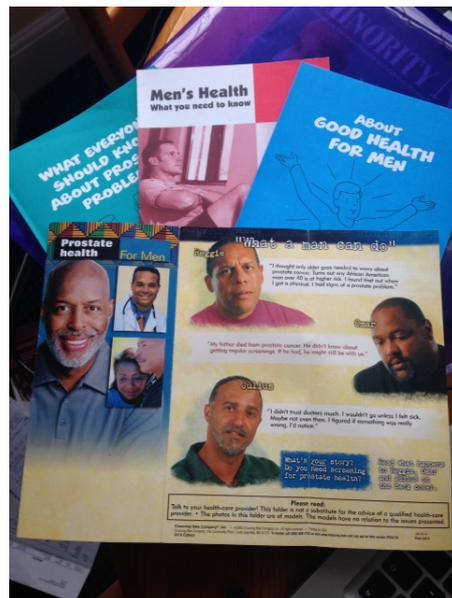


“Celebrating Life”: Survivor-led prostate cancer advocacy for Black Caribbean men in The USA and Caribbean.

Professor Laura Serrant



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1. Introduction

Globally Caribbean/African men are more likely to have poor prognosis, worse outcomes and greater morbidity from Prostate cancer than their peers. In the UK national campaigns encouraging men to be more 'prostate aware' and seek help from clinical services, have failed to reverse this trend. For Black Caribbean/African men, late presentation and lack of cultural health literacy are identified as primary factors in reducing the success of Prostate cancer focused health promotion and information strategies. While the challenge of reducing the impact of prostate cancer in the lives of Black Caribbean/African men and their families is a world wide phenomenon, the UK could learn from countries where community based and survivor led minority health programs successfully work alongside other core services improving the uptake of health information and life chances of Caribbean and African men.

Prostate Cancer is a chronic disease that causes emotional and social problems for men diagnosed with the condition and their families. There are ranges of treatments available to treat and manage the condition; however early detection is key to improving health outcomes and life chances. The only real test available for prostate cancer is the detection of Prostate Specific Antigens (PSA) in the blood. Raised levels of PSA have been shown to be present in men with prostate cancer. One of the complicating factors in prostate cancer diagnosis and treatment is the lack of agreement among clinicians both within and between countries, as to the effectiveness of PSA screening. Increased PSA levels for example, have also been shown in benign growth of the prostate (as a natural occurrence in ageing) and in a range of other illnesses including infection of the reproductive organs. This is further complicated by the lack of consensus about the levels of PSA that would warrant invasive treatment, rather than the more conservative 'watchful waiting' and monitoring of disease progression.

Prostate cancer however, is not simply a challenge to the physical body but has impact on men's self-esteem and masculinity. Prostate cancer attacks the part of the body associated with fertility, and 'being male'. Moreover many of the treatments for prostate cancer impact on a man's sexual activity, libido, erectile function and continence. This means that treatment and diagnosis of prostate cancer are very sensitive issues to negotiate. Thus making it even more important that clear, useful information and support for men and their families is paramount.

The sensitive nature of this condition means that in order to control the social burden of the disease and its eventual prevention, increased engagement through community action and peer support is needed alongside advances in research and patient care. I have worked with men's health, prostate cancer and health promotion groups in the NHS and community. So far we have failed to impact on Black Caribbean and African men's engagement with prostate cancer services. In many parts of the UK, community engagement around this issue is in its infancy or in other cases remains isolated from mainstream services.

a) Drivers to action

My interest in prostate cancer is both personal and professional.

I am a qualified nurse with over thirty years' experience in sexual and reproductive health practice, research and education. I am also a Black Caribbean woman and daughter of a

father who was diagnosed in the UK with Prostate Cancer and died in the Caribbean within a year of diagnosis. My initial interest in men's sexual health and wellbeing began during my early work around HIV/AIDS in the 1980s when fear and lack of information were some of the greatest challenges to good health. The burden of disease in HIV/AIDS and poor sexual health generally was borne by men from Black and minority ethnic groups who were stigmatised in society as carriers of disease and guilty of promiscuity. Furthermore taboos around the acceptability of talking about or advising around issues pertaining to sexual health, coupled with a lack of sexual health services to support people, particularly men led to many deaths and avoidable risks from reproductive cancers (such as Prostate cancer) as well as sexual infections. Almost twenty-five years later, my professional interest changed to personal concern as my father was diagnosed with prostate cancer and I spent many hours trying to explain choices, options and 'how did this happen' to his close friends and my family. I have always had a feeling that there must be other ways, other options that we could use in the UK to ensure that Black men, as a group at high risk of prostate cancer have appropriate, timely information and support.

b) The Winston Churchill Travelling Fellowship

I heard about the Winston Churchill Travelling Fellowship from a friend who had been a previous recipient of an award. I made my application via the website and was thrilled to be awarded a 2013 Fellowship. The Winston Churchill Fellowship provided me with an ideal opportunity to make a personal and professional contribution to improving the life chances and health experiences of Black men living with Prostate cancer. My planned focus was on finding ways to engage Black men in information about their health and in particular strategies to make them more 'prostate aware'. I felt this period of time spent overseas would enable me to get new ideas, inspiration and support from other regions where community work with Black men has had success in increasing awareness and uptake of health and cancer services. This information would be invaluable to NHS and some of the voluntary groups I work with where we are struggling to devise new integrated approaches to supporting men and their families living with this condition

My main aims were to gain knowledge, insight, inspiration and expertise to inform development of health strategies and interventions in prostate cancer services for Black and minority ethnic (BME) men and to contribute to the growing prostate cancer survivorship and awareness movement in UK by:

1. Learning best practice by visiting a range of established survivor-led recovery projects
2. Learning about community mobilisation and organisational development by talking to founders and coordinators of advocacy and self-help peer organisations
3. Talking to people involved in the strategy, policy and implementation of advocacy and awareness oriented community based programmes

I was particularly interested in the interface between the health screening and treatment systems for prostate cancer and the survivor led Black community projects. A key question for me was

'What is the role of not for profit survivor led support services in their communities and how are these 'services' carried out alongside core health intervention provision?'

I planned to spend time with community based health and advocacy programmes aimed at improving health outcomes and health literacy of Black men around prostate cancer. I

wanted to see how these programmes have managed to maintain a successful contribution to community health resulting in improved understanding of prostate cancer and uptake of services amongst Caribbean/African communities. I also wanted to explore the benefits of these services with men and their families living with prostate cancer. I selected the Caribbean region as an area that accounts for the largest number of Black migrants in my local area and the USA where community based minority advocacy in prostate health is well established.

2. Prostate Cancer among BME men in The Caribbean, USA and UK

Prostate cancer is a chronic disease that causes emotional and social problems to patients and their families. Advances in long-term control of the disease have been found to improve both length and quality of life for patients in the general population. To control the social burden of the disease and its eventual prevention, increased culturally appropriate resources and a range of strategies are necessary to ensure permanent advances in research and patient care.

The President's Cancer Panel of the National Institutes of Health in 2001 clearly stated, "Lack of accurate cancer-related information that is readily available, understandable, clear and delivered in a sensitive and culturally acceptable manner is a major contributor to the inability of patients and the public to obtain the most appropriate cancer prevention, treatment and supportive care." (Presidents Cancer Panel 2001). One way to at least partially address this situation is to create successful outreach programs, which educate men and their families in order for them to make informed decisions about their personal risk of the disease as well as other conditions affecting their health.

Prostate cancer is one of the most common men's cancers in Europe. It is estimated that 300,000 new cases appeared in 2006 in the European Union and the number will rise in the years to come (Ferlay et al 2007). In Europe there are currently more than two million men living with prostate cancer. New diagnostic methods which include the wider availability of PSA screening, and changes in men's attitudes, due to increased awareness of the disease, mean that more and more prostate cancers are found at an early stage, when treatment options are most effective.

Prostate cancer in the USA

Prostate cancer is the second leading cause of cancer related deaths in the USA, and the most commonly diagnosed cancer in American men (American Cancer Society 2014). Difficulties associated with finding information which informs about the clinical and non-clinical aspects of the disease is the necessity of finding the most reliable and appropriate facts for a diversity of individuals. In addition this information needs to make it easy for men to identify and discuss key issues with his doctors that will give him the best potential for cure and/or retention of quality of life.

Despite the advances in prostate cancer treatment and the wide variety of services available, African American men remain at highest risk of death from prostate cancer. Engagement with screening services is poor and accurate diagnosis often occurs late (or not at all) – reducing treatment options available and increasing the risk of complications arising from more aggressive treatments following late discovery of the disease.

Prostate cancer in the Caribbean

On a worldwide platform, the Caribbean islands rank in the highest risk rating categories of the 192 WHO countries, for deaths from prostate cancer. Table 1 below shows that the Caribbean islands rank as the top ten countries with only one island, Jamaica at position 17 outside this. In contrast the UK, USA and Canada rank at 58, 91 and 103 respectively.

Table 1: World Cancer Death rankings: prostate cancer 2013 Live ranks

RANK (out of 192 countries)	COUNTRY	Death rates per 100,000	Risk category
1	Dominica	46.8	Highest
2	St Kitts	31.4	Highest
3	Barbados	27.8	Highest
5	Antigua	24.8	Highest
6	Grenada	24.3	Highest
7	St Lucia	23.7	Highest
8	St Vincent	23.2	Highest
9	Trinidad and Tobago	22.6	Highest
10	Haiti	21.0	Highest
11	Dominican Repub.	18.9	Highest
17	Guyana	15.7	Highest
28	Jamaica	11.3	High
58	UK	8.2	High
91	Canada	6.6	medium
103	USA	6.1	medium

Risk ratings by rank

- Rank 1-25 (Highest risk)
- Rank 26-75 (High risk)
- Rank 76-125 (Medium risk)
- Rank 126-192 (Low risk)

The consistent appearance of Black men of Caribbean/African origin in the high risk and high death rates for prostate cancer led me to question why this is so. It points to the need to understand how we could encourage Black men to engage with health services and also to develop greater levels of health literacy. In the case of prostate cancer, timely information appears not only to be important, but also life saving.

3. Overview of Organisations Visited

I had originally planned to complete my Winston Churchill Travelling Fellowship by visiting the Caribbean islands (Barbados/Jamaica) in summer 2013, and then follow this up with a visit to the USA in Autumn 2013 (New York/New Jersey). However, one thing I learned very quickly during my Fellowship year is that things do not always go to plan! – I thought I knew this already, as I have travelled many times overseas as a researcher, but I soon realised that engaging with community and other organisations on a visit to ‘inform and experience’ rather than to ‘measure or investigate’ brings with it the need to adopt a more ‘open’ style to visits! Before I was able to go on my first visit, changes in my role at work meant that I had to defer my visit to the USA until after the New Year. In addition, I found that a few of my proposed contacts in the Caribbean were going to be attending the a convention/conference event in Grenada during the first week of my planned visit and would not be available on the Island I was due to visit. They invited me to attend the meeting (on a different Island to those originally planned) and also to do a presentation at the event. After a slight panic... It seems slight now.... I spoke to the very helpful staff at WCMT explaining these last minute changes and was given permission to attend.

This was another valuable lesson I would share with any new Fellows – how easy it is to communicate with the staff at WCMT and their willingness to help whenever possible with travel arrangements (Thanks!!)

So in the end I travelled to the Caribbean in June 2013 and the USA in February 2014.

PRE VISIT

A month before my first planned visit I made contact with several agencies and individuals from the UK who worked with Black Caribbean men around prostate cancer in order to get an idea of what they believed the key issues in the Caribbean were. I felt this would provide a current underpinning to my visits. In addition it would help to ensure that my questions and contacts whilst in the Caribbean and USA would not be restricted to my existing knowledge.

One organisation, the Association for Prostate Awareness (APA) made contact with me and invited me to attend one of their meetings and talk to the Committee and Caribbean male attendees about my impending Travel and the focus of my Fellowship. The Association for Prostate Awareness is a voluntary association that started in 2006; they are based in east London. Their work is aimed primarily at African Caribbean men in the local community where they provide support to men living with prostate cancer, their families and carers. (See http://www.prostate-awareness.co.uk/our_work.cfm). Following my visit with them I became even more convinced of the importance of community action on health education for men living with Prostate cancer. They also offered to help me to share details of my visit with their organisation and local contacts after my return.

VISITS

Over the course of June 2013 and February 2014 I visited a range organisations and met with people working across a variety of community, education, health and policy organisations in the USA and Caribbean. The main organisations and the local contacts, where relevant, are listed in Table 2 below. A full timetable is contained in Appendix 1. The staff I met with ranged from community members, working with their own neighbourhoods,

academics trying to understand prostate cancer and risk in Black men to senior health ministers. In all cases the individuals had particular interest and expertise in working with Black men and their families or had experience of community focused actions on health. In the course of my visits I was also lucky enough to meet a number of Black Caribbean men either living with prostate cancer or individuals (women and men) who had a family member with prostate cancer. The majority had participated in the programmes I visited and their reflections and experiences provided further useful insight and feedback on the benefits of the programmes. Contact details for the organisations visited can be found in Appendix 2.

Table 2: Organisations and staff visited/contacted

Country	Organisation	Contact (if applicable)
Caribbean – Grenada	CSA congress/conference	Professor Eudine Barriteau (Gender and Public policy)
		Jamaican Cancer society group
Caribbean – Grenada	Ministry of health and social security	Mrs Lydia Francis (Community health nurse)
	Men’s community health event	Dr Francis Martin (Coordinator)
Caribbean – Barbados	Chronic Disease research centre	Prof Anselm Hennis
	Barbados Cancer society	Dr Dorothy Cooke-Johnson
	Community urologist for Jamaica/Barbados	Dr Nebhanami
USA – NY/NJ and environs	Prostate.net	Virgil Simmonds
	Barber shop initiative	Anita Linton (coordinator)
	“Omar’s barbershop”, Atlantic City	Abdullah Anderson & Crew
	Atlantic city Business ad community association (ACBCA)	www.acbca.org
	Leadership Institute for Black Nurses, NY/NJ	Dr Yvonne Wesley Harriett Braithwaite
	Sidney Kimmel Center for Prostate and urological cancers, NY	Dr Joseph B Narus
	Prescription medicines and natural therapies practitioner	Wendy King
	Concerned Black Nurses of Newark	Annette Hubbard
	Community health phone in at Radio Vibes Link NJ 96.1 FM	DJ Larry Ranks
USA- Washington	National League for Nursing	Dr Elaine Patterson

		Dr Beverly Malone
Washington DC, USA	Lombardi Comprehensive Cancer Center	Everett Dodson, Community Health educator,

The organisations and people I met with fell into three categories:

1. Survivor-led recovery projects and community based peer organisations
2. Founders and coordinators of advocacy and self-help peer organisations
3. People involved in the strategy, policy and implementation of advocacy and awareness oriented community based programmes

1. Survivor-led recovery projects and community based peer organisations

These projects were commonly led or were originally conceived by men who had prostate cancer. The projects were based in the community and the most successful of them (TheProstate.net) had managed to forge links with clinical and social advocacy services as well as attracting their own funding sources.

Contacts: TheProstate.net
Omar's barbershop, Atlantic City
Barber shop initiative – Atlantic City
Men's community health event, Grenada

One of the most far-reaching and well established organisations I made contact with was The Prostate.net based in the USA. Its founder and president Virgil Simmonds, a man who has lived with prostate cancer himself for over 16 years heads up this organisation. As a result of the lack of information when he was diagnosed, Virgil began to gather information and create a network of contacts and activities to inform men about Prostate cancer. Virgil is a staunch advocate for informing Black men to take charge of their health and understand more about prostate cancer, its prevention and treatment. The approach taken by The Prostate.net is now tried and tested. It is based around localised outreach programmes which are aimed at men and provide 'culturally and gender appropriate forums to educate men about prostate cancers so they may make informed choices about personal risk of prostate cancer and other diseases. These programmes and activities traditionally take place in 'male spaces' such as barbershops, garages, and music clubs. They are further enhanced by sponsorship and association with appropriate clinical and commercial organisations such as the highly successful "Gentlemen check your engines" which occurs in association with Harley Davidson.

More recently The Prostate.net have recognised that informing men about their health means engaging women – in discussion with men attending their events they found that most were encouraged to attend for prostate screening by a significant female in their lives. I found this interesting as my research on black men using sexual health services in the UK in 2004 revealed the same things around attending screening services for sexually transmitted infections – with many men reporting that it was a female partner or relative who encouraged them to attend. The Prostate.net have reflected this more family centred approach to their work by expanding their "Gentlemen check your engines" to include concurrent health screening for women - their recent event in February was entitled "Ladies and Gentlemen Check your Engines" (see flyer)

WHAT'S TRUE FOR YOUR BIKE IS TRUE FOR YOU

LADIES & GENTLEMEN CHECK YOUR ENGINES



HEALTH AWARENESS DAY-2014
SATURDAY, FEBRUARY 8th-10am-3pm
at BERGEN COUNTY HARLEY-DAVIDSON
 124 ESSEX STREET-ROCHELLE PARK, NJ-201.843.6930

FREE SCREENINGS FOR ORAL CANCER, CHOLESTEROL, BLOOD PRESSURE, DIABETES, DONATE BLOOD! TONS OF GREAT INFO, AND BEST PART IS IT'S FREE!
 FREE RAFFLE AND GIVEAWAYS TO THE FIRST 200 PARTICIPANTS. DON'T MISS IT!
 For more information, please email support@prostatenet.org or call 1.201.289.8221

Give Blood. Get stuff!

Saturday, Feb. 8th • 10am-3pm
 Stop in for FREE seminars! Great info & give-a-ways!
 Donate Blood and spin the BCH-D/BMW Prize Wheel!
 You could win a \$10, \$15, \$20 or \$25 BCH-D/BMW Gift Card!



It's our way of saying thanks for donating...



The success of what started as a local community resource is reflected in the fact that it is now an international Not for profit organisation, which uses a matrix of informational techniques (Web site, 800#, email and personal team counsellors, public forums, newsletters and community disease interventions) to increase prostate cancer risk awareness amongst men and early engagement with appropriate services.

I first made contact with Virgil prior to leaving the UK and through him was able to link with Anita Linton, their regional coordinator in New Jersey State for the 'barbershop initiative'. This initiative was wholly community based and involved barbershops across the USA. Anita agreed to take me to meet many of the barbers involved including Omar and Abdullah's Hair Bazaar (Barbershop) in Atlantic city, which was the first shop to engage with the concept of health education around prostate health for men. Brothers Omar and Abdullah Anderson, in Atlantic City, opened the shop. Omar unfortunately died in January 2011, however, his legacy of providing a place of refuge

advice and community support in the barbershop, along with 'haircuts' continues to this day with his brother and business partner Abdul (pictured with me below). In memory of his brother the shop is locally known as "Omar's"

The barbershop initiatives were impressive both in their scope and impact. They started in 2004 and began by approaching selected medical centres in areas where there were high proportions of Black and minority ethnic (BME) communities. Anita informed me that the idea for using barbershops as a main contact point arose from the recognition of the barbershop in Black communities as not just a 'place to cut your hair' but also one of the few venues where men go to meet and congregate socially outside bars and clubs.

As part of the initiative, local barbers from these predominantly BME neighbourhoods are recruited and trained to function as lay health educators and 'sign posters' who support and encourage their clients to get screened and treated for prostate cancer. On occasion some of the established barbershops, like Omar's have even provided PSA screening 'outback' with the engagement of nurses from the local medical centres providing what we would call 'satellite' or outreach' services. The local medical centres reported that this program has enabled them to provide a higher level of community and patient use of their services - and ultimately to save lives and improve health awareness. The community links from the Barbershop and across Atlantic City were spearheaded in early days, before



we even had the word ‘outreach’ or ‘community cohesion’ by Omar and Abdullah’s parents – indeed I had the pleasure to meet their mother who own a store further down the Block which forms part of the Atlantic City Business and Community Association (see next section below)



The use of existing areas or facilities where men congregate, alongside the development of events which engaged men and their families was a feature of organisations in the USA and Caribbean that came from a survivor or peer led basis. In the Caribbean, discussions with the community groups and cancer support organisations revealed that these, often small scale and hidden support groups were vitally instrumental in increasing the awareness of prostate cancer. In Grenada, at the time of my visit small organisations and groups, were working with the local health centres and organising a men’s health event on the lines of a fete and family social on the local park. This was to be one of the first in Grenada targeting men. It was being publicised through the radio, local churches and community centres – unfortunately I was unable to attend as the day coincided with my flight out of the island – however, follow up contact with the organisers on my returned revealed that the event was well attended and they were planning other similar events in different locations.

2. Founders and coordinators of advocacy and self-help peer organisations

The second group of contacts I made during my travels were those who worked for or represented groups that coordinated or founded organisations that highlighted Black men’s health in general and/or prostate health in particular. These organisations were not necessarily delivered or conceived by men who had prostate cancer themselves, although many of them had members of their families who had been diagnosed (or unfortunately died) as a result of Prostate cancer. However, the activities of these organisations always included projects and activities aimed at improving the health of black men in general. Many of them had started from a basis of prostate awareness but decided that placing this within a broader spectrum of improving health would be most beneficial. The projects here occasionally focussed on cancers or on sexual health – but the approaches used here came from a belief that health interventions and health information targeted at Black men could impact on his basic health literacy and levels of knowledge about himself. Indirectly this improved awareness would led to greater uptake of health screening, and health services by black men – including sexual health and prostate awareness in particular.

Contacts: Radio Vibes Link NJ 96.1 FM
Everett Dodson, Lombardi Comprehensive Cancer Center outreach services
Concerned Black Nurses of Newark
Wendy King - Prescription medicines and natural therapies practitioner

Atlantic city Business and community association (ACBCA)
Barbados cancer society

My appearance at Radio VibesLinkfm NJ 96.1 FM on a Saturday morning with less than 24 hours notice was possibly one of the most enlightening and enjoyable events I attended. Although I am not sure whether I can describe it as 'attending' when I took to the microphone to talk about my Winston Churchill Travel Fellowship and it quickly turned from a brief information session to a live radio phone-in. Radio VibesLinkfm was launched on July 26, 2010 and has since established itself as the number 1 Caribbean leading reggae radio station in the new Jersey area. Winning awards for its work VibesLinkfm transmits to the local black Caribbean community in New Jersey from a residential area. Again what struck me here were the similarities in the way Caribbean people living in the USA had very similar styles of community engagement and communication as in the West Indies. Despite the vast differences in wealth and social structure, fundamentally the approaches remained the same.



The phone in was a lively affair and after my initial nervousness – in case I was asked too many detailed questions about treatments and procedures – I found that many of the listeners spoke about either their own experiences of prostate cancer, or attending screening which provided a great deal of insight into the personal challenges of the condition. One listener phoned to say he had heard about screening but was concerned about the examination – this was taken up by another listener who reassured his fellow listener and

congratulated 'us' at the radio for talking openly about such issues. The radio show host DJ Larry Ranks spoke to me about the importance of the radio station as a vehicle for educating the local community as well as providing entertainment. He informed me that for many of the community members it was important to hear health messages and information about services on their own community sites as it was only then that many people made the link that what they may perceive a 'general message' sometimes specifically related to them as Black people. He said that it was not the information that often needed changing (compared to that prepared for a general audience) but simply that it needs to be presented and explained to the black community by the black community.

The importance of utilising local members of the community as peer educators was a message repeated in many of the places I visited. During my time with Everett Dodson, head of the minority community outreach program at Georgetown/Lombardi Cancer Centre, Washington, I learned that local knowledge of communities was vital. In the outreach work for the Lombardi cancer centre, Everett acted not only as an educator about prostate cancer but also as an advocate for the cancer services at the centre. Employed by the centre, he had an important role in demystifying cancer treatments but also in educating men, their families and the local communities about the importance of continued check ups to maintain health. In this reciprocal role he could also work with clinicians and service

planners to inform them about factors in the local community which may impact on health or engagement with services.

The overlap between service provision and community engagement was repeated in my visits while in the Caribbean. The Barbados Cancer Society centre was an impressive place with a good standard of equipment and a well maintained building. During my meeting with the coordinator and founder Dr Dorothy Cook-Johnson I learned that this organisation had developed from a voluntary base and itself was funded by patronage and donations. Barbados, like many of the Caribbean islands had a very high rate of deaths from prostate and other cancers.



The cancer centre did not exclusively deal with prostate cancer but saw the ability to provide free screening and cancer care services as an important part of giving people in Barbados better chances of survival and services. Dr Cooke- Johnson and her family had worked and lived on the island for many years and since her retirement had utilised their contacts and networks to fund the centre. The centre was able to provide free services to the local community essential in an area where there was not an NHS service and treatments could be expensive. Cost was not the only issues however, the

geographical organisation of the Caribbean meant that each island could not have a full range of services, often people on smaller islands diagnosed with cancer may have the additional burden of being flown out of the Caribbean or away from home in order to be treated. Something which inevitably affected treatment adherence in prostate cancer. Dr Cooke- Johnson however highlighted some of the challenges of running an organisation that receives donations from well meaning larger countries. She showed me some very expensive, very modern portable equipment that had been donated by a USA company. The equipment had been brought by some visiting medical students who, while on the island were able to provide mobile services in the community as part of their experience on the island during their medical training. Unfortunately in Barbados where there was not the skilled people to use the equipment and the availability of spare parts was problematic, it was now redundant.



The centre had very good links with the local hospitals and physicians as well as with the research Chronic Disease Research Centre based at the University of the West Indies, Barbados Campus. Dr Anselm Hennis who lead the centre was able to share with me how he and his team were beginning to develop a robust database of evidence about many chronic conditions, including prostate cancer. Dr Hennis explained the importance of this to the region and to planning health services, information and support. As I discussed in the introduction there is a lack of current information in the UK as to how prostate cancer and other conditions affect the health of Caribbean communities. This is the same in the Caribbean itself – something that was reiterated by the Consultant urologist on the island, Dr. Nebhanami. Detailed factual information from a local evidence base is what informs health education information as well as guides the work of clinicians and health professionals. This is the same evidence base that is then used by community organisations and support groups to elicit relevant information to communicate to the local communities, whether by phone, radio or health leaflets. It was heartening for me to see that the ‘academic work’ of Dr Hennis and his colleagues could be directly communicated to the local communities in a way they could use it.

3. People involved in the strategy, policy and implementation of advocacy and awareness oriented community based programmes

The final group of organisations were those provided by clinical and educational facilities or informing healthcare policy and workforce development in this area. These had an important role to play in engaging with the peer led and community based activities to provide factual support and information to underpin their activities. In addition, these organisations also included government agencies that oversaw policy and practice development around sexual health, public health and men’s health in particular. It was often the support of a key member of these organisations that enabled the community groups to receive funding or provided an avenue for communication between them and the hospital, clinical or other social care services.

Contacts: National League for Nursing

Sidney Kimmel Center for Prostate and urological cancers, NY
Leadership Institute for Black Nurses, NY/NJ
Community urologist for Jamaica/Barbados
Ministry of health and social security - Grenada
Caribbean Studies Association (congress/conference)

The agencies and activities involved also had impact on the education and training of the workforce to enable them to provide 'survivorship' and community engaged health care as well as hospital based clinical services. This was a key aspect of the developing work in the USA and the Caribbean as both geographical regions had a relatively undeveloped health services focussed on 'community care' based provision compared to the UK. Self-care and public engagement as we know it in the UK was not well developed in either region which complicated the issue of early presentation. In addition, treatment adherence was often further complicated by the need to pay for treatment, reflected in the increased risk of death from prostate cancer in men from poorer neighbourhoods (Caribbean/USA) and those without health insurance (USA).



At the time of my visit to the USA there were several important issues that impacted on my discussions with both community groups and healthcare professionals – that was the Affordable care Act (often referred to as ObamaCare) and the lack of a cohesive approach to health care in the community. Professional groups across USA such as the Black Nurses Association and the National League for Nursing in particular were concerned about the role of nurses in providing community support for men living with poor health, including prostate cancer survivors. There were views from many of the individuals and groups I spoke to that the 'ability to pay' was a key aspect of Black men's health. As a marginalised group, often without adequate health insurance there was a tension between going for screening to find out if you had prostate cancer and then not being able to afford the associated treatments or follow-ups. This was not unique to prostate cancer but

many felt that it was a factor in successfully increasing screening uptake in poor areas – it was hoped that 'ObamaCare' would go some way to rectifying the disparities.

The Minister for public/community health in Grenada, raised similar concerns about the ability of individuals to take up treatments, during our discussions. The Minister was also concerned as to how health care providers would be able to react appropriately to the needs of the men and their communities should the push to 'increase awareness' result in a 'rush' on services. To help manage this possible pressure on services, they were working with community groups and through efforts such as the Men's Health awareness events to encourage 'self help' and wellbeing message rather than simply relying on existing clinical information which stressed to men the importance of 'going to the doctor' if you felt there was a problem.

In the USA and Caribbean nurses, particularly Black nurses from the same neighbourhoods and community groups were actively developing their own community health action programs alongside their paid roles. Dr Yvonne Wesley from The Leadership Institute for

Black Nurses, NY/NJ ran a leadership programme which aims to address both the need for diverse leadership in nursing to address areas of health disparities (such as prostate cancer) while also engaging people to sign up to the ObamaCare policy.



I presented an overview of community nursing in the UK to members of the leadership programme during their Saturday workshops and we discussed the work of the Winston Churchill Fellowship and how the funding they provided supported development and knowledge exchange projects between the UK and rest of the World. The attendees described how supporting development and knowledge exchange was at the heart of their community engagement activities. They exchanged their clinical knowledge as nurses with their own and other community groups, who told them of the challenges of maintaining health. Many of these exchanges occurred in informal spaces where people gathered e.g. churches, picnics, welfare offices, and grocery stores. The information exchanged was then used to inform small community events led by the

nurses and the community, which they felt ensured engagement from both sides and accuracy of the information shared. For the men and their families in many of these neighbourhoods, prostate cancer was a major concern amongst others relating to general health – many men had not been screened or simply did not understand the importance of the information they were given. The sessions in the community were invaluable as they enabled additional health checks to be carried out ‘on the spot’ as well as giving time for community members to ask questions relating to their health, medication or general wellbeing concerns. A key aspects of the projects supported by the nurses on the leadership course was that they evaluated the processes and outcomes used. This information could be used by themselves, service providers and the community themselves to evaluate the impact of the activities and the value added, in terms of health engagement and health literacy within the Black communities.

4. Recommendations: Answering the key question and next steps

My travels across the Caribbean and USA were invaluable in that they provided me with and opportunity to understand more about the ways in which community, individual and policy organisations working together can improve the health and life chances of Black Caribbean men around prostate cancer. The initiatives visited and people I spoke to were applying many different approaches to ensure that Black men and their families were better informed about their health and the risks of prostate cancer in particular. The approaches used differed but focused on encouraging early presentation at the first signs of problems associated with prostate health, informed men of the importance of regular check ups and provided information for health workers as well as black community members and families as to how to support men living with the disease.

So in answer to the question that sparked my Travels

'What is the role of not for profit survivor led support services in their communities and how are these 'services' carried out alongside core health intervention provision?'

I believe that the main recommendations and learning from my study visit arise in the answers to this question. The role of survivor led services in supporting Black Caribbean communities and men living with prostate cancer, and how they work with other health providers can be summarised under two main areas of activity: Approaches taken to ensure appropriate, accurate information reaches Black Caribbean men and Ensuring engagement in activities which support, engage and energise Black men, their families and communities in their health and prostate health in particular.

I have set out the key issues to be considered by service providers, charities and community advocacy groups working with Black Caribbean men around prostate cancer below under the headings "reaching black men" and "Activities that Support, Engage and Energise"

A) Reaching Black Caribbean men

- *Engaging with Black Caribbean men 'where they are'*

The success of many of the programmes that aimed at informing men about prostate health and promoting self care and awareness were successful because they were located in the communities where Black men live. Once trust and engagement was established with either a key contact (community group, business, organisation or individual) from the black community, uptake of key messages and cascading of messages to the wider community was much more successful. This also translated into longer established programmes providing a first contact point for signposting individuals to clinical and professional support services.

- *Speaking their language*

The way in which the message of prostate health was communicated is a key factor in Black Caribbean men either accepting the information as 'authentic' and 'about me' as much as the content of the information. The organisations I met went to great lengths to ensure that the information provided (whether verbal or written) was in a style that Black men understood. Translation of information for Black Caribbean men was often not about non-English usage – rather it was about using words and pictures that were

commonly understood culturally by Black Caribbean men. The radio shows and leaflets produced by the survivor and community led advocates translated 'clinical language' into colloquial language and used examples that were culturally relevant, while all the time ensuring that information was accurate.

- *Using all available media*

The use of all possible forms of media communication was key here. In both the Caribbean and the USA, radio plays a great part in the daily habits of Black Caribbean communities and men in particular. The radio is as important as mobile phones and the Internet in the modern era. In addition the reading of the newspaper and discussion around news stories are still an important part of cultural activity in the age group of men at highest risk of prostate disease. However it is important to understand that many of these men listen to 'Black' radio stations and read newspapers from 'back home' so the identification of where best to communicate information and which programmes are most listened to by the target audience is key.

- *Using existing connections with family and professionals*

Reaching Black Caribbean men and informing them about prostate health cannot be simply targeted at the men themselves. Family and professionals from (or working with) the communities were vital in the success of many programmes. Interventions and activities which also include wives, partners and health care professionals that engage with Black Caribbean men across other platforms have a part to play in early presentation and more importantly treatment adherence as a integrated approach to improving survivorship

- *Importance of supportive infrastructures and agencies*

The success of initiatives to improve the health chances of black Caribbean men in relation to prostate cancer was dependent on the existence of supportive infrastructures and agencies. This was key both at the initial set up stage and to ensure the establishment and ongoing success of activities. It did not seem to make a great deal of difference at the start up stage whether the support came from more centralised parts of the community (radio, churches, social centres) or from health agencies. However, the long term survival and impact of activities required partnerships in the form of the investment of time and/or resources from either health policy departments, health services or private businesses.

- *Value of shared experiences and learning from peers*

This was by far the most important aspect of all the services, activities and organisations I visited. Black Caribbean men learning from each other, sharing experiences of diagnosis, treatment and survivorship of prostate cancer. This took place in person, through different media platforms, in isolation or with family and friends. However the message was delivered it seems activities for men, involving or by men who lived through and with prostate disease as essential.

B) Activities that Support, Engage and Energise

In taking account of all the approaches listed above. The services, facilities and opportunities offered culminated in a range of activities, which as one man put it "celebrated life". The success of the approaches lay in the fact that they did not focus on the negative aspects of cancer diagnosis or overplay the fear factor of consequences of not being screened. Instead they focused on **supporting** men to

make informed choices, **engaging** with them in the places where they lived out their 'normal' lives and giving them the '**energy**' or personal incentives to take care of their health (irrespective of their prostate disease status).

The outcomes of this approach are a range of community focused opportunities, many of which are integrated or supported by clinical services – but all of which that are

- Informed by community "insider knowledge"
- Providing 'male spaces' where men can receive information and talk among themselves
- Enabling family and partner engagement, recognising the importance of this in optimising screening uptake, treatment adherence and survivorship in general
- Including health professionals in delivery and evaluation of clinical advice and services
- Informing policy and service development in key areas either directly through engagement with health departments or indirectly by engaging with think tanks, community partnerships or service evaluations

Next Steps

This study visit has identified a range of approaches that have been used in the Caribbean and USA to successfully increase the engagement of Black men with health and prostate cancer services. I am encouraged to try to share these approaches and ideas with colleagues and community groups as part of my dissemination of the Fellowship experience. I will host a BME focused 'Listening event' inviting local, and national stakeholders to hear about the Travelling Fellowship and work with me to inform development of UK survivor led approaches for Black men. A Listening event involves sharing experiences and collating feedback and comments from relevant people about an issue and using that to make/suggest changes or new approaches to health. Invitations to the event will be extended to my network of community groups, prostate cancer advocacy groups, and cancer care charities to identify practical opportunities for implementation of 'lessons from overseas'. From this event I ultimately aim to secure further funding to produce a survivor informed health information resource (online) for BME communities and service providers focusing on Black men's health and prostate cancer in particular. It is hoped that this will be developed from 'talking heads' in the video/audio diary. The first stage of this will be to have a return meeting with the APA (with whom I did my pre-visit) to plan the listening event.

Copies of this report will in the first instance be sent to those who supported my application to the WCMT and expressed interest in the findings. These include Dr Kate Holmes, Head of Research, Prostate Cancer UK; Denton Wilson: Prostate survivor and now involved in awareness raising in the UK, and in Jamaica; Association for Prostate Awareness. In addition, copies will also be sent to the organisations and individuals that I visited in the USA and Canada for sharing with their communities and colleagues.

5. Concluding comment

Being diagnosed with cancer is a challenge to individuals and their families and the impact of men's lives goes beyond their own physical health. When the cancer is sited in the prostate, questions of masculinity and self-identity come into play that encourage us to look at how we can support men and their families beyond a purely clinical sphere. In a sensitive arena it is important that cultural issues, needs and differences are taken into account, particularly when some ethnic groups appear to have higher risk of death or poor quality of life after treatment. My WCMT Fellowship has given me a great opportunity to explore the ways in which we can better engage with Black men as a high risk of developing prostate cancer in order to improve their health chances. I was privileged to be given the time to spend with the men, their families and the organisations who are working hard to optimise Black men's the health and wellbeing.

I hope to share my experiences and the ideas gleaned from the USA and `Caribbean with my networks in the UK. The best way I can sum up my learning here is to take the word of the men with me and encourage agencies in the UK working in this area to move towards activities, interventions and approaches, which have at the heart of them "a Celebration of life".

Appendix 1 – Travel Schedule

Places & countries with approximate dates.	Names of organisations/people visited you intend to visit.
Caribbean: June 1-15 2014	<p>Mrs Lydia Francis (community health nurse)</p> <p>Dr Francis Martin, Ministry of Public /Community Health, Grenada</p> <p>Jamaican Cancer society group</p> <p>Prof Eudine Barriteau (UWI) Nta Barrow research Centre (at CSA congress)</p> <p>Prof Anselm Hennis (Barbados)</p> <p>Meeting with the BNR Staff</p> <p>Meeting with Dr. Nebhanami at Chronic Disease Research Centre (CDRC), Barbados</p> <p>Meeting with Professor Unwin – department of Public Health</p> <p>Seminar CDRC (includes my presentation)</p> <p>Meeting with Dr. Dorothy Cook-Johnson - Barbados Cancer Society</p>
USA: February 7-21 st 2014, New York/New Jersey	<p>Anita Linton, National Barbershop initiative coordinator, New Jersey USA</p> <p>Abdullah Anderson & Crew. Omar and Abdullah's Hair emporium, Atlantic City. NJ</p> <p>Atlantic city Business ad community association (ACBCA), Atlantic City, NJ</p> <p>Dr Yvonne Wesley and Harriett</p>

	<p>Braithwaite. Leadership Institute for Black Nurses, NY/NJ</p> <p>Sidney Kimmel Center for Prostate and urological cancers, NY</p> <p>Dr Joseph B Narus. Sidney Kimmel Center for Prostate and urological cancers, NY</p> <p>Wendy King. Prescription medicines and natural therapies practitioner</p> <p>Annette Hubbard. Concerned Black Nurses of Newark</p> <p>DJ Larry Ranks. Community health phone in at Radio Vibes Link NJ 96.1 FM</p>
USA: Washington	<p>National League for Nursing. Dr Elaine Patterson and Dr Beverly Malone</p> <p>Everett Dodson, head of the minority community outreach program at Georgetown/Lombardi Cancer Centre, Washington</p>

Appendix 2 – Organisation Contact Details

Organisation	Contact Details
CSA congress/conference	http://www.caribbeanstudiesassociation.org/
Ministry of health and social security, Grenada	http://health.gov.gd/index.php?lang=en
Chronic Disease research centre, Barbados	http://www.cavehill.uwi.edu/cdrc/home.aspx
Barbados Cancer society	http://www.barbadoscancersociety.com/
The Prostatenet	http://www.theprostatenet.org/aboutUs.html
“Omar’s barbershop” aka Omar and Abdullah’s hair bazaar, Atlantic City	http://www.yelp.co.uk/biz/omar-and-abdullahs-hair-bazaar-atlantic-city
Atlantic city Business ad community association (ACBCA)	www.acbca.org
Leadership Institute for Black Nurses, NY/NJ	https://nursing.nyu.edu/about/libn
Sidney Kimmel Center for Prostate and urological cancers, NY	http://www.mskcc.org/cancer-care/outpatient/sidney-kimmel-prostate-urologic
Concerned Black Nurses of Newark	http://www.cbnn.org/
Community health phone in at Radio VibesLink NJ	96.1 FM http://www.vibeslinkfm.com/
National League for Nursing	http://www.nln.org/

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President's Cancer Panel. Voices of a broken system: Real people, real problems. National Cancer Institute, 2001.