Changing lives: engaging with Black African and Black Caribbean men at risk of, or affected by, prostate cancer

Independent evaluation
A Big Lottery Fund supported project

February 2020

ORCHID FIGHTING MALE CANCER
CBC cancer black care
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In the context of shared decision making, I think organisations such as Orchid are empowering both the professional and the patient in the process. The community work is important too: what these programmes do is allow real conversations to take place in more informal settings... people can ask questions that really concern them.

Sarah Itam, Consultant Urologist

Those who have seen the booklet and the exhibition know that it is something very important for the black community. I think Orchid are promoting it vigorously which is good; I think they are doing a fantastic job... they need to maintain their work because there is still a lot of ignorance about it. I think the message is 'don't leave it too late.'

Ben Gordon, West Indian Social Care and Education Project, Brent

Acknowledgements

We gratefully acknowledge the support of everyone who contributed to the concept, advancement and success of this project, especially that of Professor Frank Chinegwundoh MBE MBBS MS MML(Med Law) FRCS (Eng) FRCS(Ed) FRCS(Urol) FEBU, without whose support this project would not have been possible.

Contents

1 Management summary

1. Healthfocus Research evaluated the outcomes of the three-year Changing Lives project. Interviews were conducted with a **purposive sample of 38 project beneficiaries, community partners and stakeholders**. Interview data was contextualised and triangulated with outcome data reported by Orchid.
2. The project team developed **partnerships with 15 community organisations** in the seven target boroughs: these partnerships enabled the team to identify and reach men in their primary target group (black men from disadvantaged communities at risk and diagnosed with prostate cancer). In qualitative interviews conducted by Healthfocus, community partners often commented on the expertise and professionalism of project staff.
3. The project's **extensive outreach work** with community groups, faith groups, barber shops and other targeted locations resulted in engagement with approximately 8000 men from the black community. Those who completed post-event outcome forms all reported increased awareness and understanding of prostate cancer, its risk factors, signs and symptoms, and greater confidence about seeking early help from healthcare professionals. These outcomes were confirmed in qualitative interviews.
4. The outreach work also generated **significant interest amongst black women**: interviews with members of the community and partner organisations indicate that black women are often highly influential in encouraging men to discuss their health, and to engage with early diagnosis and treatment. As with men, black women attending outreach events reported increased awareness/understanding of prostate cancer issues.
5. In consultation with clinicians and men from the target audience, the project developed a suite of **culturally appropriate print and film resources** to support community engagement activity. Interview data indicate that these resources had strong appeal to members of the black community, were effective in conveying key information, and that they enabled individuals from the black community to share key messages easily with family and friends.
6. During the three-year project, the team developed partnerships with **five cancer support groups** covering six of the seven target boroughs. They worked with these groups to develop culturally appropriate promotional material, information and support. The nature and extent of the support given to each was determined by local preferences and need.

7. The project's outcome monitoring data indicates that over 200 men with whom they engaged via support groups reported feeling **less isolated, more supported and more confident** about engaging with their diagnosis, treatment and aftercare as a result of the programme's input. Interviews conducted by Healthfocus indicated that these outcomes were sustained over time. Interviews also revealed that several black men attending the support groups had been motivated to become informal **'community ambassadors'** for prostate cancer awareness and were actively distributing resources to others in their communities.

8. The project engaged with **over 400 healthcare professionals** during the project. All HCPs who completed the evaluation forms reported improved knowledge/understanding and increased confidence about meeting the needs of black men going through treatment and aftercare. Interviews with HCPs also indicated increased cultural awareness, understanding and competence. The programme reported that securing GP engagement was challenging, and only 15 of the HCPs who attended face-to-face events were GPs.

2 Key learnings and recommendations

The findings of this independent evaluation indicate that:

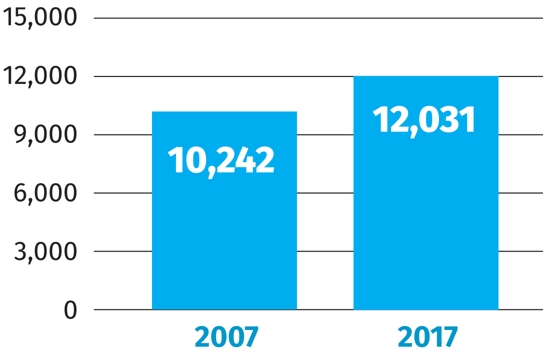
- **The 'Changing Lives' project has successfully engaged with over 8,000 black men at risk of prostate cancer, over 200 black men with prostate cancer and over 400 healthcare professionals from disadvantaged boroughs in London**
- **Women are highly influential drivers to early reporting of prostate cancer symptoms: awareness-raising campaigns need to target women as well as men**
- **Awareness-raising campaigns are not enough: black men often have attitudinal barriers to engagement with healthcare providers in relation to prostate cancer and addressing these barriers requires opportunities for dialogue**
- **The project has developed significant expertise in face-to-face engagement with black communities, and in working with community partners who can facilitate access to these communities**
- **The project have developed a suite of resources with and for the black community that have high appeal/relevance to the target audience and deserve wider dissemination**
- **Film can provide a useful discussion prompt for community engagement and awareness-raising work with HCPs: some contexts may require the use of shorter sections of the patient journey illustrated in *Letter to My Unpresented Self***
- **There is scope for development of 'community ambassador' roles within the black community in relation to prostate cancer**
- **Orchid is well-placed to build on the project's work with disadvantaged communities in London by partnering with community and health organisations elsewhere**
- **Statutory resource to support cancer support groups in London appears to be hard to find: if possible, Orchid should continue to support the groups they have worked with in the context of this project but the degree of input required suggests that this model will not be replicable elsewhere**
- **Increasing the cultural and clinical awareness of GPs in relation to prostate cancer issues is very important *but* it is widely recognised that accessing the GP audience is very labour intensive due to workforce retention issues, competing demands on GP time and the level of 'background noise': there may not be sufficient resource to target this audience**

3 Background: Prostate cancer and ethnicity

Prostate cancer is now the most commonly diagnosed male cancer in England, with over 49,000 new diagnoses in 2018. In males in the UK, prostate cancer is the second most common cause of cancer death (after lung cancer), with around 12,000 deaths in 2017.[1]

A situation report published by Orchid in 2019[2] reported that over 40% of prostate cancer cases in England in 2017 were diagnosed late, at stages three and four, when treatment is more invasive and less successful.

Deaths in England from prostate cancer



Source: ONS

The main risk factors for prostate cancer are increasing age, family history, and ethnicity. The incidence of prostate cancer in the UK is twice as high amongst black African and black Caribbean men: black men have a lifetime risk of one in four of being diagnosed with prostate cancer, compared to one in eight amongst white men. They may also develop it at an earlier age and develop more aggressive forms of the disease.

Despite this, awareness of prostate cancer in the UK black community is relatively low. A survey of over 1000 UK men commissioned by Orchid in 2018[3] revealed that 57% of black African and black Caribbean men were unaware that their ethnicity affected their risk of developing prostate cancer. The survey also found that 60% of UK men were unconfident about identifying the signs and symptoms of prostate cancer.

Awareness of the relevance of ethnicity to prostate cancer can also be low amongst healthcare professionals. A survey of GPs commissioned by Orchid in 2019 found that only 5% GPs identified ethnicity as a primary risk factor for prostate cancer.[4] 85% of GPs surveyed believed that the most effective way to increase earlier diagnoses of prostate cancer was to undertake public health awareness campaigns specifically targeting men from high risk groups and encouraging them to speak to their GP about their risk.

Living with and beyond a diagnosis of prostate cancer can also present significant challenges, with many men reporting anxiety, social isolation, problems with sexual functioning and urinary incontinence. A recent large survey of over 35,000 UK men living beyond a diagnosis of prostate cancer[5] reported that sexual dysfunction was common and that most men were not offered helpful intervention or support. Feedback from black men who have engaged with Orchid's information and support services suggests that they may have particular difficulties in accessing culturally appropriate support post-diagnosis.

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[1] PHE Cancer Registration Statistics 2018, published Jan 2020 (provisional figures)
[2] Prostate Cancer: Situation Report, Orchid September 2019
[3] Men's attitude to Prostate Cancer Risk, Orchid April 2018
[4] Prostate Cancer: Survey of GPs, Orchid August 2019
[5] Quality of Life of men living with prostate cancer in the UK: Downing et al, Lancet Vol 20, Issue 3, Mar 2019

4 About the Orchid ‘Changing Lives’ project

In 2017, Orchid (a UK charity providing support services, education and awareness campaigns and pioneering research programme for male cancers) and Cancer Black Care (an information and support organisation for black people with cancer in London) were awarded a three-year Big Lottery Fund ‘Reaching Communities’ grant to deliver a targeted programme of awareness-raising and support for black African and black Caribbean men in London at risk of, or affected by, prostate cancer.

The initial agreed geographical focus of the project was the London boroughs of **Brent, Lambeth, Newham, Hackney, Lewisham** and **Tower Hamlets**, and then subsequently **Southwark**. All seven boroughs have high BME populations and high IMDs (Indices of Multiple Deprivation).

The overall aims of the project were:

1. **To increase awareness and understanding of prostate cancer in black communities, and to encourage black men to discuss their prostate cancer risk with healthcare professionals/seek early help for relevant signs and symptoms**
2. **To provide culturally appropriate information and support for black men living with and beyond a diagnosis of prostate cancer in order to increase their confidence about engaging with treatment and aftercare and reduce isolation**
3. **To increase healthcare professionals’ confidence and competence to discuss prostate cancer with black men at risk and post-diagnosis, and provide appropriate support**

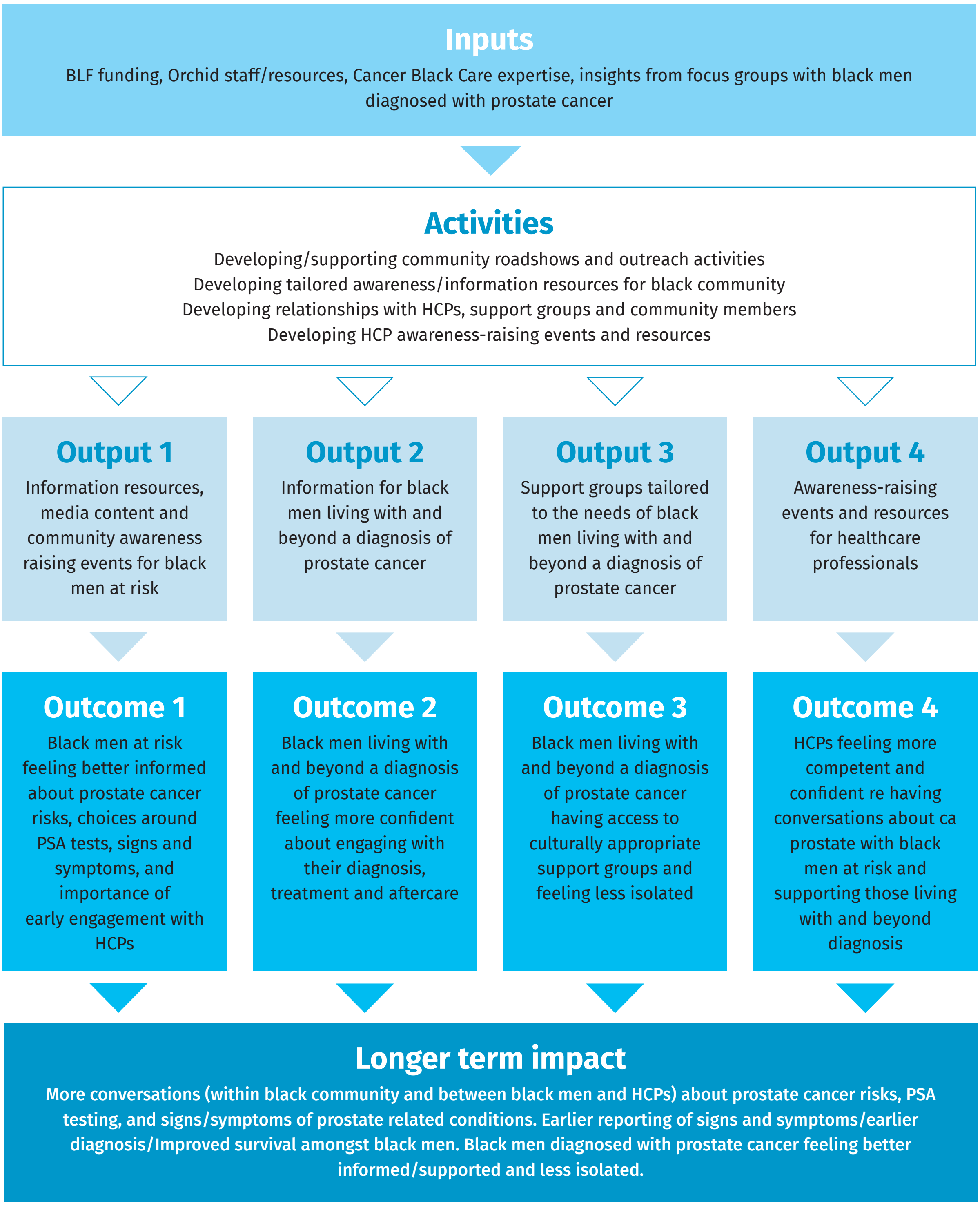
In order to achieve these aims, Orchid and Cancer Black Care planned to undertake a programme of activities from 2017 to 2020. These included the development and delivery of:

- **Tailored awareness-raising/information resources for black men (print and digital)**
- **Community roadshows and outreach activities with black communities in London**
- **Social media activity highlighting prostate cancer issues specific to black men**
- **Promotional materials and support for prostate cancer support groups working with black men in London**
- **Awareness-raising events and initiatives for healthcare professionals (HCPs)**

Project monitoring against agreed milestones was conducted throughout the three years of funding, and a progress report was submitted to the BLF (now the National Lottery Community Fund) every six months. A full account of project activity over the three years can be obtained from Orchid.

In 2019, the project commissioned Healthfocus Research to conduct an **independent external evaluation** of project outcomes, with a focus on **beneficiary perspective**s. Healthfocus developed a **theory of change** (TOC) model to summarise the activities, outputs and intended outcomes/impacts of the Changing Lives project and develop an evaluation framework.

Theory of Change framework for the Changing Lives prostate cancer project



Inputs

BLF funding, Orchid staff/resources, Cancer Black Care expertise, insights from focus groups with black men diagnosed with prostate cancer

Activities

Developing/supporting community roadshows and outreach activities
Developing tailored awareness/information resources for black community
Developing relationships with HCPs, support groups and community members
Developing HCP awareness-raising events and resources

Output 1

Information resources, media content and community awareness raising events for black men at risk

Output 2

Information for black men living with and beyond a diagnosis of prostate cancer

Output 3

Support groups tailored to the needs of black men living with and beyond a diagnosis of prostate cancer

Output 4

Awareness-raising events and resources for healthcare professionals

Outcome 1

Black men at risk feeling better informed about prostate cancer risks, choices around PSA tests, signs and symptoms, and importance of early engagement with HCPs

Outcome 2

Black men living with and beyond a diagnosis of prostate cancer feeling more confident about engaging with their diagnosis, treatment and aftercare

Outcome 3

Black men living with and beyond a diagnosis of prostate cancer having access to culturally appropriate support groups and feeling less isolated

Outcome 4

HCPs feeling more competent and confident re having conversations about ca prostate with black men at risk and supporting those living with and beyond diagnosis

Longer term impact

More conversations (within black community and between black men and HCPs) about prostate cancer risks, PSA testing, and signs/symptoms of prostate related conditions. Earlier reporting of signs and symptoms/earlier diagnosis/Improved survival amongst black men. Black men diagnosed with prostate cancer feeling better informed/supported and less isolated.

5 Evaluation aims, method and sample

Evaluation metrics must be proportionate to the project budget and timescale. Consequently, this evaluation project focuses on project outcomes rather than anticipated longer term impact. This is standard practice in project evaluation.

The aims of this independent evaluation of the 'Changing Lives' project were:

1. **To explore project outcomes (see previous page) from the beneficiary perspective**
2. **To use qualitative outcome data reported by beneficiaries to triangulate outcomes reported by the project**
3. **To identify any unexpected outcomes not captured by the monitoring processes**
4. **To identify project strengths, challenges and key learnings**

A note on terminology used in this report

Outputs are measures of project activity

Outcomes are the changes that have occurred as a result of project activities

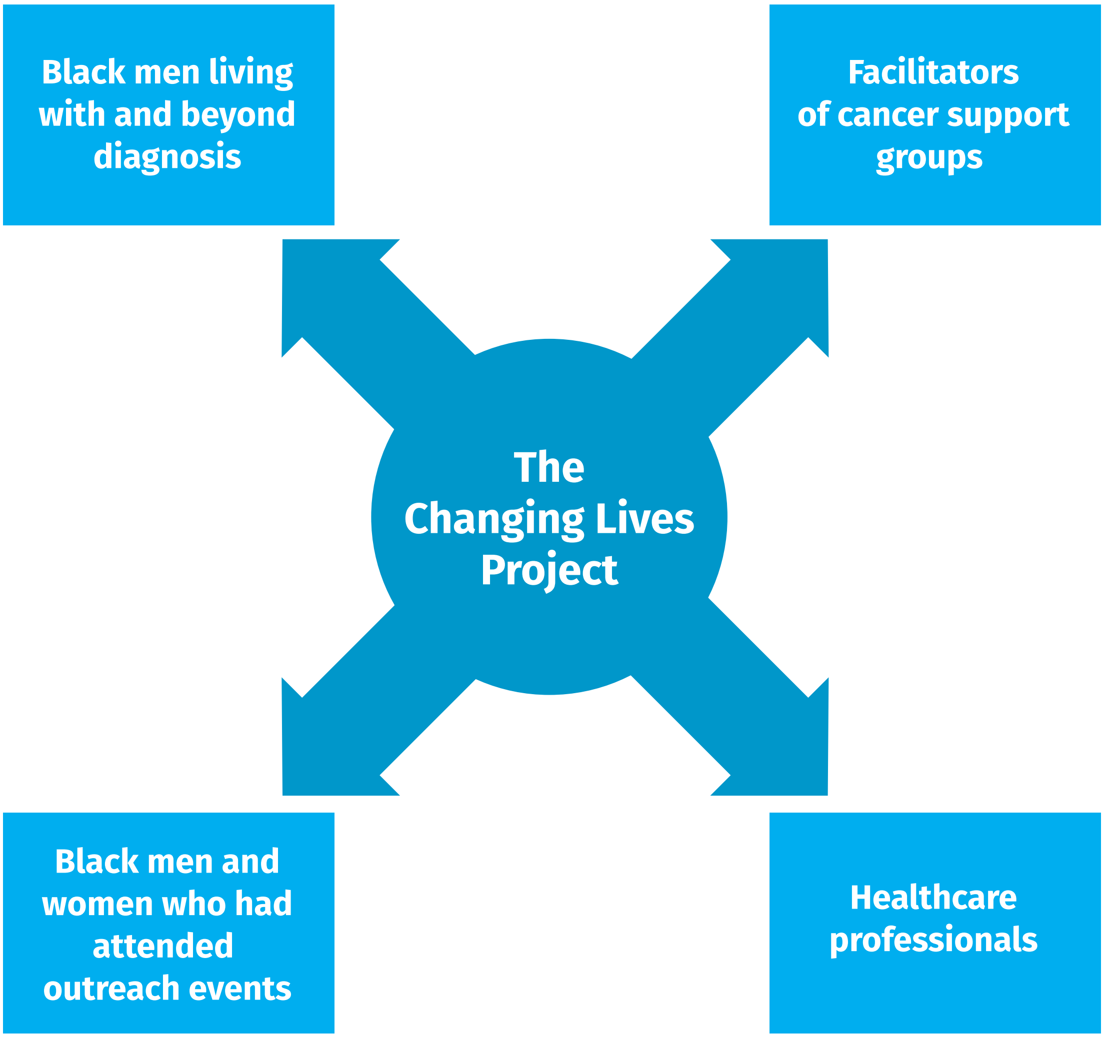
Impacts are broader and longer-term changes that, according to the causal assumptions identified in the theory of change, will occur as a result of outcomes.

Purposive sampling is a sampling approach commonly used in qualitative research whereby respondents are selected based on their characteristics and level/type of engagement with the project.

Triangulation is an evaluation approach that describes using more than one method to collect data on the same topic. This is a way of assuring the validity of reported outcomes, Triangulation often involves different types of samples as well as methods of data collection. The purpose of triangulation is not only to cross-validate data but, also to illustrate and capture different dimensions of the same phenomenon.

The primary method employed for this evaluation was qualitative interviews with a sample of the ‘Changing Lives’ project beneficiaries. Using the theory of change (TOC) model above and discussions with Orchid project staff, four subgroups of project ‘beneficiaries’ were identified – see diagram below. Although black women were not identified as project beneficiaries in the original project bid, they have been included in this beneficiary diagram as, in practice, outreach events on prostate cancer generated significant interest from women as well as men. This issue will be discussed further in the report.

Beneficiaries of the Changing Lives prostate cancer project



A purposive sample of individuals from each of the four beneficiary groups identified above was recruited by Healthfocus using contact data supplied by the project. Relevant data sharing permissions were obtained beforehand. Respondents could choose whether to be identified in the report or to remain anonymous.

In addition to the beneficiary sample, interviews were conducted with four project stakeholders (three members of Orchid and the Chair of Cancer Black Care) to discuss project activities, achievements and challenges.

The overall interview sample of 38 respondents comprised:

30 project beneficiaries
4 community partners
4 stakeholders

Further information about the interview sample can be found in the appendix of this report.

Healthfocus interview sample	**38**
Black men 'at risk' who had attended the outreach events in London (roadshows, community talks or events)	6
Black women who had attended the outreach events in London	2
Black men living with and beyond prostate cancer diagnosis attending support groups in London supported by the project	6
Facilitators of prostate cancer support groups in the target boroughs supported by the project	4
Healthcare professionals (3 nurses, 1 GP, 2 Consultant Urologists)	6
Representatives of community organisations/groups who had partnered with the project to deliver awareness-raising events	4
Project stakeholders (3 from Orchid, 1 from Cancer Black Care)	4

Interviews were conducted by telephone or face-to-face using semi-structured topic guides developed by Healthfocus.

Kay Scott, the lead researcher, also attended an outreach event in Hackney in November 2019 to conduct interviews with members of the black community engaging with the information stand.

Fieldwork was conducted between November 2019 and February 2020. Interviews were transcribed and thematic analysis of the data was conducted in Jan/Feb 2020.

Quantitative data on project activities, beneficiary demographics and outcomes used in this report to provide context for the qualitative interviews was collated and supplied by the project. An example of the post-event forms used by the project to collect this data can be found in the appendix of this report.

6 Overview of the 'Changing Lives' project activities

The primary aim of this project was to explore project outcomes from the beneficiary perspective and triangulate this with the project's internal reporting. In order to contextualise the findings, a brief overview of the main activities undertaken by the project over the course of the 3 year 'Changing Lives' project is provided here. A full account of these activities can be obtained from Orchid. Highlights of project activity reported include:

- Development of **community partnerships with over 15 statutory and voluntary organisations** to enable the project to reach black communities in the target boroughs: these include Healthwatch Brent, the Nurses Association of Jamaica UK, Southwark Council, Newham CCG, Harlesden Methodist Church, and the BME Fathers Forum
- Production and dissemination of a suite of culturally appropriate prostate cancer information resources for black men including a z-card, helpline card and awareness posters featuring Orchid's helpline number: **over the three years, over 1,600 posters, 42,000 z-cards and 26,000 helpline cards were distributed in the target boroughs**
- Delivery of **125 community outreach events** (roadshows, talks and information stands) at African Caribbean events/meeting places in the target boroughs eg Jamaican Family Fun Day and **'on street' awareness-raising activity** in markets, barber shops etc
- Via these outreach events and 'on street' activities, face-to-face engagements about prostate cancer with **over 12,000 individuals**, of whom approximately **8,000 were black men and 1,500 were black women** (partners and family members of black men)
- Co-creation of an **awareness-raising film** about a black man's experience of prostate cancer and engagement with healthcare professionals, Letter to My Unpresented Self: the film has been screened at **over 20 community/faith centres** in the target boroughs and viewed over 83,000 times on social media since its launch in 2019
- Co-creation of **a photographic exhibition** in Brent[6] (1 in 4) and associated 1-minute awareness-raising film[7] to highlight the fact that one in four black men will be diagnosed with prostate cancer in their lifetime. The one in four film has been widely shared on social media and viewed over 82,000 times on Facebook
- Provision of **ongoing support** (group facilitation, co-creation and provision of culturally appropriate promotional banners and information resources) to **five prostate cancer support groups serving black communities in target boroughs** in London. This has enabled the project to support over 200 black men living with prostate cancer
- Delivery of **14 cultural awareness-raising events** for healthcare professionals (talks, film showings) about prostate cancer in black men for healthcare professionals (nurses, hospital doctors and GPs) resulting in engagement with **over 400 HCPs**

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[6] With match funding support from Healthwatch Brent

[7] https://www.youtube.com/watch?v=BcRdDiBXTU0

Examples of resources/initiatives supported by the Changing Lives project

NHS
East London
NHS Foundation Trust

Each One Teach One
Prostate Cancer Support Group

The group provides a friendly, safe and encouraging environment in which your cancer journey is fully appreciated and understood by those who have experienced similar struggles. By sharing personal experiences members offer one another emotional comfort and moral support, as well as practical advice and tips on how best to cope.

Meeting dates & times for 2019

Wednesday	16th	January	5-7pm
Wednesday	13th	February	5-7pm
Wednesday	13th	March	5-7pm
Wednesday	17th	April	6-8pm
Wednesday	15th	May	6-8pm
Wednesday	12th	June	6-8pm
Wednesday	17th	July	6-8pm
Wednesday	14th	August	10 am-5pm
Wednesday	11th	September	3-5pm
Wednesday	9th	October	3-5pm
Wednesday	13th	November	3-5pm
Wednesday	18th	December	6-8 pm

Resource Room, Ground Floor, East Ham Care Centre, Shrewsbury Road, London E7 8QP
For further information please contact **Sabria Harve** Specialist Continence Nurse
Tel: **0208 475 2011** or **07946 782636 Mon-Fri 9am-5pm**

SUPPORTED BY ORCHID FIGHTING MALE CANCER
www.orchid-cancer.org.uk

Concerned about prostate cancer?

Call our National Male Cancer Helpline
0808 802 0010
helpline@orchid-cancer.org.uk

ORCHID
CBC

CBC
CANCER BLACK CARE

Cancer Black Care
Support Group - Brent

Providing a friendly, welcoming and reassuring space.

The second Saturday of each month
2.00pm till 4.00pm

The last Monday of each month
10.30am till 1.30pm

Cancer Black Care, 79 Acton Lane, London NW10 8UT

For further information please contact **Jean** or **Natalie** on **020 8961 4151** or by email
Jean: jean.cbc.org@btconnect.com **Natalie:** natalief.cbc.org@btconnect.com

WORKING IN PARTNERSHIP WITH

Brent
Orchid National Male Cancer Helpline 0808 802 0010
ORCHID FIGHTING MALE CANCER
NATIONAL LOTTERY FUNDED

One in four
a photographic exhibition

One in four

Every year, over 47,000 men in the UK will be diagnosed with prostate cancer. It is more common in men over the age of 50. An estimated 1 in 8 men will develop the condition in their lifetime. Black men are more at risk of prostate cancer with an incidence of 1 in 4.

Orchid National Male Cancer Helpline

For information and support call our confidential helpline on **0808 802 0010**

or email our Nurse Specialists at **helpline@orchid-cancer.org.uk**

ORCHID FIGHTING MALE CANCER

7 Summary of findings

This section reports key findings from the interviews conducted with project beneficiaries, partners and stakeholders by Healthfocus Research. These findings have been contextualised and triangulated with activity and outcome data reported by the project. Outcomes are reported in relation to each of the three target audiences: black men at risk, black men living with prostate cancer, and healthcare professionals.

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1. Awareness of, and attitudes to, prostate cancer in the black community

Members of the black community and healthcare professionals interviewed for this project consistently reported **low awareness** of prostate cancer and related signs and symptoms within the black community in London. In common with previous research, interview data indicated that:

- Many black men from the targeted boroughs were unaware that their prostate cancer risk was twice that of other men (one in four, as opposed to one in eight)
- Very few black men were aware that having a family history of prostate cancer increases their risk of prostate cancer
- The majority of black men at risk/their partners were unaware of the signs and symptoms of prostate cancer, what a PSA test is, or that black men who are asymptomatic can request a PSA test from the age of 45

Interview data also highlighted common **attitudinal barriers** to engagement with healthcare professionals about prostate symptoms and treatment. Men were often perceived to be:

- reluctant to acknowledge or discuss any urological or sexual problems
- uneasy about the prospect of digital rectal examinations
- reluctant to engage with any diagnostic or treatment procedures that might impact upon their sexual ability.

> **Consultant Urologist:** **I have heard some men say they would rather die than end up with erectile dysfunction. Most have no idea that there are now many things that can be done to resolve these issues.**

Respondents in all branches of the sample often commented that these attitudinal barriers were particularly common amongst black men.

> **Continence Nurse:** **Men bottle things up and for black men the macho thing is often particularly strong. If they can’t perform in bed…**

> **Black man, post-diagnosis:** **There are a lot of black men who don’t like the idea of a doctor pushing their finger up your bum and I say you are being so stupid. And even if you lose your erection, the doctor will tell you, I am going to get it back for you and it’s true. I’m back in the game!**

> **Black man, community partner:** **there is a taboo amongst black men: a lot of them have a taboo about anyone touching their bottoms. I think that is why a lot of men delay going to see the doctor if they have symptoms.**

The strength and complexity of these attitudinal barriers highlights the need for interactive dialogue about prostate cancer with members of the target community in addition to national awareness-raising campaigns.

2. Black men at risk feeling better informed about prostate cancer risks, choices around PSA tests, signs and symptoms and the importance of early engagement with healthcare professionals (Outcome 1)

In order to engage with black men at risk across the seven target boroughs, the project developed community partnerships with over 15 statutory and voluntary organisations to enable them to reach black communities in the target boroughs: these included Healthwatch Brent, Southwark Council, Newham CCG, and numerous faith groups. These partnerships enabled the project to have a presence at events and organisations frequented by members of the black community in London, and to maximise reach into the target audience.

Representatives of four community partner organisations were interviewed by Healthfocus at the end of the project. Several commented that they had been impressed by the knowledge, expertise and motivation of project staff.

> **Community Partner:** **We were looking for a partner to work on prostate cancer with – we had identified this as one of our priorities as we had become aware that the prevalence was higher in black men and we have a very diverse population here. When I met Ali from Orchid, I was struck by the organisation's knowledge and its focus. We worked with them for two years and I found them to be highly professional and committed.**

Over the three years, project staff delivered 125 community outreach events (roadshows, talks and information stands) at African Caribbean events and meeting places in the target boroughs. In addition, staff also visited areas with a high footfall of African Caribbean men, such as Brixton market, to engage more informally with members of the black community and distribute awareness-raising materials.

Early consultations with members of the target community indicated that faith groups and barber shops were particularly good forums for engagement with older black men. Orchid staff subsequently visited 10 barber shops in each target borough to raise staff awareness/deliver resources, and developed partnerships with a range of faith groups for the purpose of delivering community talks.

> **Community Advocate:** **West Indian men go to barber's shops: they meet there. It's a social gathering place as well as getting their hair trimmed. If you really want to get hold of them, that is where you will find them. You need to use the environments that they are already going to.**

> **Support group Facilitator:** **A lot of people from ethnic minorities find it difficult to access information: you have to go into the communities. We take the Orchid materials out into the Pentecostal Church and the African Forums...Faith group work is a good way to access the black community. I think Orchid have made a huge contribution.**

Via outreach events and activities, the project was able to engage face-to-face about prostate cancer with **over 12,000 individuals** during the three-year project, of whom approximately **9,500** were from the black community: **8,000 were black men and 1,500 were black women**.

As the above figures illustrate, although women were not originally identified as a target audience for this project, prostate cancer stands and roadshows often generated considerable interest from women as well as men. Women often reported to project staff that they 'monitored' the health of the men in their families, and that they were the 'drivers' to male engagement with healthcare. Comments made by respondents in the external evaluation – both healthcare professionals and members of the black community in London – often echoed this view.

> **Consultant Urologist: For many men that I see in clinic, they are only there because their partners encouraged them to seek medical help; and any diagnosis of cancer is a family diagnosis.**

> **Black women at outreach event: Women have a really important role in encouraging their partners to go. Especially if you are a man from a West Indian or African background, you are the man of the family, you are the big strong 'I am', so for you to go to the doctor...**

At the start of the project, post-event monitoring forms were developed (see appendix) to capture outcomes for men and women attending outreach events. In practice, the informal nature of many outreach events meant that it was only possible for staff to administer these forms in some settings. Over the three-year period, post-event outcome data was captured for 1,402 of the 9,500 members of the black community with whom the project engaged at outreach events: of the 1,402, 1,113 were black men and 289 were black women. The project reports that all of the 1,402 black men and women who completed the outcome monitoring forms reported that the information they had received had improved their knowledge and understanding of prostate cancer, its risk factors, and signs and symptoms to look out for. All black men who completed the forms reported feeling more confident about visiting their GPs in relation to prostate cancer after attending outreach events.

Qualitative interviews conducted by Healthfocus confirmed how valuable the outreach events had been in increasing awareness/understanding of prostate cancer, providing an opportunity for discussion, and increasing the confidence and motivation of members of the black community about discussing these sensitive issues more openly with family members and healthcare professionals.

> **Administrator, Tower Hamlets Staff Forum: Orchid ran awareness event for our staff council. A lot of people came back saying that they only knew the name of the illness and didn't know how it happened. Men need information about this because it's a subject they don't normally talk about. It's a sensitive area and Orchid did it very well.**

> **Nurse and Church Health educator, Southwark: In the discussion, it came out that lots of the men had no idea where their prostate was, and there were several scare stories about screening and what it involves. And they had no idea they were at higher risk. At least 3 people said to me, I will be making an appointment with my GP this week.**

> **Community Partner, Brent: The session was very good, very interactive. Orchid came and gave a talk to our African Caribbean group... my friends and colleagues are much more aware of it**

now, and we realised what a high proportion of us may get it.

Consultant Urologist: There is a huge need. We see loads of men who say they have been refused PSAs by their GPs, even amongst black men with a family history who are at high risk. I think these talks really help because, with no national screening programme, we have to rely on them having the confidence to ask for tests, and not to be put off if they are concerned.

Several ‘at risk’ men who had attended outreach events expressed surprise that, given how common the disease is amongst black men, their GPs had never raised the issue with them.

Black man at risk: Even when you go and see your GP, they don’t tell you this stuff. Why doesn’t anyone else tell us about it? I think the talk was really good, and everyone took one of those fold out things at the end.

To support these awareness-raising activities within the black community, the project developed – in consultation with clinicians and members of the target community – a suite of culturally appropriate prostate cancer information resources for black men. These resources included a pocket-sized z-card, wallet-sized contact card and awareness posters. All the resources featured photos of black men, key information about prostate cancer and Orchid’s National Male Cancer Helpline number.


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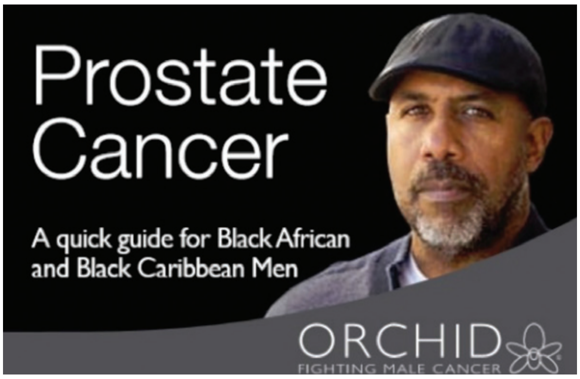
helpline@orchid-cancer.org.uk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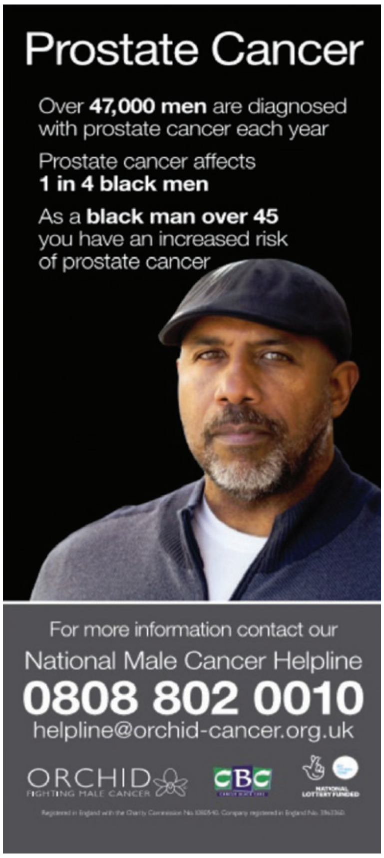
ORCHID
FIGHTING MALE CANCER


Prostate Cancer

Over **47,000 men** are diagnosed with prostate cancer each year

Prostate cancer affects **1 in 4 black men**

As a **black man over 45** you have an increased risk of prostate cancer

For more information contact our National Male Cancer Helpline
0808 802 0010
helpline@orchid-cancer.org.uk

Images, right: During the project, over 1600 posters, 42,000 z-cards and 26,000 helpline cards were distributed in the target boroughs

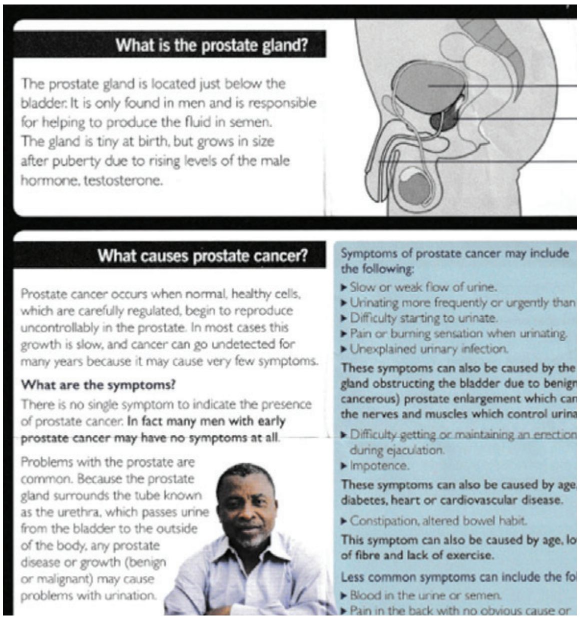
Qualitative interviews with beneficiaries conducted by Healthfocus indicated that:

- The appearance of project print resources generated interest from both men and women in the target community
- The text content provided key information about the prostate and about prostate cancer that many black men and women had been previously unaware of
- The resources were effective in conveying that black men are at a relatively high risk (1 in 4) of developing prostate cancer compared to other men, and that early diagnosis can have a big impact on outcomes
- The foldable, pocket-sized format of the z-card held strong appeal and facilitated private reading
- The resources enabled community partners and individuals engaging with outreach events to share key messages easily with family members, friends and colleagues

Black man at risk: I didn't really know what my prostate did, or where it is, until I saw that leaflet. It's good that it's small because you can just put it in your pocket and take it out when you're on your own.

Black man at risk: To me, it was saying, don't leave it too late! I had no idea about the signs. I showed it to my friends and they didn't know either.

Black woman: I have heard the word 'prostate' and I know a few of my family have had trouble with it, but I didn't know anything else or what he should look out for.



What is the prostate gland?

The prostate gland is located just below the bladder. It is only found in men and is responsible for helping to produce the fluid in semen. The gland is tiny at birth, but grows in size after puberty due to rising levels of the male hormone, testosterone.

What causes prostate cancer?

Prostate cancer occurs when normal, healthy cells, which are carefully regulated, begin to reproduce uncontrollably in the prostate. In most cases this growth is slow, and cancer can go undetected for many years because it may cause very few symptoms.

What are the symptoms?

There is no single symptom to indicate the presence of prostate cancer. **In fact many men with early prostate cancer may have no symptoms at all.**

Problems with the prostate are common. Because the prostate gland surrounds the tube known as the urethra, which passes urine from the bladder to the outside of the body, any prostate disease or growth (benign or malignant) may cause problems with urination.

Symptoms of prostate cancer may include the following:

- Slow or weak flow of urine.
- Urinating more frequently or urgently than
- Difficulty starting to urinate.
- Pain or burning sensation when urinating.
- Unexplained urinary infection.

These symptoms can also be caused by the gland obstructing the bladder due to benig cancerous) prostate enlargement which ca the nerves and muscles which control urina

- Difficulty getting or maintaining an erectio during ejaculation.
- Impotence.

These symptoms can also be caused by age, diabetes, heart or cardiovascular disease.

- Constipation, altered bowel habit.

This symptom can also be caused by age, lo of fibre and lack of exercise.

Less common symptoms can include the fo

- Blood in the urine or semen.
- Pain in the back with no obvious cause or

In 2019, the project launched an awareness-raising film as an additional resource for use at outreach events with members of the black community and healthcare professionals. The film, *Letter to My Unpresented Self* [9], was planned and co-created with members of Newham support group and is based on personal experiences. So far, it has been screened at over 20 community/faith centres in the target boroughs and viewed over 83,000 times on social media.

In qualitative interviews conducted by Healthfocus, black men who had attended outreach events at which the film had been shown often commented that they identified strongly with the issues raised in the film (difficulty in discussing urinary symptoms, wariness about digital rectal examinations, concern about sexual issues). Viewers often commented that the concerns expressed by the main character reflected their own

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[9] The film is now available to view online https://orchidfilm.org

attitudes and concerns. In essence, it communicated to viewers that prostate cancer was an issue that was relevant to black men. The use of a relatively young man as the main character was often regarded as a significant strength, as prostate cancer was typically viewed as a disease of older men.

> **Black man at risk: The fact that there was a black male who wasn't too old and who spoke a language that was familiar was good, it was good to see black images on the screen that were positive, it was relatable.**

Respondents interviewed for this evaluation often commented that the film had acted as a useful discussion prompt when shown at community events. The key take out of the film and subsequent discussions was the importance of 'getting checked out'. Several men commented that the film had increased their motivation to speak to GPs and others in their communities about prostate cancer, and had increased their confidence to do so.

> **Community Partner: I think the film was good... it got them talking afterwards and I know one of them went to get checked out.**
>
> **Black man at risk: I didn't know until I watched the film that there was a higher rate of prostate cancer among black men. Everyone took away the message that they need to get themselves checked out and talk to other black males about this.**
>
> **Black man at risk: I asked my GP if I could have my prostate checked and he said oh don't listen to all that stuff you hear in the media, you're perfectly healthy and there's no reason to check your prostate if you don't feel any discomfort...before watching the film I didn't have the confidence or knowledge to challenge that, but now next time I go back, I am going to ask again.**

A further element of community outreach work conducted by the project was the development of a photographic exhibition (*One in Four*) and associated one-minute awareness-raising film[10] to highlight the fact that one in four black men will be diagnosed with prostate cancer in their lifetime. The photographic exhibition was developed with match funding support from Healthwatch Brent, who promoted the free exhibition extensively in the local community and online. All the men featured in the exhibition lived or worked in the target boroughs.

The exhibition was situated in Bent Civic Centre for four months, from May to August 2019, and then moved to Harlesden library, which has a high footfall of local residents. Harlesden is an area with a high IMD and a very high proportion of Black African or Black Caribbean residents. Was widely viewed by members of the local community.

The *One in Four* awareness-raising film based on the exhibition has been widely shared on social media and **viewed over 82,000 times on social media.**

Project staff have conducted further work with appropriate local press and media using print, online, broadcast and social media to increase awareness of their activities in the target communities. Further national agenda-setting promotional activity has been conducted on social media, including celebrity endorsements and work with parliamentarians. A fuller account of this aspect of the project can be obtained from Orchid.

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[10] https://www.youtube.com/watch?v=BcRdDiBXTU0

3. Black men living with and beyond diagnosis feeling more confident about engaging with their diagnosis / treatment / aftercare, having access to culturally appropriate support groups and feeling less isolated (Outcomes 2 and 3)

The main focus of project work with men living with and beyond a diagnosis of prostate cancer has been to identify cancer support groups in the target boroughs and work with the group Facilitators to ensure that these groups are supported, culturally relevant, and promoted to black men living with and beyond a diagnosis of prostate cancer.

Project staff were able to identify five cancer support groups in London that they could work with: these groups cater for people living with cancer in six of the seven boroughs covered by the grant (Brent, Lambeth, Newham, Hackney, Lewisham and Southwark). Some of the groups are specific to prostate cancer, but others are generic cancer support groups. It was not possible for the project to identify or establish a support group in Tower Hamlets.

Working in partnership with group Facilitators and their members, the project developed a suite of culturally appropriate promotional materials (posters, leaflets and pull up banners) for each group. These resources were made available to group Facilitators for use at community events, and project staff also distributed promotional materials to local GP surgeries and community centres in the target boroughs. Images used in the materials clearly communicated that the groups were relevant to the black community.

In addition to promotion, the project worked closely with group Facilitators to identify the type of input that would enable each group to provide appropriate support to black men living with and beyond a diagnosis of prostate cancer. The nature of the project's input varied between groups, but included facilitation of group meetings, providing speakers on prostate cancer issues, and funding social events. Several group Facilitators and members interviewed by Healthfocus mentioned the importance of these social events in reducing isolation and enabling men to have more

informal discussions about their condition and its consequences.

The project report indicates that the project engaged with 270 black men with a diagnosis of prostate cancer over the three years. Of these, 217 were men attending support groups: the remaining 53 were diagnosed men with whom staff had engaged during outreach events.

Four support group Facilitators and six black men who were members of support groups were interviewed during the external evaluation. All support group Facilitators interviewed were very positive about the support and promotional work provided by the project. In a challenging funding climate, Facilitators often expressed the view that their support groups would be unable to operate without the support of project funding and staff.

> Support Group Facilitator: **The project funded some speakers and social outings for support groups which enabled the men to bond and feel less isolated. They could talk to each other one to one, which was great. It strengthened the group and it gave them hope, something to look forward to. We don't want to talk about prostate cancer all the time, sometimes we just want to talk about other things.**

> Support Group Facilitator: **The project are the backbone of the group because we have very busy clinics and there are days we cannot make it, so Orchid come and facilitate the group. They have also booked speakers, helped us to produce flyers and funded some social events for us – sometimes it's easier to talk when you are doing things. Without them, it would be very difficult to keep the group going.**

> Support Group Facilitator: **The project has assisted us in having our own leaflets for more publicity, and a banner we can use at events. The banner has been particularly helpful in reaching more people, and I think quite a few people have come to us through seeing the leaflets in the doctors' surgeries and hospitals. If we hadn't been supported by Orchid, the group would have been at risk because there is no other funding at all.**

The project report that **all 270 of the post-diagnosis men** with whom they engaged reported feeling **less isolated and more confident** about engaging with their diagnosis, treatment and aftercare as a result of project input into support groups or community events.

Healthfocus interviews with post-diagnosis black men attending groups supported by the project were consistent with this finding: all were extremely positive about the information they had received from the project and all reported feeling much less isolated as a result of attending the group meetings and related social events.

Analysis of interview data indicated that the groups provided invaluable support for men coping with (often embarrassing and isolating) side effects of treatment, and that this support was not readily available elsewhere. Several men commented that they had been encouraged by healthcare professionals to attend the support groups, emphasising the important role of healthcare professionals in signposting men towards appropriate community support.

> Black man with prostate cancer, support group member: **People are shy to talk about it outside, some are really closed in but when they hear others speaking about things like stress incontinence, they will gradually start to talk and ask questions.**

> **Black man with prostate cancer, support group member:** **I was sent here first by my GP. I didn't know anything about it when I was diagnosed. We talk about the treatments, side effects, any problems... I am happy coming here. And it helps me to talk to other people in my family. It makes you feel more confident about talking to others.**

> **Black man with prostate cancer, support group member:** **I was quite isolated at first, I thought it was the only person going through it and I thought I was going to die soon. It's very helpful here and we learn about coping with the problems.**

Interviews with men attending groups also revealed an unexpected outcome of the project's work with this audience. Several of the black men participating in project-supported groups had become very motivated to 'spread the word' about prostate cancer incidence and its signs/symptoms within their communities and social groups. This 'cascade' activity was helping to ensure that the project's key messages (1 in 4, signs and symptoms, importance of talking to HCPs and early diagnosis) reached members of the black community who might not otherwise receive them. These 'community ambassadors' were often using the project's targeted resources for the black community – particularly the z-card – to support their activities. Again, the importance of raising awareness of prostate cancer issues amongst women as well as men was mentioned by several respondents.

> **Black man with prostate cancer, support group member:** **We are trying to empower men generally to go and see their GP and talk about having a PSA test. I see our role not only as information sharing but also as 'apostles' telling other men about prostate cancer, particularly because it is 1 in 4. We talk to women as well – we say, if your partners is going to the toilet several times a night, he needs to see the GP. Informing the women too is hugely important.**

> **Black man with prostate cancer, support group member:** **The one area where you get a group of black men who will talk about anything is in the barber shop. When I go to the barber shop, I try to open up conversations about prostate cancer.**

> **Black man with prostate cancer, support group member:** **I have given this leaflet to people. I want them to know where to go and what to do. Sometimes when I go on the bus, I give it to the men. Most people really appreciate it... some of them hide it because they are embarrassed, but they still keep it. The small booklets are good because they can put them in their pockets.**

> **Black man with prostate cancer, support group member:** **I gave a presentation at a Caribbean cricket dance. I took a couple of hundred of the leaflets and gave them out.**

> **Partner of Black man with prostate cancer, support group member:** **Because of the project and the materials they produce, he (partner) is really focused on spreading the word – don't wait until it's too late.**

4. Healthcare professionals feeling more competent and confident regarding having conversations about prostate cancer with black men at risk and supporting those living beyond diagnosis (Outcome 4)

Over the course of the three-year project, a series of talks and awareness-raising events with healthcare professionals (HCPs) in the target boroughs were conducted. A total of 405 HCPs attended these events: participants included GPs, GP Nurses, Urology nurses and student nurses. Post-event evaluation forms were completed by 236 of the 405 healthcare professionals with whom the project engaged. These forms indicated that fewer than half (44%) of HCPs attending project events had prior awareness of the issue of prostate cancer in the black African and black Caribbean population. All HCPs who completed evaluation forms reported improved knowledge and understanding and increased confidence about meeting the needs of black men going through treatment and aftercare.

GPs had initially been identified by the project as a key audience for messages about prostate cancer, particularly as they act as ‘gatekeepers’ to PSA tests and are often unaware of the increased risk amongst black men (a survey of GPs commissioned by Orchid in 2019 found that only 5% GPs identified ethnicity as a primary risk factor for prostate cancer). Moreover, several of the Urologists interviewed for this project also commented that they often saw men with prostate cancer who had been refused PSA tests by their GPs.

> **Consultant Urologist:** **We see loads of men who say they have been refused PSAs by their GPs, even amongst black men with a family history who are at high risk. It’s totally hit and miss. And there is a big job to be done in terms of GPs understanding the use of Multiparametric MRI and active surveillance.**

In practice, project staff found that securing engagement with GPs was challenging. A project event organised jointly with Healthwatch Brent for GPs in Brent in 2018 (Interacting effectively with Black African and Black Caribbean communities in order to deliver increased patient satisfaction and

Summarised HCP data from Orchid post-event evaluation forms (source: Orchid, n = 236)	**YES**	**NO**
1. Were you aware of issues/concerns affecting black men’s prostate cancer treatment or care prior to the training?	44%	55%
2. Have you attended any training/seminars on this topic prior to today?	8%	92%
3. Has the information/training you received today improved your knowledge and understanding of issues affecting black men’s prostate cancer treatment and care?	100%	
4. Are you confident that the information/training you have received today will help you meet the needs of black men going through prostate cancer treatment and aftercare?	100%	

improve prostate cancer outcomes) generated a relatively low response despite extensive promotional activity with local surgeries, the inclusion of a talk from a Consultant Urologist (Professor Chinegwundoh) and a free lunch.

Although GP participation was low, an interview conducted by Healthfocus indicated that this event had prompted at least one GP to focus more actively on the issue of prostate cancer. A GP in Brent interviewed for this evaluation reported to Healthfocus that the event had prompted him to contact all the black men aged over 50 years on his list with some information about prostate cancer, and that this had resulted in the detection of 3 new cases of prostate cancer to date. The proactive contacting of black men over 50 in his practice was reported to be an ongoing activity.

> **GP, Brent: The session was good, we were encouraged to detect more cases. We decided to do a search for black African and black Caribbean men aged 50 plus and then we sent letters, about 50 of them, and we told them that if they were black or if they had a family history it was more common. We have kept it going and so far we have picked up three new cases.**

Over the course of the project, staff distributed key information (about relative risk amongst black men, local support groups, and the Orchid helpline) to 329 GP practices across the 7 Boroughs, with an estimated reach of around 1,500 GPs and many more patients. However, only 15 of the 405 HCPs who attended HCP talks were GPs. The relatively low uptake amongst GPs is a common finding amongst organisations attempting to engage with primary care, and is likely to reflect both workload pressures and the range of education and training opportunities on offer to them.

In practice, the majority of the 405 HCPs who engaged face-to-face by Orchid were nurses. Project staff found that nurse groups were often receptive to the offer of talks, and that this was a time and cost-efficient way of accessing healthcare professionals at scale. Nurses interviewed by Healthfocus often commented that they had further disseminated project information and links to colleagues and patients with whom they worked after the talks.

> **Nurse: I found the session really interesting and it has definitely made me think about the way I talk to men from the black community and the concerns they might have. And I have passed the information about the support groups.**

> **Nurse: I have sent the link to people I know, and I have put the pamphlet with the phone number on the board: it's a very private issue... at least they can ring somebody.**

Since May 2019, the film, *Letter to my unpresented self*, has been shown at talks for healthcare professionals. As mentioned previously, this film is based on the 'diagnosis journeys' and experiences of black men attending a support group in one of the target boroughs.

5. Project legacy

As a result of the work conducted in this project, Orchid has received several requests to deliver outreach events (talks and roadshows) at London boroughs outside the target London boroughs and beyond. Orchid have acquired considerable expertise in engaging with the black community about prostate cancer and hope to continue this work on a wider geographical scale by partnering with other statutory and voluntary bodies.

The Orchid team also hope to identify and upskill key individuals in partner organisations further afield who can be trained to deliver community events using the model and resources developed by Orchid during this project.

The print and film resources used in this project, which were developed in consultation with clinicians and members of the black community, will continue to be produced and made available to individuals and organisations.

Orchid hope to continue to support the patient support groups in London after the end of the project, as they recognise that their input is key to the sustainability of several of these groups. However, it is unclear at present whether Orchid will be able to supply this input after the end of the project grant in 2020.

Several members of the support groups in London who have become informal ‘community ambassadors’ for prostate cancer awareness continue to disseminate key messages and resources to the black community in barber shops, at faith groups, and at community events.

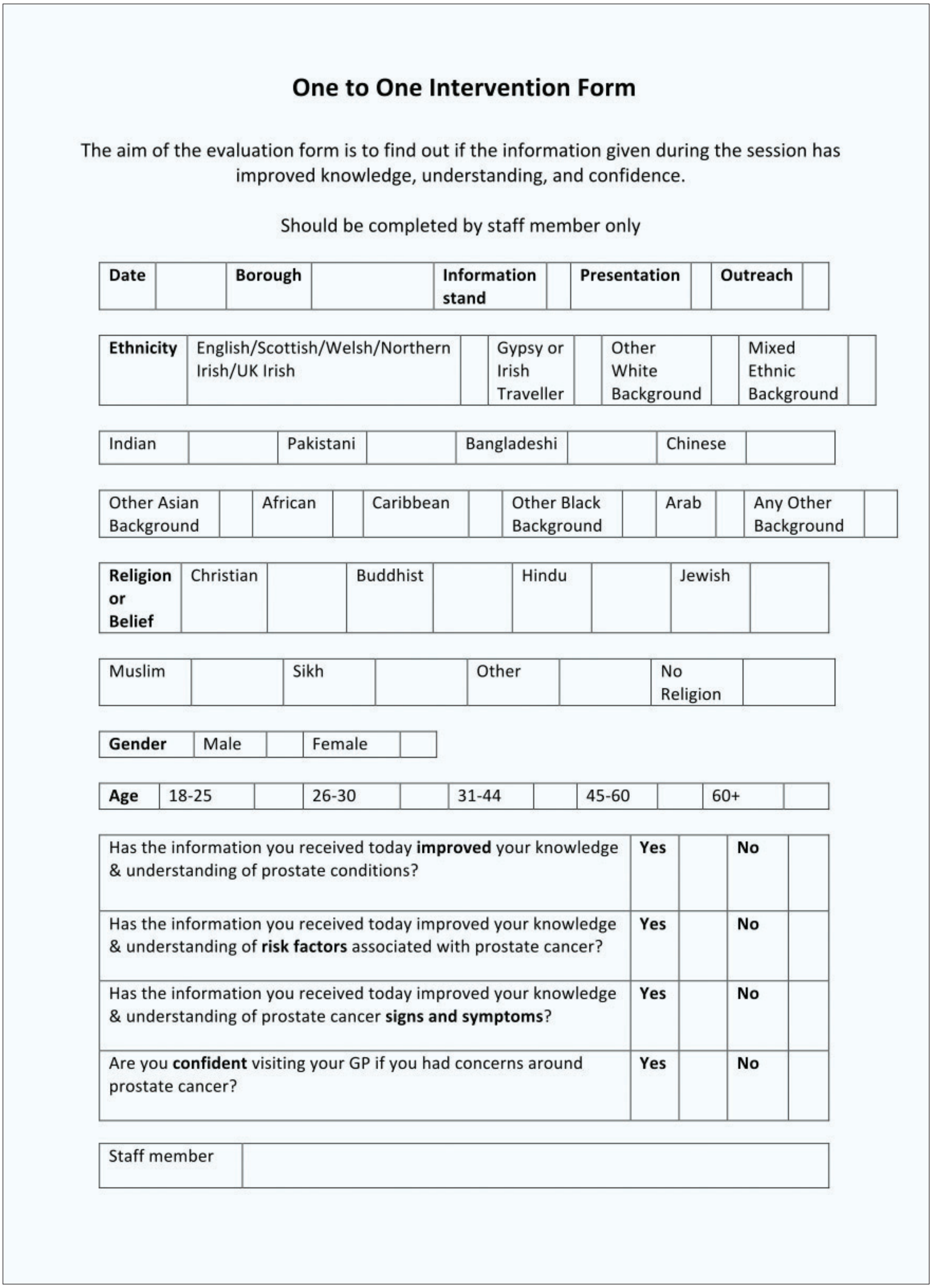
Orchid continues to work with the media, social media, celebrities and parliamentarians to raise awareness of prostate cancer in the black community at national level.

Above: Stills from the film *Letter to My Unpresented Self*

Appendix 1: interview sample

Black men and women who have engaged with project outreach events	
	8 x black men who had attended project events
	2 x black women who had attended project events
Members of support groups supported by the project	
	6 x black men living with and beyond prostate cancer diagnosis attending project-supported groups
Facilitators of support groups supported by Orchid	
Madhu	Facilitator of Hackney Men vs Cancer support group
Anon	Facilitator of cancer support group, South London
Sabria	Continence Specialist Nurse and founder of East Ham support group (Each one Teach one)
Selina	East Ham support group Facilitator
HCPs who have engaged with project events	
Catherine	Nurse, midwife and church health projects worker
Sarah Itam	Consultant Urologist
Chris Booth	Rtd Consultant Urologist, CD of CHAPs, Clin Adv TACKLE
Anon	Nurse and community advocate
Marjorie Otieno	Senior Cancer Research Nurse, UCLH
Dr M (anon)	GP Brent
Representatives of Community Partner Organisations	
Ruhel Ahmed	Tower Hamlets staff council forum
Lee Townsend	Community Worker, BME forum
Ben Gordon	WISE West Indian Social Care project, Brent
Ian Niven	Manager, Healthwatch Brent
Project Stakeholders	
Rebecca Porta	Chief Exec Orchid
Julia De Petrillo	Prostate Cancer Project Administrator, Orchid
Ali Orhan	Prostate Cancer Information Manager, Orchid
Frank Chinegwundoh	Chair, Cancer Black Care, and Consultant Urologist

Appendix 2: Post-event outcome monitoring form



One to One Intervention Form

The aim of the evaluation form is to find out if the information given during the session has improved knowledge, understanding, and confidence.

Should be completed by staff member only

Date		**Borough**		**Information stand**		**Presentation**		**Outreach**	

Ethnicity	English/Scottish/Welsh/Northern Irish/UK Irish		Gypsy or Irish Traveller		Other White Background		Mixed Ethnic Background	

Indian		Pakistani		Bangladeshi		Chinese	

Other Asian Background		African		Caribbean		Other Black Background		Arab		Any Other Background	

Religion or Belief	Christian		Buddhist		Hindu		Jewish	

Muslim		Sikh		Other		No Religion	

Gender	Male		Female	

Age	18-25		26-30		31-44		45-60		60+	

Has the information you received today **improved** your knowledge & understanding of prostate conditions?	**Yes**		**No**	
Has the information you received today improved your knowledge & understanding of **risk factors** associated with prostate cancer?	**Yes**		**No**	
Has the information you received today improved your knowledge & understanding of prostate cancer **signs and symptoms**?	**Yes**		**No**	
Are you **confident** visiting your GP if you had concerns around prostate cancer?	**Yes**		**No**	

Staff member	

Independent evaluation
carried out by

healthfocus
RESEARCH

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