancer than to prevent it spreading in the first place.

Raising awareness

Evidence from the group showed that raising awareness of prostate cancer in the hardest to reach communities is best achieved by active community engagement. Some of the best examples of reaching out to men in BME communities included leafleting in shopping centres and organising events such as comedy clubs or a barbecue, to which men only were invited. It was found that men are easier to reach in this kind of relaxed and informal setting.

In some cases, it can be effective to reach out to the women closest to the men in question, as they often make GP appointments on their behalf. Men are not always as willing as women to share information about prostate cancer and this can also be due to cultural differences – for example some African Caribbean men might be worried about telling their families due to genetic risk factors whereas others might be more willing to confide in family members for the same reason.

There was concern that even some well-informed men aren't aware of prostate cancer, and that it would be beneficial if awareness campaigns were to recruit high-profile public figures who would be recognised by men of all ethnic backgrounds.

Conclusions and recommendations

Throughout the discussion, it became evident that improvements are required in several key areas if increased awareness of prostate cancer and better outcomes are to be achieved for men from BME communities. It was also recognised that greater understanding of ethnic and cultural differences by health professionals could help improve access to care and treatment.

A series of short and long term recommendations have been drawn from the discussion to contribute to driving these improvements.

Improving ethnic data collection

- As is the case in Scotland, the NHS in England needs to incentivise the collection of ethnicity data in primary and secondary care.
- Linking data to a patient's NHS number in primary care would prevent duplication in secondary care and help reduce the gaps in data.
- Health professionals need to tell patients why their ethnicity is being recorded. If men know data will be used confidentially and positively it will encourage more men to be open.
- Where possible, ethnic data should be self-ascribed and not attributed by a health professional.
- Clinical Commissioning Groups (CCGs) and Health and Wellbeing Boards (HWBs) need to acknowledge the problem of higher prostate cancer incidence in some BME communities – particularly in African-Caribbean men - and improved data collection will help make the case for action. The fact that data is so incomplete means that the prevalence in some BME groups cannot be fully understood.

Engaging health professionals

- Health professionals need to be engaged as much as the community to get the best results. Education on cultural differences – and knowledge and awareness of the term “BME” itself in some areas – will help GPs forge better relationships with their patients.
- GPs and health professionals need to be more aware of the risk factors for prostate cancer in order to ask their patients the right questions and to initiate discussion about the PSA test where appropriate, especially with those at higher risk such as black men.
- Incentives for GPs to provide men with balanced information and to reach out to the most at-risk might be needed for earlier detection. The initial upfront costs are outweighed by the benefits of saving men from advanced prostate cancer.

Empowering patients

- Ensure men are informed about prostate cancer and made aware of diagnostic examinations and treatments which are available to them. Cultural sensitivities and language barriers should be taken into account when designing information for men in some BME communities.

- Additionally, ensure men are aware of their entitlements, including access to a PSA test based on informed decision-making, choice of a male or female doctor or nurse for the DRE; and further down the line, access to cancer drugs including the Cancer Drugs Fund.
- A campaign on “Knowing Your Numbers” in relation to PSA levels – alongside cholesterol, glucose and blood pressure levels - would familiarise men with what their healthy PSA level looks like and educate them about the pros and cons of the PSA test.

Replicating best practice

- It is vital that successful outreach programmes to BME communities are sustained and up-scaled nationally if the most at-risk men are to be reached.
- Increased engagement by CCGs and HWBs with these programmes, aligned with increased funding and support for the voluntary sector, could help to achieve this.
- A multi-disciplinary working group, such as the group assembled at the discussion, is well-equipped to showcase best practice and actively campaign for increased awareness and improved outcomes.

High visibility campaigning

- In the short term, a TV advertising campaign on prostate cancer with a focus on the higher risk for black men – similar to the Department of Health Be Clear on Cancer campaigns on bowel and lung cancers – would raise awareness on a large scale.
- Recruiting a high-profile celebrity or public figure with a BME background who has been affected by prostate cancer would help connect with men from all communities.
- There are too many men who are unaware of where the prostate gland is and what it does. Aiming for 90% of the male population to be aware of the prostate gland and associated diseases could be achievable in the next five to ten years.

Taking research to the next level

- There are currently few incentives in the UK for academics or other professionals to write research grant proposals as the chances of receiving funding are low and a change is needed.
- Major funders are needed to commission research which can look at survival rates and levels of prostate cancer aggression in men from BME communities.
- Research is underway on finding a new diagnostic test for prostate cancer but a replacement of the PSA test is some years away. Further outreach to the research community will speed up this process.

Appendix: Case studies of best practice

Case Study – Newham community prostate clinic

“The clinic was held in a community setting as opposed to an NHS setting. Although staffed by NHS staff, people felt more comfortable. People tend to go to a health setting if they are unwell. In a community setting the motivation is different.”

Dr Frank Chinegwundoh, Consultant Urologist, Barts

Overview

The Newham community prostate clinic project ran from December 2010 to December 2011 and was set up collaboratively between Cancer Black Care, the Prostate Cancer Charity (now Prostate Cancer UK), Kings College, The North East London Cancer Network, Newham PCT and Newham University Hospital NHS with the agreement of the Department of Health’s Prostate Cancer Advisory Group. The idea behind the initiative was to provide an alternative to general practice for men interested in finding out more about their prostate gland and prostate cancer.

The project was externally evaluated by Professor Emma Reams of Kings College, London. The main project funding was provided by Newham PCT.

Strategy

The Newham clinic was essentially an outreach service located in a community hall based in the African and Caribbean Community Centre in Newham. The venue was located in a busy street, had a number of shops and stalls nearby and was accessible for public transport.

The clinic ran twice a week between December 2010 and December 2011. The service operated on a “drop in basis” and an average appointment lasted between 30 and 90 minutes depending what tests were given. The men could have their prostates examined, have a measurement of the speed of their urinary flow or have a PSA blood test. Results were given to the patient and copied to their GP.

Outcomes

Over the course of the year, nearly 328 men were seen, with nearly half of the attendees defining themselves as Black African or Black Caribbean. Overall, 70% of men who attended had been symptomatic with urinary issues. A total of 84% of the attendees opted to have a PSA test, to which the pros and cons were explained to them. A total of 59 men were referred to secondary care. From these men, 10 were diagnosed with prostate cancer.

Lessons learnt

Overall, the clinic was considered to be a success but there were numerous lessons learnt that will be useful for driving forward future pilots:

- Venue was accessible and acceptable to white and African Caribbean men;
- The venue was known to many and was in a good location – it was easy to find;
- No appointments were needed and clinics were timed to include after working hours;
- Men were willing to travel some distance to attend the clinic;
- Advertising spread quite far from the centre;
- No appointment was needed which was a major attraction;
- Men were expecting to be tested at the clinic which is why many had come in the first place;
- Initially staff had a “script” to refer to about PSA testing but it wasn’t used with every man as it “didn’t work” and men just wanted the test because that was why they had come;
- As PSA testing is done as a routine blood test, it was seen as non-threatening and non-invasive unlike a DRE so men were happy to take the test;
- Advertising campaign wasn’t adequately “heavyweight” which meant that clinic attendance peaked and troughed around phases of publicity;
- Signage outside and in the reception area of the venue was inadequate but there were sensitivities around what any signage might say.

The welcome from the reception staff proved to be critical in helping shape the man’s experience of the clinic. Men reported that friendly and welcoming staff who explained the process fully enhanced the overall experience of visiting the clinic.

Case Study – Raising awareness in Nottingham’s African Caribbean community

Overview

Rose Thompson, Director of BME Cancer Communities (BMECC), was approached by Nottingham City PCT to lead a community initiative project on prostate cancer, specifically reaching out to African Caribbean men. The PCT had found it difficult to reach out to this community. In 2008, 23% of the population of Nottingham were in BME groups compared to 15.3% in England. The number of men from BME communities in Nottingham has since increased.

Strategy

BMECC facilitated two community organisations – Bright Ideas and Co-operative Community Action – to raise awareness of prostate cancer in the African Caribbean community. Also involved in the work was Nottingham’s African Caribbean Health Network (ACHN), which is made up of concerned professional volunteers from health and social services. In order to reach out to the men in question, the organisations involved held a series of events over the two-month period including a comedy club, dominoes clubs, a barbecue and other lively entertainment. People involved in the delivery of the events and services included the following:

- Prostate Cancer Nurse Specialist and Urology Outreach team
- PCT Lead registrar
- GP (ACHN member)
- Support Group members
- Two African Caribbean community centres
- Creative artists – a singer and a comedienne
- BME Cancer Information Specialist

Other resources which were used to engage African Caribbean men over the course of the project included information leaflets and booklets, anatomical models, DVDs, Q&A sessions and user-friendly evaluation forms.

Outcomes

The programme was a success: a total of 150 men were reached over the course of the two-month programme and two follow-up reports were produced. However, the organisations involved in delivering the project did not receive any communication from Nottingham City PCT in the follow-up stage until it was announced that further prostate cancer awareness work would be added to an existing in-house project. The PCT issued an apology but unfortunately did not provide any funding to the organisations to continue their work.

Case Study – Macmillan Cancer Support and Derby City PCT cancer information event

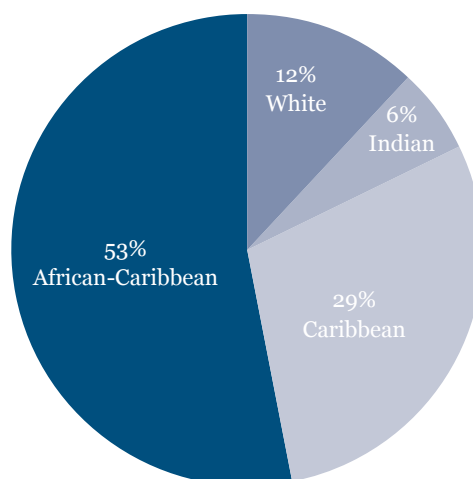
Overview

In July 2012 Macmillan Cancer Support and Derby City PCT worked together to host a cancer information event in Derby following on from Ethnic Minority Cancer Awareness Week. The Macmillan Mobile Information and Support Service works closely with local community champions and partner organisations to provide high quality information and support to everyone affected by cancer, in particular those communities who may find it hard to access information and support or experience barriers in doing so. Being mobile ensures that Macmillan services are even more accessible and that information can be taken into the centre of each and every community.

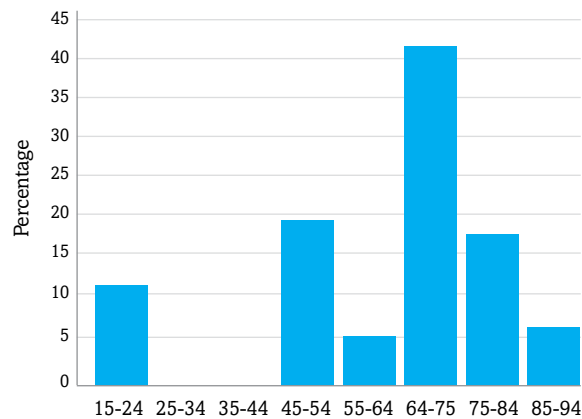
Although the awareness day looked at cancer more generally, prostate cancer was discussed in some detail and was particularly well-attended by the African Caribbean community.

Strategy

The event was hosted at the Hadhari Centre on Burton Road in Derby. The rationale behind the event was to raise awareness of cancer signs and symptoms and determine opinion on cancer services, barriers to care and suggestions for improvement. All those attending – including volunteers and representatives from partner organisations – were asked to register their details and state their ethnicity in their own words. The majority of attendees described themselves as African-Caribbean, while just under a third of people described themselves as Caribbean.



The following graph charts the age of the registered attendees:



The day was well attended by the target community – a total of 59 people attended with a ratio of 41% men and 59% women. Feedback was collated which proved informative.

On registering, nine people disclosed a personal experience of cancer of their own or in their family, including four incidences of prostate cancer.

Outcomes

Of the people who attended the men's cancer awareness session, all attendees agreed that the session was informative and that, as a result of the session, they felt better equipped to spot the signs of cancer and understand what they could do to reduce their risk of cancer. Of these, 66% strongly agreed.

All attendees agreed or strongly agreed that as a result of the information and guidance they had received throughout the day that they would do something differently to address their cancer risk or access to cancer support. Comments made on the evaluation forms included:

- “Very good day – I learned lots of things”;
- “It was very good to be shown what to eat to be healthy and have a healthy lifestyle”;
- “Inspiring”.

Tony Michael, the Chairman of the Hadhari Centre said: “the word cancer sends shivers down the spine and is usually met by a wall of silence and an uneasiness to discuss it openly. Although cancer can, and does, affect most people directly or indirectly, it is still a subject that we don't discuss openly; particularly in the African Caribbean community.

“By using the Hadhari Centre in Derby to run an awareness-raising event for this community, we were able to profile the issue. It was well planned, informative and extremely useful in providing a discussion platform led by a professional team of visiting Macmillan and local health staff. The day included people who shared their personal experience of cancer and gave those who attended the opportunity to have an open discussion. The role of the Macmillan cancer specialists was deeply appreciated and we are exploring the potential of holding open discussion surgeries to keep the issue high on the agenda.”

Quotes from attendees on the day include the following:

- “It was informative; a hard day but a very good day”;
- “It was positive to hear from people who have been through the whole process, from realising they had it to how the information was received by family members and the support from family and friends”;
- “I felt OK discussing the matter in public and hope this area of fear will be met with confidence by other people”;
- “I am not alone in my feeling of anxiety and worry about the effects of treatment”;
- “I realise that cancer is not a taboo subject and that it can be treated if diagnosed early”;
- “I am ill: I did not choose cancer but I have to deal with it. I have a wonderful group of family and friends who provide encouragement and support”;
- “Grant (not real name), a cancer sufferer, has been inspirational in giving support and encouragement in my cancer journey”;
- “I am grateful for this opportunity. Thank you to all of the people who made this day possible, especially the Macmillan staff”.



Prostate Cancer in BME Communities

Raising
Awareness
and Improving
Outcomes

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