

A REPORT ON

Raising awareness of prostate cancer in black communities in Basingstoke

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Abstract

In the UK, prostate cancer disproportionately affects black men more than any other ethnic group. Black men have higher incidence and worse outcomes of prostate cancer compared to their white UK counterparts. They may present with prostate cancer at a much later stage during the cancer trajectory. This could be due to a lower awareness of the signs and symptoms of prostate cancer, an unwillingness to report symptoms or a lack of trust of the National Health Service [NHS] or a combination of these. Therefore the aims of this project were to raise awareness of prostate cancer in black communities in Basingstoke and to evaluate the engagement and raising awareness campaigns.

Methods

This project involved two phases; the first phase focused on raising awareness of prostate cancer in black men and their families/significant others. The awareness was delivered using public facing activities such as stands and talks with participants. Additionally, online raising awareness activities were undertaken with either black men alone or black men and their families. The talks involved providing information on prostate cancer, for example, what is prostate cancer, facts and figures pertaining to prostate cancer in black men, the risk factors and what participants can do to mitigate these risk factors. The awareness sessions were conducted by members of the research team. The second phase of the project involved an evaluation of the raising awareness campaigns through interviews. A total of 320 black men and their families were involved in the raising awareness sessions and of these 12 black men were interviewed.

Findings

Three main themes emerged including, increased knowledge and mindset change regarding prostate cancer, empowered to take community and personal action as well as strategies and tools to raise awareness of prostate cancer among black communities.

Conclusion

The raising awareness campaigns had a positive effect in terms of increasing participants' awareness of the risk factors associated with prostate cancer. Moreover the campaigns enabled them to make lifestyle adjustments that could help them to reduce their likelihood of developing this condition. Furthermore, participants' knowledge was improved and this resulted in them becoming empowered and motivated to make a difference to their lives and that of the community that they serve through creating dialogues and sharing what they had learnt about prostate cancer.

Summary of recommendations

- There is an urgent need for culturally specific information on prostate cancer in black men to become available in GP surgeries for the purposes of raising awareness of this disease to black men and their families.
- In raising awareness and disseminating information about prostate cancer in black men and their families, the use of culturally specific events and gatherings should be considered.
- The findings of this research also highlight the need to train and educate members of the black communities who could then act as community advocates to help spread awareness of prostate cancer within these communities.
- A further recommendation of this research is to consider making PSA testing routinely available to all black men aged 45-years and above, in all GP practices as black men are known to have an increased risk of developing prostate cancer.

- The use of social media and the creation of a website with culturally specific information to increase awareness about prostate cancer amongst black communities should be considered to further enhance black men and their families' knowledge and understanding of the disease.
- There is an urgent need to increase GPs' and their employees' awareness and understanding of the impact and risks of prostate cancer on black men. In doing this, it is anticipated that black men will be able to obtain a timely PSA test.

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Chapter One | Introduction

1.1 What is prostate cancer

The prostate is a small gland that is only found in men. The prostate gland is close to the rectum and produces a thick, white fluid that mixes with the sperm from the testicles to create semen (Macmillan Cancer Support, 2015). Cancer can develop in the prostate cells. Prostate cancer may remain localised and stay inactive for many years. However, there is a risk that the cancer can grow quickly and spread to other parts of the body. Most men with early prostate cancer do not have any symptoms. Unusual changes to the way men urinate may be a side-effect of an enlarged prostate pressing against the urethra. This may not be a sign that the prostate is cancerous, and could be related to another health problem. If the cancer spreads beyond the prostate, common symptoms include pain in the back, hips and pelvis, erectile dysfunction, blood in the urine, and unexpected weight loss (Prostate Cancer UK, 2014)

1.2 Prostate Cancer in the United Kingdom

In the UK, prostate cancer is the leading cause of death in men (Cancer Research UK, 2022). According to Cancer Research UK (2022), approximately 52,300 men are diagnosed with prostate cancer each year, that is more than 140 every day [2016-2018]. Evidence shows that over 12,000 men die from the disease each year, that is approximately 33 deaths every day (Cancer Research UK, 2022). Research suggests that the lifetime risk of being diagnosed with prostate cancer is approximately 1 in 4 for black men, 1 in 8 for white men and 1 in 13 for Asian men (Lloyd et al, 2015). According to NHS England (2022), approximately 3898 men in August of 2022 received prostate cancer treatment compared to 3057 in the same month last year. This surge was as a result of the joint launch between the NHS and Prostate Cancer UK campaign on raising awareness of prostate cancer in England. Men affected with prostate cancer may experience a wide range of debilitating symptoms including incontinence, impotence, bowel problems, fatigue, psychological problems and bone pain in its most advanced stage (Alexis, 2020). These symptoms can significantly impact on their quality of life.

There are various factors that can predispose a man to developing prostate cancer including:

- Race: men of African and Caribbean origin are disproportionately affected by prostate cancer,
- Age: men aged 50 or over are considered at higher risk of developing prostate cancer,
- Hereditary: men with a close relative (e.g., brother or father) who have been diagnosed with prostate cancer,
- Diet: a diet high in animal fats may increase the risk, whereas a diet high in soy may be protective,
- Obesity and a lack of exercise are risk factors that may contribute to a man developing prostate cancer.

(Macmillan Cancer Support, 2015; Harvard Medical School, 2018)

1.3 Prostate Cancer Screening

There is no national screening programme for prostate cancer in the UK (NHS 2018; Stark, 2009). This is because there isn't a reliable test that can pick up prostate cancer that needs treatment at an early stage (Cancer Research, UK 2022). Moreover, there is a lack of evidence suggesting that screening may not lead to better healthcare outcomes. Given that there is no approved screening programme for prostate cancer, checking for the presence of it can be done in the following ways, either using the prostate specific antigen (PSA) blood test or the digital rectal examination (DRE) or by both methods simultaneously (Lehto, 2010; Hoffman, 2011). It is clear that both the PSA test or the DRE are not reliable enough to detect prostate cancer however they are used as initial markers for further investigations into prostate cancer.

Men may have a prostate biopsy which involves using thin needles to take small samples of tissue from the prostate. The tissue is then examined under a microscope to check for cancer. A prostate biopsy is seen as the most accurate way of detecting cancer (Prostate Cancer UK, 2017). If cancer is found, the cells within the tissues will be graded on a scale of 1-5, known as the Gleason grade, depending on their patterns which determines how quick the cancer will grow. The higher the grade, the more likely that the cancer has spread outside of the prostate.

1.4 Prostate Cancer Treatment

Once a diagnosis is made, a discussion will take place about different treatment options. This will vary based on whether the cancer is localised or not (cancer within the prostate that has not spread to other parts of the body). Locally advanced cancer refers to cancer that has begun to spread to areas just outside the prostate or has metastasised. In treating prostate cancer there are a number of options that should be discussed with the patient and their significant other or next of kin if appropriate. The different treatment options include watchful waiting, active surveillance, radical prostatectomy, external beam radiotherapy, brachytherapy, hormone therapy, high intensity focused ultrasound, cryotherapy, Radium 223, Abiraterone/Euzalutamide and cabazitaxel. Metastatic prostate cancer is often treated with chemotherapy (NHS, 2018).

Studies show that the effects from treatment are known to cause fatigue, muscle tiredness and limpness (Ervik & Asplund, 2012) and erectile dysfunction (Simon-Rose et al., 2016). Patients are also made infertile by being unable to produce semen (Gannon et al., 2010) and may experience dry orgasms (Hartman et al., 2014). It has been highlighted how the adverse effects of prostate cancer treatment can have a detrimental impact on the psychosocial and physical wellbeing of men (Alexis & Worsley, 2018). Some men report feeling emasculated and feminised by prostate cancer treatment (Alexis and Worsley, 2018; Ervik & Asplund, 2012).

1.5 Basingstoke Ethnic Data

Table 1 below provides a comprehensive picture of the race and ethnic groups in the borough of Basingstoke and Deane at the 2011 and 2021 census. Data from the 2021 census show that approximately 185,200 individuals live in Basingstoke and Deane. This population has increased by 17,355 people since 2011 (approximately 10.3%). Furthermore, the Black, Black British, Black Welsh, Caribbean or African population in the region has increased from 1.1% in 2011 to 2% in 2021, while the proportion of the White English, Welsh, Scottish, Northern Irish or British population has decreased from 88.2% to 81.9% percent during the same period of time.

Table 1: Ethnic Groups in Basingstoke

Ethnic Group	2011 Numbers (%)	2021 Numbers (%)	Number (%) Change (2011-2022)
Asian, Asian British or Asian Welsh	6715 (4%)	10967 (5.9)	4252 (63.3%)
Black, Black British, Black Welsh, Caribbean or African	1909 (1%)	3611 (2%)	1702 (89.2%)
Mixed or Multiple ethnic groups	2813 (1.7%)	4717 (2.5%)	1904 (67.7%)
White English, Welsh, Scottish, Northern Irish or British	148078 (88.2%)	151572 (81.9%)	3494 (2.4%)
White Other	7810 (4.7%)	12268 (6.6%)	4458 (57.1%)
Other ethnic group	474 (0.3%)	2019 (1.1%)	1545 (325.9%)
Totals	167718	185154	17355 (10.3%)

Source: Basingstoke and Deane Borough Council (2022)

1.6 Wessex and national prostate cancer data

According to the National Disease Registration Service [NDRS] (2022a), there are 418,526 men living with prostate cancer in England for the period 1995 to 2019. Of these figures, the National Disease Registration Service (2022a) was unable to provide evidence of the number of BAME men living with prostate cancer as such data were not available. However in the last 5 years, from 2015 to 2019, there are 190,964 men living with prostate cancer in England and table 2 provides details of men by ethnic heritage who are living with prostate cancer in England (NDRS 2022b).

Table 2: Number of men living with prostate cancer in Wessex

Ethnic Groups	Numbers
Black	6676
Asian	3738
Mixed	847
White	163,232
Other	2117
Total	190,964

Source: NDRS (2022b)

Evidence obtained from NDRS (2022c) suggests that for 2015 to 2019 there are 580 men who are living with prostate cancer in Basingstoke and Deane. However, more current data are not available because NDRS (2022c) does not have such data at their disposal. However, table 3 below provides data showing prostate cancer standardised mortality rates by ethnic groups for England and Wales (Office for National Statistics, 2021). The data below show that black men are at a greater risk of dying from prostate cancer than white and Asian men. In table 3, no data were available for the Bangladeshi ethnic group.

Table 3: Prostate Cancer Ethnic Groups:

Age Standardised mortality rates for 100,000 males in England and Wales for 2017 to 2019

Ethnic Groups	Numbers
Black Caribbean	88.2
Black African	60.6
Black other	71.5
Indian	22.6
Pakistani	19.7
Asian Other	19.2
Mixed	50.3
Other	25.2
White	52.4
Bangladeshi	no data

Office for National Statistics (2021)

Table 4 provides the number of newly diagnosed cases of prostate cancer in black men in England for the period 2013 to 2019 for men aged 0-49. In 2015, there was a marginal increase in the number of black men diagnosed with prostate cancer with 2016 showing a reduction in the numbers. Reasons for this increase and then the subsequent reduction in the numbers in the following year are unknown.

Table 4: Number of newly diagnosed cases of prostate cancer in men aged 49 and below in England by selected ethnicity for the period 2013-2019

Year	Age 0-49			Unknown ethnicity
	All cases	Black men		
	No	No.	%	%
2013	417	61	15%	8%
2014	480	64	13%	11%
2015	454	76	17%	14%
2016	476	58	12%	14%
2017	489	80	16%	6%
2018	534	76	14%	11%
2019	538	79	15%	17%

NDRS (2022d)

Table 5 shows the number of newly diagnosed cases of prostate cancer in England. The table particularly demonstrates the number of black men diagnosed with prostate cancer for the period 2013 to 2019. The data show that in 2018 more black men aged 50 and over were diagnosed with prostate cancer compared to previous years. According to the data, 2014 was the year with the least number of black men diagnosed with prostate cancer.

Table 5: Number of newly diagnosed cases of prostate cancer in men aged 50 and above in England by selected ethnicity for the period 2013-2019

Year	Age 50+			Unknown ethnicity
	All cases	Black men		
	No.	No.	%	%
2013	41904	1233	3%	4%
2014	40580	1184	3%	6%
2015	41255	1221	3%	8%
2016	41217	1232	3%	7%
2017	41542	1460	4%	5%
2018	49659	1586	3%	7%
2019	46941	1497	3%	10%

NDRS (2022e)

Chapter Two | Literature review

2.1. The context

It is widely recognised in the literature that black men of African and Caribbean heritage have a significantly increased risk of developing prostate cancer. Black men are 2 to 3 times more likely to be diagnosed with prostate cancer than their white UK counterparts (Alexis, 2020a). There is also evidence suggesting that they develop this condition at a younger age (Bleyer, Spreafico and Barr, 2020). According to Anderson and Marshall-Lucette (2016) revealing that black men are diagnosed at an average age of 67.9 years compared to an average age of 73.3 years for white men. Black men have also been found to present to their GP at a later stage of the disease progression (Anderson & Marshall-Lucette, 2016). This could partially account for why black men are three times more likely to die from the disease than their white UK counterparts (Ben-Shlomo et al., 2008). It presently remains unknown why black men are disproportionately affected by prostate cancer. However, possible explanations for such differences include demographic characteristics, socioeconomic status and racial differences in genetic biology which may be attributed to differences in dietary intake or hormonal factors (Anderson & Marshall-Lucette, 2016).

In view of the above evidence, it is especially important that black men are aware of the signs, symptoms and risk factors of prostate cancer, as well as the treatment side effects. Thus, it is concerning that studies have shown that black men lack awareness about the prostate and prostate cancer (Parliamentary Stakeholder Group, 2012). Nanton & Dale (2011) found that black men lacked awareness and they were disproportionately affected by prostate cancer. Furthermore Nanton and Dale (2011) also revealed that they lacked awareness of what the prostate was and where it was in the body in contrast to white men. Additionally, Nanton and Dale (2011) also reported that black men felt they had a lack of information regarding prostate cancer. In the study, the participants criticised health professionals for not being appraised of the side effects of treatment, and for not being involved in the decision-making regarding treatment. Other studies revealed that black men expressed anger towards the healthcare system particularly at their physicians who were not forthcoming about bodily changes and the impact that treatment for prostate cancer had on their sexual function and their masculinity identity (Letts et al., 2010; Alexis and Worsley, 2018). Indeed, they pointed out that they needed more information specifically to address their cultural needs and about treatment options (Alexis, 2020a).

Research has also found that a further barrier to black men seeking timely care for prostate cancer is the challenges they experience in accessing healthcare services to that of their white UK counterparts (Thompson, 2014). It is well documented in the literature that disparities in access to healthcare services for Black, Asian and Minority Ethnic (BAME) groups exist (Szczipura, 2005; Thompson, 2014) and that they experience different prostate cancer treatment outcomes to that of their white UK counterparts (Ben-Shlomo et al., 2008). These inequalities have resulted in general lower levels of trust in the healthcare system, with the perception that it is set up against black men's health. Thus, they were more likely to use informal interpersonal sources, such as family, friends and co-workers to obtain information on prostate cancer, but these can be dangerous and unreliable (Ross et al., 2011).

Fear over receiving a positive diagnosis, and what occurs during prostate cancer screening prevented some black men from seeking treatment. Studies have shown that the perceived risk of impotence and incontinence from a positive diagnosis was a feared side effect that prevented black men from seeking treatment (Alexis and Worsley, 2018; Wall and Kristjansen, 2005). Talking about prostate cancer was taboo, with men ashamed and embarrassed to discuss the topic with their peers because they perceived a positive diagnosis as a threat to their masculinity (Bamidele et al.,

2018). There is also some evidence suggesting that black men are reluctant to seek support through fear of being humiliated and emasculated as a result of the DRE test for prostate cancer. Some men have described this as an invasion of privacy and an insult to their manhood (Potts, 2000).

The above evidence highlights the need for culturally diverse means of raising awareness of prostate cancer among the black communities. It is clear that a more proactive approach to giving and providing information, supporting black African and black Caribbean men combined with training in cultural diversity were needed. With this information, it is crucial that this study is conducted to raise awareness of prostate cancer in this particular area.

2.2 Aims of the study

This project had two main aims. The first aim was to raise awareness of prostate cancer in black communities in Basingstoke and the second was to evaluate the engagement and raising awareness campaigns. The project would achieve these by addressing the following objectives:

- To highlight to black men and their significant other/families' the signs and symptoms, and the risk factors associated with prostate cancer,
- To find out what participants have found helpful from the raising awareness and engagement sessions,
- To understand if the prostate cancer raising awareness information have been useful in helping them to change their health seeking behaviours,
- To explore black men and their significant other/families' understanding and knowledge of prostate cancer,
- To signpost black men and their significant other/families to further information and support,
- To understand black men and their significant other/families' perceptions of prostate cancer.

Chapter Three | Research design and methods

3.1 Methodology

This project involved two phases; the first phase focused on raising awareness of prostate cancer. The raising awareness sessions were delivered using public facing activities such as stands and talks with participants. Moreover, online raising awareness activities were undertaken with either black men alone or black men and their families. The talks involved providing information on prostate cancer, for example, what is prostate cancer, facts and figures pertaining to prostate cancer in black men, the risk factors and what participants can do to mitigate these risk factors. The awareness sessions were conducted by members of the research team. During the second phase of the project, participants were interviewed to evaluate the engagement and the raising awareness campaigns.

3.2 Recruitment

In the first phase, the awareness raising sessions were conducted through churches, barbershops, walk and talk groups, black voluntary organisations in Basingstoke, health events, the local media such as newspaper and radio and through individuals contacting the lead researcher [snowball sampling]. Moreover, the research team conducted a number of public facing activities at the Basingstoke Town Centre Mall and other Community Centres as well. Furthermore, this project was also made known through a number of media activities [written articles and interviews] in Basingstoke. Table 6 below provides a breakdown of the number of participants and the various organisations that were involved in the raising awareness sessions. These sessions ran from January 2022 to December 2022.

Table 6: Number of raising awareness sessions

Organisations	Number of participants
Churches	30
Walk and Talk Groups	67
Barbershops	22
Basingstoke Town Centre Mall and Community Centres	81
Black Voluntary Organisations	71
Individuals	26
Local Media [newspapers and radio]	6
Health Events	17
Total	320

In the second phase, participants were recruited to evaluate the project and to gain their understanding and knowledge of prostate cancer once they had attended a raising awareness session. Once participants had attended either a public facing activity or talk, an information sheet was offered to them for the purposes of participating in the interview. In most cases participants

made contact following a PSA test. In other cases they made contact prior to having a PSA test. Once they had made contact, arrangements were made to interview them at a mutually convenient date and time.



Figure 1: Dr Obrey Alexis and Dr William Garbrah during a raising awareness session

A total of 320 black men and their families were involved in the raising awareness sessions and of these 12 black men were interviewed. The purposes of these interviews were to evaluate the engagement and the raising awareness campaigns including participants' knowledge and understanding of prostate cancer, the risk factors as well as the signs and symptoms. To be included in the project the following criteria were applied:

Inclusion criteria

- Living in Basingstoke.
- Above 18 years.
- From all genders and socio-economic status.
- From a black Caribbean or black African heritage.
- Mixed heritage will be included as long as they identify themselves as black.

Exclusion criteria

Participants to be excluded are:

- Whites and other ethnic groups.
- Children under the age of 18.

3.3 Data Collection

Data were collected using semi-structured interviews. In light of essential COVID19 measures in place during the pandemic, the semi-structured interviews were conducted either face to face using Audacity or using an online channel (for example Zoom or Google hangouts), depending on the participants' preference. The time for each interview was mutually agreed with participants. Each interview [one to one or focus group] lasted between 30-60 mins and was conducted either video recorded with camera off or audio-recorded. Twelve interviews were conducted [8 one to one interviews and 2 focus groups with two participants in each group]. The interviews were conducted from January 2022 to September 2022. The semi-structured interview guide included the following example questions:

- Can you please tell me about your experiences of engaging in the raising awareness of prostate cancer activities in Basingstoke?
- Can you tell me what you knew about prostate cancer before you were given the information?
- Can you tell me about your knowledge now that you have received information about prostate cancer?
- Can you tell me about your perception of prostate cancer?
- What are your views regarding the information you have received in relation to prostate cancer?
- Can you tell me about your understanding of the risk factors of prostate cancer?

3.4 Data Analysis

Following the interviews the data were later transcribed verbatim and analysed using a process of thematic analysis (TA) by Braun and Clarke's (2006). TA is a method for systematically identifying and organising patterns of themes across an entire dataset (Howitt, 2010). The initial stages involved reading and re-reading all the interview transcripts to become familiar with the breadth and depth of information pertaining to participants' awareness of prostate cancer before and after attendance at the raising awareness session. Initial detailed coding of all corresponding statements was then carried out, which remained as close to participant's words as possible. The resulting list of initial codes were then sorted and collated into potential themes, a process which involved clustering. Potential themes were reviewed and revised until they met Patton's (1990) dual criteria of 'internal homogeneity' (meaningful coherence of data within a theme) and 'external heterogeneity' (clear distinctions between each theme). The selected themes were then named and refined further, to ensure they captured the essence of both the data and the overall narrative. Secondary analysis was carried out by other members of the research team before the final set of themes were agreed and theme names revised. The final analysis is presented in the findings section. Table 7 below identifies the demographic data of black men who were interviewed for this project.

Table 7: Interviewees Demographic Data

Participants	Nationality	Age range
Participant 1	Black Caribbean	50-59
Participant 2	Black African	60-69
Participant 3	Black African	50-59
Participant 4	Black African	60-69
Participant 5	Black Caribbean	50-59
Participant 6	Black African	60-69
Participant 7	Black African	50-59
Participant 8	Black Caribbean	60-69
Participant 9	Black African	40-49
Participant 10	Black African	50-59
Participant 11	Black African	40-49
Participant 12	Black African	60-69

Chapter Four | The results

Analysis of the interview data revealed three main themes: 1) increased knowledge and mindset change regarding prostate cancer, 2) empowered to take community and personal action, and 3) strategies and tools to raise awareness of prostate cancer among black communities (please see Diagram 1 below). These themes and subthemes will be discussed in detail below.

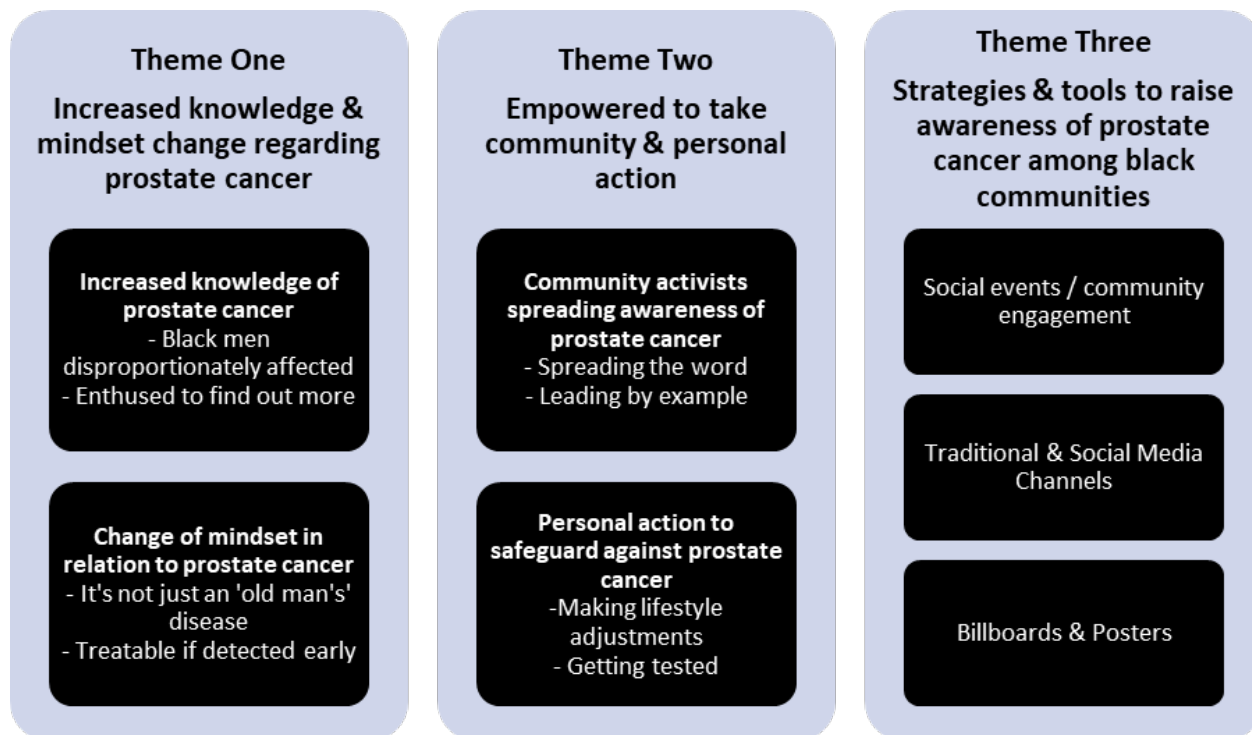


Figure 2: Overview of themes and subthemes

4.1 Increased knowledge and mindset change regarding prostate cancer

4.1.1 Increased knowledge of prostate cancer


Most participants stated that prior to their engagement in the raising awareness of prostate cancer activities, they only had limited knowledge about the disease and had not given much thought to it:

“ I had heard about prostate cancer but not much until I had this information, (Participant 2, Black African)

I'd never heard of it until a friend of mine introduced [...] told me about you [...]. I think that's the first time I ever heard about this, (Participant 4, Black African).


Participants were unanimous in stating that the information they had received during the raising awareness sessions had improved their knowledge and understanding of prostate cancer, and had put this disease at the forefront of their minds. For example, several participants reported being unaware that Black men of African and Caribbean heritage were at a higher risk of developing and dying from prostate cancer. They had been shocked by the sobering statistics presented to them during the talk:

“ I now know how much higher that prostate cases are in Black African men vs White men, (Participant 3, Black African).

 *Well the thing I'm aware of now is the high risk in Black males of a certain age, (Participant 5, Black Caribbean).*

Information that I have now, that is more on the black and or African and Caribbean men. And that it affects us all, that race and ethnicity, more than others. I wasn't aware of that at first, (Participant 6, Black African).


The information provided during the awareness sessions was found to equip participants with the necessary knowledge to look up further information on prostate cancer. Indeed, several participants referred to actively exploring websites such as Prostate Cancer UK on the internet and learning more about the condition:

 *I read a little bit more and that's when I learned about the treatment for prostate cancer, (Participant 3, Black African).*


I think after we discussed it, I think it came to my mind that [...] I really went further and read more about prostate cancer and I think I've learnt more since the last time we talked, (Participant 4, Black African).

4.1.2 Change of mindset in relation to prostate cancer

The analysis also revealed a change in participants' attitudes towards prostate cancer following their participation in the raising awareness sessions. For example, they reported that they no longer perceived prostate cancer as an 'old man's disease', as they learnt that Black men are especially at risk of developing prostate cancer from a younger age (i.e., 45-years or younger):


 *I knew that it affected old men. I didn't know it could affect young men, I mean as young as I am so ...um...I would say that actually that was really a very important session, (Participant 10, Black African).*

Some participants also remarked that they no longer perceived prostate cancer as a deadly disease, but as potentially curable and controllable if treated in the early stages. Thus, the raising awareness sessions had been useful in emphasising to participants that early detection was of paramount importance:

 *And that's the key here early intervention, who can be cured or controlled within early intervention and get treatment at the early stages, (Participant 1, Black Caribbean).*

I know that prostate cancer is real but if it is detected earlier, it can be treated. So, when you have the symptoms or when you feel like you have the symptoms, you don't have [to be] embarrassed. You have to talk to your GP and be open about it so that the GP will know what is happening with you so that the GP can give you the right treatment, (Participant 2, Black African).

Thus, one participant stated that their enhanced awareness of prostate cancer following the raising awareness session had helped reduce their fears about the disease:


 *I think [...] when you don't understand something [...] you can be fearful, you can have a lot of fear and I think prostate cancer, like other debilitating illnesses such as [...] diabetes, blood pressure, mental health is a [...] it can bring a lot of a lot of fear, but I think great awareness [...] I think of that, so I think it's a case of demystified fear, (Participant 1, Black Caribbean).*

The next theme discusses how the raising awareness sessions empowered participants to both start a discussion on prostate cancer with other members of their community, as well as to take personal action to safeguard against the disease.

4.2 Empowered to take community and personal action


4.2.1 Community activists spreading awareness of prostate cancer

Some participants commented that black communities found it difficult to openly talk about prostate cancer because of the stigma surrounding it, such as the perceived loss of masculinity:

 *We think about the stigma that goes with prostate cancer. So sometimes when we have the symptoms we suppress or hide it until sometimes it becomes too late to do something about it, before we try to come out and say something about it, (Participant 2, Black African)*


Sometimes, especially we the blacks because of cultural, traditional tendencies we find it very difficult to come out. Also because prostate affects your sexual performance, we find it very difficult to talk about it openly or plainly, (Participant 5, Black Caribbean).

The information the participants received on prostate cancer gave them the confidence to start a conversation with other community members about the disease. Indeed, most participants felt that it was their responsibility or duty to utilize this knowledge by acting as community activists spreading awareness on prostate cancer among their community:

 *Those of us who have got the knowledge have to spread the news. It is not going to be easy but when we persist, gradually everybody will become aware of it, (Participant 2, Black African).*

I think again moving on undoubtedly I'd be looking to spread the word, educate all the people, you know, I thought [...] by no means did I think I knew it all and it's evident [...] I knew something about prostate cancer, but [...] certainly not enough and I'm certainly more educated now and I'd be looking to spread that knowledge, you know, to [...] I guess suitable individuals and I'm quite excited to doing that, so I'll definitely be, you know, spreading the word, (Participant 3, Black African).


A few participants also stated that they wanted to lead by example and act as role models within their community, for example by getting tested at their GP surgery:

 *[...] and leading by example as well, it's one thing having the knowledge, but I think what's key here also is taking appropriate steps thereafter, (Participant 1, Black Caribbean).*

I now know more and I've acted on the information I've gained, this is what I've done. You're more likely to get people to engage if they can see what action you've taken. And I personally would be in a position to say well right, I know a little bit more because I've had an invasive check, but I've also done a PSA test, you know, this is what I've actually done and it's fairly seamless, you know, have a chat with your GP, you know, the internet, do your own personal research, (Participant 3, Black African).

4.2.2 Personal action to safeguard against prostate cancer

The information the participants received also empowered them to take personal action to help safeguard themselves against developing prostate cancer. For example, some participants referred to making lifestyle adjustments such as reducing their intake of fatty foods and increasing their exercise:


 *I'll be trying to look at where and what I'm eating and how I've been doing things, (Participant 6, Black African).*

I mean I eat a lot of cheese, I've got to admit that so, and it does cross my mind sometimes and I might try to have a week where I don't eat as much, you know. Obviously, I'm a vegetarian so obviously cheese does play a big part, so you know, it did kind of upset me a bit when I heard that, you know. So I stopped eating so much cheese when I heard [...] I did use to eat it quite often, (Participant 8, Black Caribbean).


So my awareness of prostate cancer right now, you know, has made it even more important for me to be mindful of the things I eat. So after that session I've now tried to ... I've reduced my milk intake. I used to take milk every morning with porridge, but I've stopped that for some time. So those are some of the things ...um...lifestyle changes I'm now starting to gradually introduce ...um...you know, as a result of my new perception of prostate cancer, (Participant 9, Black African).

Well I was thinking when I finish work that I should really go and get myself back into some sort of physical shape. Go walking more, (Participant 5, Black Caribbean).

Thus, the education they received on prostate cancer gave them some personal control over the disease, although they acknowledged that not all risk factors were within their control to manage:

 *[...] the emphasis is really on milk products most, that's something I can change through my diet. Yeah, and well the other thing is, things that I can't change like it being prevalent among Black people, I cannot change. But, yeah, avoiding certain things like [...] you said red meat, milk things like that, (Participant 7, Black African).*

Some participants also remarked that the raising awareness sessions had encouraged them to contact their GP surgery to initiate discussions about getting tested for prostate cancer:

 *Maybe the first bit for me is to go for this PSA test and then from there I know what I am doing, (Participant 6, Black African).*

I probably would take the advice especially finding out from my GP how I can get tested, (Participant 7, Black African).

Yes, I've got one since then and I had a conversation with my GP yesterday around my test results, (Participant 9, Black African).

However, a few participants reported experiencing challenges when speaking to their GP surgery and were unsuccessful in having the appropriate tests carried out:

Since our conversation [...] I tried to get a test which was unsuccessful [...]. I phoned my GP surgery and said, you know, can I speak to the doctor, they asked me what it was about and I said, you know, I'm participating in this study for males over the age of 50 and I need to get the PSA test done and the receptionist went and asked someone and then they came back and said well have you got a blood card or something or, you know, have you got any official documentation, I said no and they said well we can't just give someone a blood test who just walks in off the street, and I said even if you know that I'm over a certain age, I'm male and I'm more at risk of catching this, can I not just have a test. Unfortunately, I was told no. I can't unless I have documentation or I'm showing symptoms, no I can't, (Participant 5, Black Caribbean).

Thus, a few participants also highlighted the need for GP staff to become more aware of prostate cancer:

So if the GP staff become more aware of this, I think they might be more likely to want to help people who say I need this test. I want to check where I am and not come into the surgery when they're having symptoms and it's too late, (Participant 5, Black Caribbean).

This also led to some participants proposing that the PSA test should be part of a regular health check-up:

I think what we need to do is promote prostate cancer awareness as part of a holistic health check, (Participant 1, Black Caribbean).

...why can't they put it as one of the conditions...to be amongst those cancers that need to be screened, you know what I mean, (Participant 4, Black African).

Participants cited various strategies and tools that could potentially be used to raise awareness of prostate cancer among black communities. The next theme discusses these in more detail.

4.3 Strategies and tools to raise awareness of prostate cancer among black communities

4.3.1 Social events / community engagement

Some participants proposed that existing social gatherings in places that black men and their families regularly frequent, such as places of worship and barbering shops could be used to create awareness of prostate cancer among black communities:

I think it has to be when we meet socially or otherwise, you know, it might sound crazy but we chat enough even when we go into barbers shops. There are so many areas where we meet socially, you know, and I just think there is scope or potential to have that dialogue [...] ok, not necessarily an in-depth chat but you could certainly broach the subject, you know, barbers shops, I don't know, community centres. I know they're a dying breed [...] but I think word of mouth, (Participant 3, Black African).

...Also maybe targeting places of worship that are frequented by Black people, including the ...um...women, so they can be aware of what goes around, so maybe they could encourage ...um... participation, (Participant 6, Black African).

I think just campaigns like this one where maybe Black men are taking the lead to [...] yeah, it does help to promote awareness. Also maybe targeting places of worship that are frequented by Black people, including the [...] women, so they can be aware of what goes around, so maybe they could encourage [...] participation, (Participant 7, Black African).

Other participants proposed linking talks about prostate cancer to social events such as Black History Month and carnivals, where there would already be a large existing gathering of black men and their families:

...health and cultural awareness campaign in public in person or online and linked to celebrations, such as carnivals, black history month, music celebration, academic celebrations and events where people attend, (Participant 1, Black Caribbean).

You see what I mean, you have the Notting Hill Carnival in London where you will have many black people attending. So why not have a stand there and talk about prostate cancer, (Focus group 1, Black African, Participant 9).

You can tap into existing opportunities, for instance, when they have the cultural event at Eastrop Park in Basingstoke you know you have a captive audience of a lot of BAME attenders. Why not have a stand there and talk to them about prostate cancer, (Focus Group 1, Black African, Participant 10).

Some participants suggested the need to provide education/training to interested individuals who will be issued a certificate to act as activists to spread the awareness of prostate cancer among black men and their families.

...what about say like yourself as an academic and people in your team having a course of study on prostate cancer for the local community. Yeah and they can have a certificate of attendance, (Participant 1, Black Caribbean).

...So go into the community, have talks with them and you can do that by recruiting advocates, you know, champions of prostate cancer for BAME ...um...who can be trained on delivering these sessions ...um... and then these champions can engage with community groups and, you know, deliver these sessions, (Focused group 1, Black African, Participant 10).

4.3.2 Traditional and social media channels

Some participants also commented that awareness regarding prostate cancer could be spread amongst the black community via traditional media (e.g., TV and radio) through culturally specific programmes and adverts:

And probably like a one-to-one discussion or people coming on TV or radio, just to inform people about prostate cancer. And it's probably since we're talking about the black community, have a programme specifically [...] designed just to target the black community, (Participant 4, Black African).

I think one of the most forceful sources of media outlets is actually television. I mean I don't watch that much television [...] but it would be nice for someone to put an advert out there so to make people aware that this is serious, (Participant 5, Black Caribbean).

Other participants referred to the use of social media channels, such as, twitter, facebook and NHS websites to help raise awareness of prostate cancer among black communities:

Yeah, the internet is another means [...] I mean, for example, Facebook, I can log into my Facebook right now and virtually there's loads of nonsense of course people put on Facebook. Things to make you laugh and all sorts of stuff, you know, so that could be another way of changing people's perceptions. So instead of talking about all the negatives and gossip out there, it's like promoting things that can actually benefit human beings, (Participant 5, Black Caribbean).

[...] the internet as well. Generally, I think the NHS websites, and twitter can be used to raise awareness of prostate cancer, (Participant 7, Black African).

Interestingly, a few participants suggested using black influential personalities such as celebrities to sensitise black communities about prostate cancer.

“ So recently a few weeks ago there was a very powerful video that featured, I’m sure you would have seen this, that featured some Black celebrities ...um...,about prostate cancer, you know, about getting yourself checked for prostate cancer. I thought that was a very powerful tool. Getting the Black celebrities that black men, you know, celebrate from time to time. I think there was this guy, what’s his name, Idris Elba. Black men may take notice and may go get checked out for prostate cancer. So having a few black celebrities in that video may help. I thought that was quite a powerful one. But I think the key message for that video was ‘go get yourself checked, (Focused group 1, Black African, Participant 10).

There’s a lot of influencers around, isn’t there? So [...] you know, on the internet and things like that, so if you’ve got someone you follow a lot then maybe you could go to someone who influences and push it that way, you know [...] and that’s the way people seem to [...] not for the older generation so much but for the younger generation that’s how they get their information, you know, So using influencers can get the message out in the public domain, (Participant 8, Black Caribbean).

4.3.3 Billboards and posters

Finally, a few participants suggested that billboards and posters in locations such as GP surgeries could be an alternative way of disseminating information about prostate cancer to the black community:

“ [...] if we can have posters in appropriate places for me and others to be aware of prostate cancer and encourage checks and dietary changes to your life, encouraging exercises and activities and stuff then yeah that would be another way to promote prostate cancer to black men and their families, (Participant 6, Black African).

I think putting billboards up everywhere will help to raise awareness of prostate cancer, (Participant 8, Black Caribbean).

Chapter Five | Discussion

This project aimed to raise awareness of prostate cancer in black communities in Basingstoke including an evaluation of the engagement and raising awareness campaigns.

This study found that the participants lacked knowledge and understanding about prostate cancer prior to their participation in the raising awareness activities. For example, they were not aware that prostate cancer disproportionately affected black men and younger black men compared to their white UK counterparts. Consequently, prostate cancer was not something that they gave much consideration to in their daily lives. These findings are consistent with previous research that has also documented black men's poor awareness and lack of knowledge of prostate cancer (Pedersen, et al., 2012; Anderson et al., 2013; Cremin, 2015; Alexis and Worsley, 2018). Thus, the raising awareness activities were effective in increasing their understanding of prostate cancer and in the process they brought this disease to the forefront of their minds. This finding is consistent with the Parliamentary Stakeholder Group's (2012) result. They stated that people who attended the men's cancer awareness session found that it provided useful information and as a result of the session, they were better equipped to spot the signs of cancer including how they could reduce their risk of developing prostate cancer.

Analysis of the interview data also revealed that the raising awareness activities were successful in encouraging participants to initiate a discussion with their GPs regarding getting tested for prostate cancer. This is a significant finding given that previous research has demonstrated black men's distrust in healthcare professionals, which has subsequently contributed to them presenting to their GPs at a later stage of the disease progression (Ben-Shlomo et al., 2008; Thompson, 2014). However, of concern was that a minority of participants were unsuccessful with their requests for a PSA test, despite being at higher risk of developing prostate cancer and at a younger age. Thus, some participants felt PSA screening should be made routine, while others felt that action was needed to increase GPs and their staff awareness of prostate cancer.

The raising awareness sessions were also instrumental in enabling participants to exert some personal control in reducing their risk of developing prostate cancer. It allowed them to understand and evaluate their own potential risk of developing prostate cancer, and to take action to reduce this. For example, some participants reported making changes to their diet or increasing their exercise levels on learning that a diet high in animal fat and obesity were known risk factors (Macmillan Cancer Support, 2015; Harvard Medical School, 2018). Although they acknowledged that some risk factors were outside their personal control (e.g., age and ethnicity).

Data analysis showed that signposting participants to other support services was useful in providing them with the necessary resources to further enhance their knowledge and understanding of prostate cancer. For example, some participants commented that they had been unaware of websites such as Prostate Cancer UK. However, following the campaigns, they reported having gone to them to seek out further information on the condition and had found this information useful.

The findings from this study also revealed that participants wanted to utilise the information they had been provided with on prostate cancer. Moreover, they wanted to spread awareness to other members of their communities wherever possible, for example with family members and friends. Indeed, some now saw this as their responsibility to do so, and even wanted to become community activists or campaigners for prostate cancer awareness. This is also a powerful finding as the raising awareness sessions empowered participants to start a discussion about prostate cancer within communities where it was noted to be treated as a taboo topic. Indeed, the participants themselves acknowledged that the stigma surrounding the disease, for example, perceived impotence and incontinence resulting from treatment for prostate cancer, acted as a barrier to it being talked about. This is consistent with previous research which found that the shame and embarrassment

associated with a positive test prevented black men from talking about the condition with their peers through fear of emasculation (Alexis & Worsley, 2018; Bamidele et al., 2018). This suggests that raising awareness campaigns could be a powerful tool for breaking down the stigma in relation to prostate cancer within black communities.

Participants referred to various strategies for raising awareness of prostate cancer among black communities. For example, they cited using both traditional and social media as potential channels for spreading awareness. However, participants most frequently cited a more culturally specific strategy. They referred to using public facing activities in places where black men regularly frequented. Specifically, they suggested targeting places such as churches, community centres and barbers' shops. This is aligned with previous research that revealed black men felt information on prostate cancer needed to be tailored to their own cultural or individual circumstances (Alexis, 2020b). Indeed research conducted by the Parliamentary Stakeholder Group (2012) found similar findings to this project. In raising awareness of prostate cancer in black men and their communities, it is best to actively engage with them through faith leaders, other social events and through families as well as loved ones.

Chapter Six | Conclusion & recommendations

6.1 Summary of conclusion

This study used culturally specific information to raise awareness of prostate cancer among the black African and black Caribbean communities, as far as the authors are aware.

Consistent with previous research, black African and black Caribbean men in the Basingstoke area initially had limited awareness of prostate cancer, particularly in relation to their increased risk of developing the condition and higher mortality rates. The information presented at the raising awareness sessions was positive in informing the participants of the potential risk factors for prostate cancer, which allowed them to make lifestyle changes to reduce the likelihood of them developing the disease in the future. Critically, it also encouraged participants to start a conversation with their GPs about getting tested.

Prostate cancer was viewed as a taboo topic among the black African and black Caribbean communities. However, the awareness sessions enabled black men to develop a better understanding of prostate cancer in terms of the signs and symptoms and what they should do if these are apparent. Crucially, it equipped them with the knowledge and power to open a dialogue with other family and community members on the topic. Participants were keen to share the information they had been given with others and even act as community advocates. Participants referred to using culturally specific events and gatherings as a way of spreading awareness of prostate cancer, targeting places where a large gathering of black men and their families would be visiting.

The fact that two of the investigators were black men could have contributed to creating a good rapport between the participants and the researchers, and them having trust in the information given to them. However, it must be acknowledged that the sample size for this study was quite small. In total 12 participants were recruited into the study, which was fewer than had been anticipated. Therefore, it is not possible to generalise from these findings. All participants also reached out to the research team following the raising awareness talks to be interviewed. This suggests that they recognised the importance of raising awareness of prostate cancer among black communities and were intrinsically motivated to share what they had learnt with others. Finally, the participants were interviewed shortly after they had attended an awareness talk, therefore the longer-term influence of this information on them remains unknown.

6.2 Recommendations for practice

In order to help raise awareness of prostate cancer among the black communities the following recommendations should be considered:

- There is an urgent need for culturally specific information on prostate cancer in black men to become available in GP surgeries for the purposes of raising awareness of the disease to black men and their families.
- In raising awareness and disseminating information about prostate cancer in black men and their families, the use of culturally specific events and gatherings should be considered.
- The findings of this research also highlight the need to train and educate members of the black communities who could then act as community advocates to help spread awareness of prostate cancer within these communities.
- A further recommendation of this research is to consider making PSA testing routinely available to all black men aged 45-years and above, in all GP practices. This is because black men are known to have an increased risk of developing prostate cancer.

- The use of social media and the creation of a website with culturally specific information to increase awareness about prostate cancer amongst black communities should be considered to further enhance black men and their families' knowledge and understanding of the disease.
- There is an urgent need to increase GPs' and their employees' awareness and understanding of the impact and risks of prostate cancer on black men. In doing this, it is anticipated that black men will be able to obtain a timely PSA test.

6.3 Recommendations for future research

The following recommendations for future research are made based on the findings from this study:

- A study exploring GPs knowledge and understanding of prostate cancer and its impact on black men and their communities. It is hoped that this study will introduce effective strategies which could be adopted by GPs for the benefit of black men.
- A further recommendation for research would be to replicate this study in the Wessex region and/or national level. This could have potential benefits for black men, their families and communities as a whole.
- A follow up study to ascertain if participants had continued to spread the knowledge they had gained during the raising awareness sessions.
- A project that involves raising awareness of prostate cancer in secondary schools and colleges.
- An economic evaluation study examining the cost and benefit of raising awareness of prostate cancer in black men.

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