

A close-up photograph of a person's hand covering their ear, suggesting a desire to avoid hearing something. The background is blurred, showing what appears to be a white lab coat, possibly a doctor's office.

Time2Reason

about prostate cancer

Improving Awareness of Prostate Cancer in Black African
and Black Caribbean Men in Manchester

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Prostate cancer - The Facts

How common is prostate cancer?

- Prostate cancer is the most common cancer in men in the UK and accounts for a quarter of all new cases of cancer diagnosed in men in the UK
- In 2011, in the UK, around 41,700 men were diagnosed with prostate cancer, that's more than 110 every day
- Black men have the highest risk of developing prostate cancer among all ethnic groups
- Over the last 35 years prostate cancer rates in Great Britain have more than tripled, although much of the increase is due to increased detection through widespread use of the Prostate-Specific Antigen (PSA) test
- On average 1 in 4 Black men will be diagnosed with prostate cancer at some point in their life

How many men survive prostate cancer?

- Forty years ago, more than 2 in 10 men diagnosed with prostate cancer survived for at least ten years, now it is more than 8 in 10; however, much of this increase can be attributed to the increased use of PSA testing in the UK which has led to the diagnosis of many prostate cancers which would have gone undetected.
- Out of 20 common cancers in England and Wales, ten-year survival for prostate cancer ranks third highest.
- 84% of prostate cancer patients diagnosed in 2010-2011 in England and Wales are predicted to survive ten or more years.

How many men die from prostate cancer?

- Prostate cancer is the second most common cause of cancer death of UK men, after lung cancer
- In 2012 in the UK around 10,800 men died from prostate cancer, that's 30 every day
- Almost three-quarters of prostate cancer deaths occur in men aged 75 and over

Background - tackling racial disparities in health

BHA for equality produced a report, *The State of Health – Black and Other Minority Groups* (2013), setting out the continuing disparities in health in relation to particular health conditions and particular racial groups.

The Report cited national evidence from the National Cancer Intelligence Network (NCIN, 2012) that showed that although many cancers are lower in Black and other minority groups there was a higher incidence of prostate cancer in Black men as well as:

- **Higher incidence of stomach and liver cancers and myeloma in Black ethnic groups aged over 65**
- **Higher incidence of Liver cancer in Asian ethnic groups**
- **Breast cancer in the Black ethnic group occurs at a younger age, and Black women were more likely to be diagnosed with an aggressive form of the disease and result in poorer outcomes**

The State of Health report identified a number of measures to tackle these differences. In delivering this programme of work on prostate cancer BHA for Equality have attempted to put some of these measures into practice to show the effectiveness of a programme of work that:

- (a) Provides health information and support targeted at those groups with the worst cancer incidence and mortality rates, to ensure that their service needs are met.
- (b) Includes cancer awareness raising sessions and events to: engage, inform and empower communities to access relevant cancer services; inform BME groups about the low uptake of screening and the impact of late diagnosis; develop support networks that provide information and advice to patients, carers and their families and meet the cultural, linguistic and religious needs of BME groups.
- (c) Delivers community based activities which are targeted at particular communities, led by the voluntary sector and supported by a national charity (in this case Prostate Cancer UK) as part of its partnership approach in delivering services to Black men in local areas
- (d) Includes the development of programmes to specifically recruit and train community health champions/trainers from different ethnic backgrounds.
- (e) Provides evidence to encourage long term investment in group based education for high risk groups such as Black men with prostate cancer and encourage the increase in self-management programmes and peer-to-peer support networks.

Introduction

Prostate Cancer UK commissioned BHA for equality to deliver *Time2Reason*, a Manchester-based campaign which aims to raise awareness of the signs, symptoms and risk factors associated with prostate cancer as well as the relevant tests available. The target audience for the work was Black African and Black Caribbean men in Manchester.

The strapline for the campaign *Time2Reason* emphasised the necessity for Black men to talk or ‘reason’ (slang) about prostate cancer.

Methodology

The work was undertaken over a 6 month period between July and December 2014 and comprised:

- Hosting 3 health and wellbeing events, with a target of engaging with 50 Black men at each event. These offered attendees the opportunity to engage directly with cancer specialist from Christie Hospital, Prostate Cancer UK and BME Cancer Communities, a social enterprise initiative based in Nottingham that specialises in the support, development and delivery of specific cancer services to Black and Other Minority Groups.

- Hosting a series of community based events in partnership with local voluntary organisations that provide services to Black and other minority groups. The following organisations were involved:

African Caribbean Care Group
African Caribbean Mental Health Service
African Community Association of Bolton
Moss Side Leisure Centre
New Testament Church of God (Cheetham Hill)
Trafford African & Caribbean Over 50s Club (Old Trafford)
Seventh Day Adventist Church (Crumpsall)
West Indian Sports and Social Club (Moss Side)
World Harvest Christian Centre (Beswick)

- Targeted outreach to members of the public based at local leisure centres, local supermarkets, local black businesses including barber shops and hairdressers.
- Targeting Black men at the 2 day Manchester Caribbean Carnival to assess their knowledge of prostate cancer through a simple survey on the signs and symptoms as well as the provision of information on the condition. Over the 2 days we approached 85 Black African and Caribbean men of who 23 participated in the survey

The programme of work was promoted through the local voluntary sector infrastructure organisation (MACC), networks that target Black and other minority groups and asylum seekers and through one of the local community radio stations – Peace FM – that specifically targets African and Caribbean communities.

‘It might save u life’

‘Ah important ting fe do’

‘It neva tek long, a quick ting dat man.’

Engagement and Impact

Through the duration of the project (6 months) 543 people were involved in the interventions, of which 414 were men (191 categorised as Black African and 223 as Black Caribbean).

The events and awareness sessions created opportunities, in community settings, for both men and women to talk, share opinions and understand the benefits of testing, types of treatment and how sometimes deep rooted cultural barriers and hearsay can impact on life expectancy. The sessions enabled a dialogue with Black African and Caribbean men which allowed them to acquire the facts to better understand the impact of prostate cancer on the individual, their spouses and family. Additionally it encouraged participants to dispel myths and challenge preconceived ideas about prostate cancer as well as start to question the feelings of shame and embarrassment faced by men that deter them from visiting their GP.

'I didn't know women did not have a prostate... I've learned something new today.'

An opportunity was provided to engage directly with cancer specialists and more importantly, each other, on a topic that is viewed to be of a very personal nature and unlikely to be discussed openly, sometimes compounded by cultural taboos and stigma. The inclusion of cancer specialists such as urology nurses and the specialist nurse from Prostate Cancer UK provided an opportunity for participants to seek information on treatment, current research and clinical trials. Additionally individuals were able to seek one-to-one advice from the prostate cancer nurse relating to existing symptoms following the presentation on prostate cancer. The health and wellbeing events gave participants the courage and opportunity to be more open, improve understanding of the topic and seek advice.

A small survey was conducted at the start of the campaign during the 2 day Manchester Caribbean Carnival, of 23 Black men, to establish what they knew about prostate cancer. The findings identified the following:

- 65% thought women had a prostate and could get prostate cancer
- 39% did not know the symptoms but 26% recognised the symptom of blood in urine. None of the men realised that there may be no signs
- 83% had never heard of the PSA test
- 35% of the men did not know the risk factors of prostate cancer but 30% felt that diet was the highest risk factor
- Although 61% of the men agreed that the rate of prostate cancer was higher in Black men none of them identified ethnicity as a risk factor
- 57% were unaware of the connection between men, whose mother or sister have had breast cancer, being at increased risk of prostate cancer

Black Men and Prostate Cancer - Lessons Learnt

Research findings (Macdonald et al, 2004) show that men are less likely to seek help and generally view seeking medical advice as emasculating and are particularly concerned about appearing to consult for trivial matters. Additionally there is evidence from the British Journal of Cancer that men delay seeking help for urological cancers. Working with Black men to raise their awareness of prostate cancer therefore presents particular challenges and the following points were noted as being key measures of success in developing this work:

1. Prostate Cancer UK provided BHA with financial support to deliver this work. Equally important the charity also provided relevant resources that Black men could identify with. An excellent example of this is the booklet 'What do you know about your prostate? Information for Black Men'. The booklet is one of many resources that are part of Prostate Cancer UK's African Caribbean programme 'Partnering for Progress'. The information materials featured images of Black men/people on the cover, therefore emphasising the fact that the information contained within was aimed at and relevant to that ethnic group. Prostate Cancer UK also provided the services of a prostate cancer champion (Denton Wilson) and Prostate Cancer UK specialist nurse (Suresh Rambaran), both of whom are Black African Caribbean men. This proved invaluable, as they were able to deliver their talks/presentation using terminology and language that Black men could immediately relate to and understand.
2. Community champions have a significant role to play in awareness raising. It is important to have Black men who can tell their personal stories relating to prostate cancer. Only they will be able to convey their experiences in a way that resonates with another Black man whilst delivering important key messages.
3. Local community radio stations provided an invaluable service in not only promoting the work but also providing local people with information through a programme on prostate cancer and Black men which was supported by a phone-in. Manchester's Peace FM Community Radio and BBC Radio Manchester provided significant support in promoting the Time2Reason Campaign. Additionally, local voluntary organisations and networks were supportive through publicising the events and the campaign.
4. It was recognised that Black women have a significant role in spreading the messages about prostate cancer, spotting the signs and symptoms and encouraging men to seek medical advice. Engaging with Black women should be embedded into future programmes of work undertaken by Prostate Cancer UK and other prevention programmes related to urological cancers.
5. People from African-Caribbean and African backgrounds are more likely to be given a diagnosis of schizophrenia or psychosis. Consideration should be given to whether health information needs to be adapted, and information delivered in other ways, to get key messages across clearly about cancer risks to men with a mental health condition. The idea of a prostate cancer DVD was raised by one participant.
- 6 The target of 50 men in attendance at each of the 3 health and wellbeing events was ambitious. The maximum attendance of Black men was 29 at an event jointly planned with the Seventh Day

'Some of the members have just shared with me that they have had prostate cancer because of you being here today. I've worked with them for years and I didn't even know!'

‘Prostate cancer is a serious thing. I’ve had the full test... you know what I mean, the finger up the bum. I’ve done it, but I know a lot of brothers won’t go there.’

Adventist Church. Working with faith groups is therefore an effective way to communicate key health messages to Black men and minority communities generally. It is important to ensure that cancer awareness events are organised in partnership with local community organisations or faith groups to encourage maximum attendance. Impromptu awareness raising was also conducted by visiting barber shops. Prostate Cancer UK resources were taken to the barber shops and displayed, and used to start a conversation with clients to draw out the levels of understanding as well as provide information on the facts relating to prostate cancer. The barber shop approach worked extremely well due to the informal style of engagement.

7. The support provided by the *Time2Reason* campaign was limited to having a one-to-one confidential discussion with individuals where clarity was required on aspects of the presentation at an event; referring individuals to their GP or the Prostate Cancer UK helpline. Men who were affected by prostate cancer as well as individuals who were carers, felt there was no support available that meets their needs and enquired about the availability of ongoing awareness raising and support.
8. The development of a prostate cancer support network for Black men, and those affected by it, will be pursued through mainstream cancer organisations but officers at BHA felt such a development could have been established in tandem with the awareness raising rather than be viewed separately to enable continuity of the work. However, BHA’s relationship with the Black men’s support group, Friends and Brethren (FAB), hosted by BME Cancer Communities has provided us with good evidence to pursue establishing a similar group in Manchester.

Key Achievements

This programme of work on prostate cancer awareness has started a dialogue with Black African and Caribbean men about their experiences, fears and anxieties in accessing tests and treatments. Positive feedback was received about the campaign and Black men who participated in the programme acknowledged that they recognised some of the symptoms and were proactive in seeking advice from their GP. Equally Black African and Caribbean women acknowledge that they had a significant role in giving greater support and encouragement to partners and family members to talk about their concerns and where necessary seek medical advice and request a PSA test.

We were successful in dispelling the myths and reducing stigma surrounding the internal examination used to diagnose prostate cancer by providing an opportunity for men to share their experiences with others of having the Digital rectal examination (DRE) and its importance. This is a significant achievement, as fear of the DRE is one of the main barriers hindering Black men from visiting their GP. To hear another Black man openly speak about having the examination in a language and dialect that another Black man can relate to gets the message across in an effective manner. Comments gathered during our work included:

'I regularly speak to the guys who come to the gym about prostate cancer, but they don't want to hear. As soon as they hear about the finger up the bum test, they don't want to know. You can't tell them! Let me have some of the pocket guides, I'll personally hand them out when they come in.'

'I've had the proper test done – it was very quick. I don't know what the fuss is about.'

'It might save u life'. 'Ah important ting fe do', 'It neva tek long, a quick ting dat man.'

The men we met who had experience of prostate cancer were mainly quite open about their personal experiences and the quality of service provided by their GPs, hospitals and cancer organisations. Our engagement with these men has enabled us to identify potential community champions to support future work.

The campaign enabled BHA for Equality to distribute over 2,000 copies of Prostate Cancer UK's information resources to members of the public as follows:

- What do you know about your prostate: Information for Black Men (476 copies)**
- Diet, Activity and Risks (350 copies)**
- The PSA test and prostate cancer: a quick guide (491copies)**
- Know your prostate: a quick guide (769 copies)**
- Prostatitis: a guide to infection or inflammation of the prostate (205 copies)**
- Prostate cancer: A guide for men who've just been diagnosed (81 copies)**

Evaluation of the awareness events showed that overall 80% of the men that attended had an increased awareness of the signs and symptoms of prostate cancer and 60% had a better understanding of what the PSA test involved, its purpose and what it measured.

Increased awareness was also evident from the comments recorded, a selection of which are detailed below:

'I didn't know women did not have a prostate... I've learned something new today.'

'My uncle currently has prostate cancer. I've been meaning to get myself tested. I'll call my GP on Monday.'

'I was not aware that if my father had prostate cancer that I am at risk. I best get myself checked out.'

'Prostate cancer is a serious thing. I've had the full test... you know what I mean, the finger up the bum. I've done it, but I know a lot of brothers won't go there.'

'My mother and sister had breast cancer and my dad died of prostate cancer so perhaps I should go to my GP for the test.'

'This is useful information, thank you. I will share with my family.'

'This is a growing issue. The thing is if caught early it can be treated. But you know us men; we leave it until it's too late.'

'Some of the members have just shared with me that they have had prostate cancer because of you being here today. I've worked with them for years and I didn't even know!'

'We need more awareness on this topic.'

'Please continue awareness programme.'

'Very interesting. Good to have someone explain it in detail.'

'This has been a great eye opener.'

'We would like to run a similar session at our Withington church.'

'We really need more of these awareness sessions. Please come again.'

It is difficult to fully measure the impact of BHA's work in encouraging early diagnosis of prostate cancer from such a short term awareness campaign. However, from the comments above, participants involved in the campaign have improved their knowledge of the condition and know where to access help and advice. It was also encouraging that BHA officers were contacted by one man, following a community session, who was calling from his GP surgery, seeking clarification on the name of the test that he should be requesting from his GP. This information was provided along with the offer of support following the test results.

BHA's involvement in this programme of work has given us the opportunity to develop our work on cancer, thereby tackling disparities in health, and it has also further validated BHA's engagement approach as being effective. This included our model of engagement with faith groups (which has been used in the past in delivering awareness sessions on HIV and Hepatitis C) being applied to prostate cancer. The awareness raising sessions undertaken with Black-led churches were particularly successfully and stemmed from existing partnership work.

Finally, the involvement of mainstream cancer organisations at the awareness events has allowed them to engage in discussions with Black men. Long-term we hope this will have a positive impact on other cancer services to Black and other minority communities and present opportunities for future partnership working.

Conclusion

‘When cancer is diagnosed at an early stage treatment options and chances of a full recovery are greater. This means raising awareness of what to look out for and when to act; tackling negative attitudes to cancer and barriers to seeing the doctor amongst the public; supporting primary care so they are able to manage and refer patients with symptoms that might be cancer appropriate and ensuring optimum and prompt access to diagnostic tests and referral pathways that can facilitate the diagnosis of cancer.’ (National Awareness and Early Diagnosis Initiative, NAEDI)

BHA’s engagement activity with Black African and Caribbean men was undertaken on a short term basis but managed to reach over 500 people. This is a small step in tackling a health condition that adversely impacts on Black men but equally affects their families and friends. Awareness raising cannot be undertaken effectively on a short term basis and work such as that conducted by BHA should be embedded into national cancer prevention programmes that specifically target groups which are deemed to be high risk. Participants welcomed the *Time2Reason* campaign with one person commenting ‘I would like to see a lot more of this kind of awareness’... and ‘the government should recognise our needs.’

Evidence shows that Black men are less likely to be tested for prostate cancer even though they are more likely to develop it (BJGP, 2015). Black men are more likely to develop the disease earlier than men of the same age from other ethnic groups and 9 in ten Black men are unaware of their increased risk to prostate cancer (Prostate Cancer UK).

The quote from NAEDI is particularly relevant to Black communities but measures are not in place to ensure that sustainable programmes of awareness are targeted at communities with high rates of cancer incidence and morbidity. Until this change comes about some communities will continue to be affected by disparities in access, treatment and outcomes in the health system.

Through effective engagement, we have made some progress in increasing awareness about prostate cancer within Black African and Caribbean people who participated in the campaign but a lot more work remains to be done.

‘I was not aware that if my father had prostate cancer that I am at risk. I best get myself checked out.’

‘We really need more of these awareness sessions. Please come again.’

Recommendations

In view of the above evidence related to the cancer awareness sessions targeting Black men BHA for Equality makes the following recommendations based on its findings:

Cancer prevention and early detection is incorporated into all of the Manchester Clinical Commissioning Group (CCG) strategic commissioning plans but it is unclear how a CCG's commitment to making improvements at a local level will impact on high risk groups such as Black men with prostate cancer. Clinical Commissioning Groups need to review the impact of certain conditions on particular ethnic groups and commission services to meet those needs.

Good practice in increasing cancer awareness should be developed using examples from successful campaigns in cancer and other disease areas and such good practice should be embedded into mainstream health practice or strategy development. Many examples exist in the voluntary sector but little of this practice is embedded into the practice of statutory health bodies or national campaigns such as 'Be Clear on Cancer.'

There should be a greater level of partnership working between voluntary and community organisations that provide services to Black and other Minority Groups and mainstream cancer organisations to ensure good practice is applied in engagement activity and such good practice is replicated across the country.

Some cancer organisations provide information that is targeted at Black and other minority groups both written and in other formats. Such information requires further development beyond symptom recognition to include healthy eating and diet. During its work BHA identified an interest, particularly among the Caribbean community about the benefits of particular foods. It would be helpful to produce a healthy eating guide which focuses on African, Caribbean and Asian foods similar to that produced by Cancer Equality (Coping with Eating Difficulties when you have Cancer, 2007).

There is a potential opportunity for a national distribution programme of the prostate cancer pocket leaflets and other cancer information to increase information dissemination to Black communities via barbers and hairdressers. This should be explored by Prostate Cancer UK and other cancer charities.

Cancer organisations should look at the feasibility of also targeting Black women as an alternative route to promoting key messages about prostate cancer and other urological cancers that affect men.

Consideration should be given to looking at a programme of training for GPs, perhaps initially conducted on a pilot basis with GP patches, on cancer and high risk groups to encourage early diagnosis and 'fast tracking' by GPs of particular patients to specialist cancer services.

There is an interest in establishing a prostate cancer support group in Manchester that would:

- Provide support and practical help to Black men living with prostate cancer and those affected by it such as carers and family members.
- Offer a safe and confidential space in which individuals can exchange experiences, meet others and enable peer to peer support and mutual aid.
- Provide cancer-related information and resources that are easily accessible by group members.
- Signpost members to relevant agencies and services that address their cultural needs.
- Arrange regular information sessions about prostate cancer to engage, inform and empower members to access relevant cancer services.
- Provide support to members to organise and deliver regular fundraising activities to contribute to the sustainability of the group.

Alongside the above BHA would recommend the development of a prostate cancer champions' recruitment programme in Manchester and other areas. The support of cancer organisations is sought to pursue this goal.

Cancer organisations should consider a national programme of work with faith groups to raise awareness about cancer. This could be done through the Churches Together Network.

Cancer organisations should consider how they links into the key community radio stations when running local campaigns, during prostate cancer awareness month (March) and Ethnic Cancer Awareness Month (July).

The national football museum is now based in the centre of Manchester and presents an opportunity for partnership working with Prostate Cancer UK and its 'Men United' campaign. This opportunity should be reviewed in future plans for regional work by Prostate Cancer UK.

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