The Influence of Culture on the Views of Black African/African-Caribbean Men Living In the UK Towards Cancer

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Declaration

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution; and that no portion of the work referred to in this thesis has been submitted in support of any application for another degree or qualification in this or any other university or institute of learning.

Abstract

In the United Kingdom (UK), men face a significantly higher risk of contracting and dying from cancer. Prostate, lung and colorectal cancer are the most common cancers diagnosed in men; with prostate cancer disproportionately affecting black men. Little is known about black African (BA) and black African-Caribbean (BAC) men's view towards cancer; yet culture and acculturation determine the way in which people understand, explain and develop their attitudes towards cancer. Hence, cancer prevention and early detection strategies may not be sensitive to UK-based black men views, affecting their awareness of risk factors and early detection services. An evidence based understanding about black men's views towards cancer is needed to effectively target cancer prevention strategies. This qualitative study explored the influence of culture on the views of UK based BA and BAC men towards cancer.

In collaboration with black community organisations based in Leeds, Manchester, Birmingham, and London, 27 participants were recruited. Convenience and theoretical sampling methods were used. Data were collected from June 2013-February 2014 using semi-structured one-to-one interviews. Data were analysed using the grounded theory analytical method.

BA and BAC men have their own distinct beliefs concerning the causes of cancer, which influence how they view cancer as a whole. Seven categories: '*Cultural views*'; '*Religious beliefs*'; '*Avoiding Babylon*'; '*Alienation*'; '*Suspicious mind*'; '*Advertisements and information influence very little*', and '*Gap in service provision (Bridging the gap)*' were identified as sub-categories revolving around the core category: 'Cancer through black eyes'. Cancer was not viewed as a purely medical condition through black eyes. Black men's views towards cancer were closely linked to socially constructed perspectives of themselves, linked with their cultural and religious beliefs; what being black male means in society, the meanings of historical phenomena like slavery, and the meanings they ascribed to social systems and establishments, such as healthcare systems. Clinical risk factors such as smoking and obesity had different meanings and symbolisation through black eyes. There were macro- and micro-level similarities and differences between BA and BAC men.

Cancer-related services, such as public-health campaigns, aimed at black men need to be sensitive enough to understand cancer through black eyes. Public health campaigns based on only the clinical meaning of cancer mismatch with black men's understandings of cancer. Accordingly, the effort made to increase public awareness of cancer and to reduce health inequality in this regard may continue to be ineffective. Findings from this study can be used to inform public health policy makers, and healthcare professionals more broadly, including professionals involved in health promotion, as well as charitable organisations aiming to provide services that will be utilised by BA and BAC men.

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The Author

The Author of this thesis was born and raised in Ethiopia, Africa. In 2001 he travelled to the UK and trained as a mental health nurse at Birmingham City University, qualifying in 2006. He subsequently practiced as a nurse in a number of mental health settings. In 2008 he completed an MSc (by Research) in Developmental Geography at Coventry University. His research interests at that time focused mainly on public health and health development for ethnic minority groups. The author subsequently worked actively as a Research Nurse at Central Manchester University Hospitals NHS Foundation Trust and the University Hospitals of Birmingham. A growing interest in research and the needs of ethnic minority groups developed further when an opportunity arose to apply for a PhD Studentship at the University of Central Lancashire. During the PhD programme the author became increasingly aware that little was known about black men's views towards cancer. As a black man born in Africa and currently living in the UK, undertaking this study allowed the author to make an important contribution towards improving the available evidence-base on how black men view cancer and how these views are influenced by culture.

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Abbreviations

ACS	American cancer society
AIDS	Acquired Immunodeficiency Syndrome
BA	Black African men
BAC	Black African-Caribbean
BES	Best Evidence Synthesis
BME	Black and Minority Ethnic
CAQDAS	Computer Assisted Qualitative Data Analysing Software
CDC	Centres for Disease Control and Prevention
DH	Department of Health
DRE	Digital Rectal exam
EPPI	Evidence for Policy and Practice Information and Co-ordinating Centre
FBA	First Generation Black African
FBAC	First Generation Black African Caribbean
GLOBOCAN	Global Cancer
GT	Grounded Theory
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
MeSH	Medical Subject Headings
NAEDI	National Awareness and Early Diagnosis Initiative
NCDs	Non-Communicable Diseases
NCEI	National Cancer Equality Initiative
NCI	National Cancer Institute
NHS	National Health Service
ONS	Office for National Statistics
PICO	Population, Intervention, Control and Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
SBA	Second Generation Black African
SBAC	Second Generation Black African Caribbean
SMSR	System for Mixed Methods Research and Mixed Studies Reviews
UK	United Kingdom
UN	United Nations
UNDP	United Nations Development Programme
USA	United States of America
WHO	World Health Organization

Introduction

Cancer is one of the world's major public health issues, leading to high morbidity and mortality rates worldwide (Ferlay et al., 2010a, 2010b). Many factors determine a country's response to health priorities (World Health Organisation [WHO], 2002). In the developing world, and specifically in the case of Africa, the prevalence of other diseases such as HIV/AIDS infection, tuberculosis, malaria and Ebola are compounded by a lack of resources, this often means that cancer is the most disregarded disease in many African countries (Jemal et al., 2012; WHO, 2002), receiving little attention from public health officials (American Cancer Society [ACS], 2011b).

Furthermore, the majority of African people associate cancer with certain death (Muthoni & Miller, 2010; Sheppard, Christopher, & Nwabukwu, 2010). Some of the reasons for this association includes a vicious cycle of poverty, lack of education regarding symptoms, lack of early detection programmes, and importantly, a lack of success stories about cancer survivors (Adebamowo, 2007; Parkin et al., 2003). For African patients who manage to access available health services locally or abroad, cancer is often diagnosed at a late stage, limiting treatment options, decreasing survival rates and increasing mortality rates (ACS, 2011a).

Despite better early detection programmes for cancer available in the Caribbean islands (Aiken & Eldemire-Shearer, 2012) compared with Africa, the trend of late cancer diagnosis within the black community in the Caribbean still remains a major challenge, particularly among men (Aiken & Eldemire-Shearer, 2012).

Although cancer health promotion, with early detection and treatment is advocated in the UK, low levels of screening uptake and late diagnosis of disease are common within the

UK's black community, particularly among men (Cancer Research UK, 2009; Department of Health [DH], 2011).

The distribution and burden of cancer varies across different groups in society based on income, age, ethnicity and gender (Freeman, 2004; National Cancer Intelligence Network, 2011; Siegel, Naishadham, & Jemal, 2013). In the UK, men face a significantly higher risk of contracting and dying from nearly all the common cancers that occur in both sexes with the exception of breast cancer (DH, 2011; White, Thomson, Forman, & Meryn, 2010). Prostate, lung and colorectal cancer are the three most common types of cancer diagnosed in men (Cancer Research UK, 2012b). Prostate cancer disproportionately affects black men compared to any other racial and ethnic group, both in the UK (Ben-Shlomo et al., 2008; Cancer Research UK, 2012a) and in the United States of America (USA) (National Cancer Institute [NCI], 2008; Siegel et al., 2013). Lung and colorectal cancer incidence rates are also higher among black men in the USA (NCI, 2008; Siegel et al., 2013). However, in the UK there is no reliable national data on patterns of cancer incidence, mortality and survival in black communities (Cancer Research UK, 2009; DH, 2011).

In the USA, cancer-screening uptake is low among black men even for those with a family history of cancer (ACS, 2013). Knowledge, attitudes, cost and mistrust of health professionals and the healthcare system are commonly reported as reasons for the low screening uptake rate in the USA (Brandon, Isaac, & LaVeist, 2013; Roberts, 2010).

In the UK, although there is no evidence to suggest that black men have worse or better access to diagnostic services (Metcalfe et al., 2008), they are less likely to attend screening (Austin et al., 2009; DH, 2011; Rajbabu et al., 2007; Szczepura, 2005). The reasons for this discrepancy between the availability and utilisation of services by black men are unclear. A

recent systematic review suggested that while black men bear the highest burden of the disease, limited efforts have been made to ensure they have access to relevant information to support them in making informed decisions to utilise early detection services (Pedersen et al., 2012). Further, studies have shown that there are inequalities between UK black men and the general population in levels of awareness about cancer screening, common risk factors and early warning symptoms (DH, 2011; Rajbabu et al., 2007; Szczepura, 2005; The Prostate Cancer Charity, 2008; Waller et al., 2009; Webb et al., 2004). However, studies focused on knowledge of, attitudes towards, and views about, cancer have been population-based surveys with minimal recruitment of black participants, or focused on a mix of different ethnic minority groups. Furthermore, these studies have not disaggregated the data based on different black subgroups such as black African (BA) and black African-Caribbean (BAC) men. Hence, the reasons why black men are less aware of cancer risk factors, warning symptoms and early detection programmes remain unclear. In addition, how black men explain and view cancer has not yet been fully explored (Waller et al., 2009).

Little is known about UK BA and BAC men's knowledge of, and attitudes towards, cancer (DH, 2011; Pedersen et al., 2012; The Prostate cancer Charity, 2008); yet culture determines the way in which people understand, explain and develop their attitudes towards illness including cancer (Burr, 2003; Dein, 2004). Acculturation and country of origin also affects knowledge and beliefs about cancer (Abraído-Lanza, Armbrister, Flórez, & Aguirre, 2006). People who migrate to a different country bring with them their own culture, beliefs, values, priorities, and aspirations (Kohnert, 2007) to their adopted country. In addition, healthcare researchers have been slow to recognise the range of cultural and ethnic diversity within the black population (Brown, Wilson, Boothe, & Harris 2011). Hence,

current cancer prevention strategies such as public health promotion and early detection strategies may not be sensitive to, address or reflect the cultural beliefs and views of UK-based black men towards cancer, which in turn may affect their awareness of risk factors to, early signs and symptoms of, and early detection (screening) for, cancer.

Primary prevention based on raising public awareness of cancer and potential risk factors is important for minimising the burden of cancer (WHO, 2002). Having sufficient information about people's views towards cancer in society is vital for identifying the groups in society that may benefit from a more targeted strategy for cancer prevention and early detection (Schernhammer et al., 2010). Having a comprehensive understanding of black men's knowledge and views towards cancer is therefore vital for encouraging them to seek help and advice about the disease, thus reducing mortality.

This study sets out to explore the views of BA and BAC men towards cancer. These men's understanding, reasoning, and explanations will be elicited, with particular attention to the way cultural background may determine how BA and BAC men understand and explain cancer and how they engage with cancer-related services in the UK. At the outset of conducting this study consideration was given to a number of pertinent points and overarching questions which are presented in the following paragraphs.

As a result of the focus on infectious diseases like HIV/ AIDS, public health campaigns focusing on cancer in Africa and the Caribbean have been minimal (Jemal et al., 2012). Consequently, people are likely to be unaware of the signs and symptoms of cancer (Muthoni & Miller 2010). Furthermore, they are likely to hold views towards cancer influenced by cultural, traditional and religious thinking (Shah et al., 2008; Sheppard et al., 2010). After moving to the UK, where cancer health promotion, information and early

detection screenings are available, the following overarching questions can be posed in relation to BA and BAC men's established patterns of thinking:

1- To what extent do they still hold the same outlook on cancer as they held in their countries of origin?

2- Can their cultural, traditional and religious thinking provide explanations for delayed uptake of cancer-related services and late diagnoses?

3- If this is not the case, what is the explanation for the patterns of late cancer diagnosis evidenced among BA and BAC men both in the UK and their countries of origin?

4- To what extent are BA and BAC men aware of/to what extent do they access available cancer-related information and early detection services?

Exploring how culture influences BA and BAC men's views about cancer will enhance evidence-based knowledge that could be used to develop more effective health promotion programmes targeting the African and Caribbean communities, thereby increasing awareness of early signs and symptoms of cancer.

Thus, the aim of this study is to explore the influence of culture on the views of BA and BAC men living in the UK towards cancer. This research aim has been developed based on the evidence gathered from existing literature. The literate review section (Chapter 3) will outline how the gap in knowledge was identified and the researcher's justification for devising the research aim and its four specific objectives. The study has been conducted using *Constructivist Grounded Theory* qualitative research methodology and a one-to-one interview method, details of which are provided alongside data collection, data analysis, and other relevant methodological issues in Chapter 4. The findings of this study are

presented in Chapter 5. Based on the interpretation of the findings, the emerging *theory of cancer through black eyes* is discussed in Chapter 6. The conclusion of the thesis is presented in the final chapter of the thesis (Chapter 6). Figure 1 below shows the structure of the thesis chapter by chapter (from Chapter 1- chapter 6). Accordingly, the next chapter (Chapter 1) will outlines the background to the study and provide contextual information about the research topic, starting with comprehensive information regarding men's health in general and global trends in cancer.

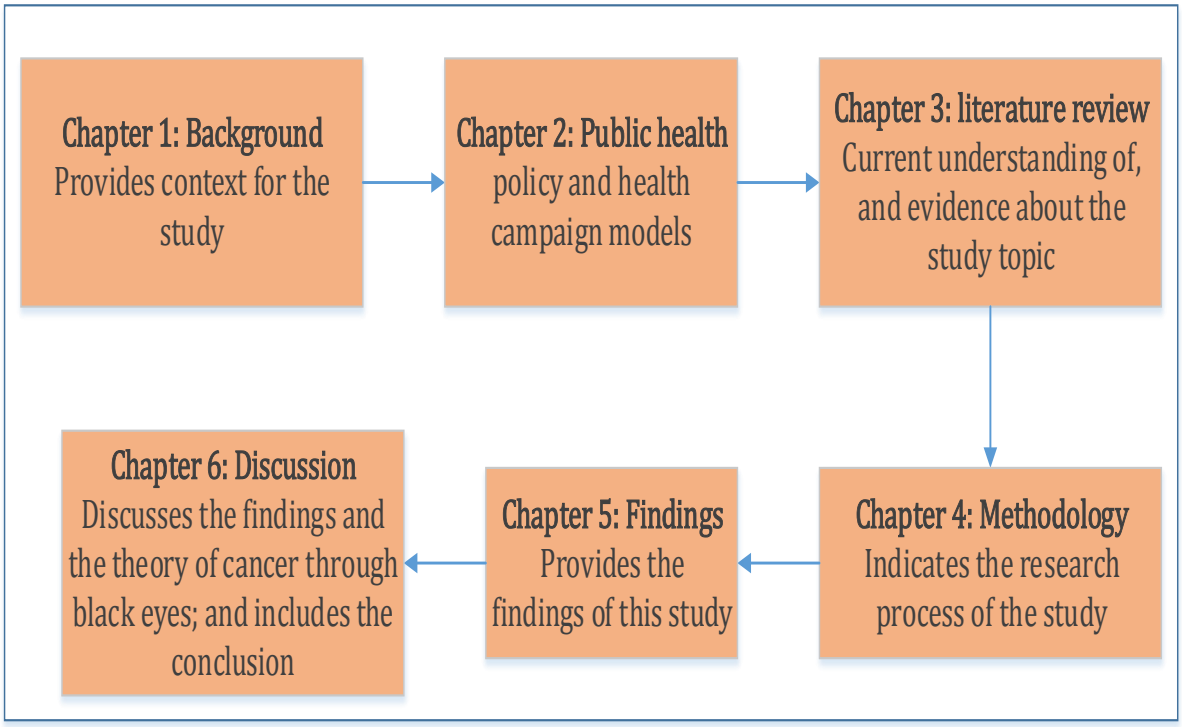

Figure 1: Structure of the Thesis

Chapter 1 **: Background**

1.1 Overview

The background chapter provides context for this study. It includes critical information gleaned from previously conducted studies about the research topic, men's health in general, global trends in cancer, the distribution and burden of cancer, and common cancer types among men—particularly black men. The chapter also explores important issues relating to the research problem and examines key components of the study, such as population, language, culture, and religion in the African, Caribbean, and black populations in the UK. The demographics of cancer and cancer survival in developed countries and in developing countries are provided, in an attempt to indicate the cultural and regional contexts within which the views of BA and BAC men currently living in the UK towards cancer are situated.

1.1.1 Culture and Health

Providing a single definition of culture that is accurately and universally accepted is challenging. The term 'culture' is often confused with ethnicity and race (Dein 2004). Dein (2004) argues that culture is distinct from ethnicity and race and can be defined as a set of guidelines that individuals learn as members of a particular society which impacts on how they view the world, how they experience it and how they behave in relation to others. From a contemporary medical anthropology perspective, health and health outcomes are determined by three convergence factors; namely, biology (anatomy), social factors and culture (Armenakis & Kiefer, 2007). Hence, to offer effective healthcare provision, it is important to understand how people think about health and illness, and also the impact of culture on people's health (Armenakis & Kiefer, 2007; Szczepura, 2005). Since culture is

one of the main factors that determines how people understand and explain health and illness, culture may determine what services individuals will access if they become ill, and what types of treatment they will accept (Dein, 2004; Helman, 2001).

Dein (2004) reviewed a number of explanatory models for cancer in several different cultural groups. Health-promotion programmes, preventative measures for reducing cancer risk factors, promoting healthy lifestyle choices, uptake to cancer screening programmes and adhering to cancer treatment were all potentially compromised by cultural beliefs. Healthcare professionals explanatory models related to their biomedical training and this may differ to the explanatory models held by patients and lay people (Dein 2004). A lack of understanding of different cultural perspectives and beliefs may impact on health promotion activities. Although there are common attitudes (fear of cancer itself and death, associating cancer with sin, being mindful of body image and sexuality) held by people across different cultural backgrounds, the understanding and perception of cancer are highly variable across different cultures such as in African, Asian, Caribbean, and Latino communities (Dein, 2004). As well as some common similarities, there are also gender-related differences between the perception of men and women about cancer. For example, a study carried out in the US found that African American women feared that if they are diagnosed with cancer, they would become unattractive, would become a burden to their partner, or their partner may leave them (Lannin, Mathews, Mitchell, & Swanson, 2002). Some communities have strong beliefs about traditional healers. For example, a qualitative study found that traditional healers in Nigeria held that cancer was caused by magic, bad blood, bad air, incest and adultery (Nwoga, 1994). Such beliefs impact on the proposed treatment modalities which included magic, herbs, divination and psychotherapy (Nwoga, 1994). Cultural beliefs impact on beliefs about health and illness. In multicultural countries

such as the UK, peoples' perceptions of wellbeing are likely to vary, based on their cultural background across different sections of society. Providing a clear understanding of how culture impacts on views towards cancer can only enhance healthcare professional abilities to deliver culturally competent care.

1.2 Men's health

Gender is one of social determinants of health (Ballantyne, 1999; Lee & Owens, 2002; Peate, 2007; Robertson, 2007; Roy, Tremblay, Oliffe, Jbilou, & Robertson, 2013; WHO, 2014a), serving as one parameter to compare health-related inequalities in society (Broom & Tovey, 2009; Peate, 2007; WHO, 2014a). Gender is also instrumental to crafting health policies and procedures, by studying women's and men's health from a gender perspective (Broom & Tovey, 2009; Tolhurst et al., 2012). Contemporary feminist theory argues that due to a postmodern cultural shift, more than two genders exist (Tolhurst et al., 2012). However, for the purpose of this study the traditional meaning of gender, referring to males and females, is used for its suitability within an orthodox cultural context. In light of the traditional meaning of gender, femininity and masculinity influences peoples' health-related perceptions and behaviours (Lee & Owens, 2002; Peat, 2007; Roberts, 2007).

A large body of literature suggests that men are less concerned with minor symptoms and are reluctant to seek medical help (see, for example, Lee & Owens, 2002; Peat, 2007; Roberts, 2007; Roy et al., 2013). Men are biologically predisposed to earlier death (Lee & Owens, 2002). In addition to the biological factor; behavioural, social, and cultural factors influence health differences between men and women (Broom & Tovey, 2009; Lee & Owens, 2002; White & Cash, 2004). These behavioural, social, and cultural differences encourage men to engage in risk-taking behaviours and unhealthy lifestyles, and they are

less likely to make positive health-related lifestyle changes (Lee & Owens, 2002; White & Holmes, 2006). This is particularly the case among men from low socioeconomic groups, such as the majority of black men (Staples, 1995; Williams, 2007).

Literature focused on health comparisons between men and women suggests that there are gender differences in health, including men's high premature mortality rates (potentially from avoidable causes) and a lower life expectancy than women (White & Holmes 2006). Men's resistance to seeking help for physical and mental health problem (Roy et al., 2013; Oliffe, Robertson, Kelly, Roy, & Ogrodniczuk, 2010); high prevalence and mortality rates of chronic illness such as heart diseases (Helgeson, 1995; Lee & Owens, 2002), and cancer (Cancer Research UK, 2011, 2013a; NCI, 2008; White et al., 2010); can be seen as evidence to indicate the magnitude and burden of public-health related major illnesses among men. Existing evidence also suggests there are gender-related similarities and differences in cancer experiences between male and female patients (see, Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Hilton, Hunt, Emslie, Salinas, & Ziebland, 2008; McCaughan, Prue, Parahoo, McIlfatrick, & McKenna, 2012). For example, the findings of McCaughan et al.'s (2012) longitudinal qualitative study indicated that after receiving chemotherapy for colorectal cancer, most male and female participants showed similar experiences and coping behaviour. However, female participants reported experiencing longer-term physical side effects than their male counterparts (McCaughan et al., 2012).

It is important to identify men's health needs, concerns, and any alarming trends in health issues, in order to improve men's health (Robertson, 2007). Therefore, it is argued that any debate about men's health issues should move from comparing men's and women's health and focus on why men's health needs differ, for example, basing this on socio-demographic

characteristics, sexual orientation and culture (Robertson, 2007). This study is centred on men's health in relation to culture and explores BA and BAC men's views towards cancer.

1.3 Global trends in cancer

Cancer has been viewed as a disease afflicting economically developed countries (Parkin et al., 2003). In 2004-5, Europe and the USA spent eight billion Euros on cancer research; another three billion Euros were spent in the rest of the world (Eckhouse et al., 2008). This signifies the magnitude of the cancer problem worldwide. However, in recent years cancer has emerged as a major public health problem in developing countries, matching its effect in industrialised nations and becoming a global health challenge (United Nations (UN), 2011). This has been linked to the increase in behaviours associated with common risk factors such as smoking, excessive use of alcohol, obesity, lack of physical activity, and rapid urbanisation (Stewart & Kleihues, 2003; UN, 2011); as well as a steady growth of aging populations in developing countries (Collingridge, 2007; Jemal et al., 2012).

A United Nations (UN) High-Level Meeting on Non-Communicable Diseases (NCDs) was held in September 2011. This meeting was the second of its kind to focus on a global health issue, the first in 2001 having related to fighting HIV/AIDS (UN, 2011). The main outcome of the 2011 NCDs meeting was the recognition that the growth in prevalence of cancer in developing countries is becoming a global epidemic. The summit also emphasised that by promoting public awareness of risk factors and healthy lifestyle behaviours (e.g. healthy diet, physical activity) through more integrated public health campaigns, cancer incidence rates could be reduced (UN, 2011; WHO, 2011b). Following the 2011 UN summit declaration, in 2013, the World Health Organisation (WHO) published a global action plan focused on the prevention and control of NCDs with the ambitious goal: ''population to

reach the highest attainable standard of health and productivity at every age and NCDs will be no longer a barrier to well-being or socioeconomic development'' (WHO, 2013, p.3). To undertake a comprehensive assessment on the prevention and control of NCDs, The UN General Assembly organised a high-level meeting on NCDs, which was held on 10th and 11th July 2014 in New York (WHO, 2014b). The outcome of this summit was not yet published during the writing up of this thesis. However, current evidence suggests that the prevalence rate of cancer will continue to increase worldwide.

More than a quarter of all deaths worldwide are cancer related. In 2008, 7.6 million deaths (13.1%) out of a total of 58 million deaths worldwide were from cancer (WHO, 2011a). Deaths from cancer are projected to continue rising, with an estimated nine million people dying from cancer in 2015 and a further 13.1 million cancer deaths estimated for 2030 (WHO, 2011a).

A number of common cancers in developing countries, including prostate, breast, and colorectal cancers, result in significant mortality figures due to a lack of preventative measures and a shortage of diagnostic and treatment facilities (Aiken & Eldemire-Shearer, 2012; Jemal et al., 2012; Parkin et al., 2003). In developed countries, common cancers are associated with reasonably high survival rates (Ferlay et al., 2007, 2010b). However, cancer survival rates are low among black people in developed countries, including the UK, mainly as the result of late diagnosis (Cancer Research UK, 2009; DH, 2011). This raises some questions about whether black people in developed countries, such as the UK, access and utilise available services, and whether existing services are effectively promoted to reach black people. It is vital to learn the reasons for these low survival rates among black people so improvements can be made.

1.4 Current evidence from the UK and USA

White et al. (2010) found that men face higher incidence and mortality rates for common cancers that occur in both sexes. Ben-Shlomo et al. (2008) in the UK and the National Cancer Institute (NCI) in the USA (NCI, 2008) have shown that black men are three times more likely to be diagnosed with prostate cancer and are more likely to die from it than any other racial and ethnic group. The NCI data further shows that, in the USA, black individuals had higher cancer incidence (except breast cancer* please see Table 1.1) and death rates than other racial and ethnic groups. Nevertheless, these figures do not differentiate between different 'black' ethnic subgroups, such as African-born, Caribbean-born, American-born, European-born and Haitian-born black communities, making it unclear whether one subgroup bears the highest burden of cancer, nor whether all black people face the same level of risk.

Table 1.1: Incidence and Death Rates of Breast, Colorectal, Lung, Bronchus, and All Cancer Sites in The USA per year Per 100,000 Population From 2003-2007
Source: National Cancer Institute, 2008

Racial/ Ethnic Group	Breast		Colorectal		Lung & Bronchus		All cancer sites	
	Incidence	**Death**	**Incidence**	**Death**	**Incidence**	**Death**	**Incidence**	**Death**
All	127.8	25.5	51.6	19.4	64.5	54.7	470.1	192.7
African American/ Black	**118.3**	**33.8**	**62.1**	**26.7**	**76.6**	**62.0**	**504.1**	**238.8**
Asian/pacific Islander	89.0	33.8	41.6	12.3	39.4	26.9	314.9	115.5
Hispanic/ Latino	89.3	16.1	39.3	13.6	33.3	23.6	356.0	129.1
American Indian/Alaska Native	69.8	16.1	40.8	17.0	44.0	39.9	297.6	160.4
White	**132.5***	25.0	51.2	18.9	65.7	55.0	477.5	190.7

The National Cancer Intelligence Network and Cancer Research UK (2009) report titled 'Cancer incidence and survival by major ethnic group, England, 2002-2006' was the first publication to present the overall picture of cancer and ethnicity in England. This report, compiled from cancer registration data and linked together with hospital episode statistics to derive ethnicity information, indicates differences in specific cancer sites, most commonly among Black and Minority Ethnic (BME) communities. For example, Asian women have increased incidence rates for cancers of the mouth; black and Asian women have poorer survival rates for breast cancer; and the incidence rates of multiple myeloma

and stomach cancer are significantly higher among black people. As can be observed from the report, however, there are many instances in which a patient's ethnicity was not registered, and moreover, there was a problem with achieving complete linkage of patient information between the cancer register and the hospital recorded statistics datasets. Hence, the report may only show a small portion of the actual picture. Nevertheless, as its main message, the report highlighted the need to produce targeted awareness and early detection campaigns to different communities, such as black men, in order to increase cancer awareness and early diagnosis. However, such campaigns need to be based on sufficient information about the targeted people's views towards cancer (Schernhammer et al., 2010).

While USA based studies (see e.g. Allen, Kennedy, Wilson-Glover, & Gilligan, 2007; Oliver, 2007) have shown a connection between black men's views towards cancer and low uptake of early detection services, in the UK there is a lack of evidence whether this late diagnosis is related to BA and BAC men's views towards cancer (Pedersen et al., 2012; Waller et al., 2009).

1.5 African people in the UK

Background data compilation for this study began in 2011. During 2011, the available Census UK-2001 data regarding African immigrants in the UK was a decade old and quite out of date given the growing number of African immigrants to the UK as a result of globalisation, war and conflict in recent years (De Haas, 2008; Kohnert, 2007; Owen, 2002, 2009).

Hence, 51 African embassies in the UK, Paris, and Belgium were contacted in November 2011 to obtain up-to-date data regarding the number of their respective nationals currently residing in the UK. The embassies of six countries were based in Paris; another four

embassies were based in Belgium and the remainder in the UK. It was not possible to locate embassies for Sao Tome or Somalia in the UK, Paris, or Belgium. The embassies were contacted by telephone and email and embassy officials were asked if they had accurate or estimated records to indicate how many people from their respective countries were currently living in the UK. In their responses, embassy officials emphasised that the figures were only a representation of what they had on their records. Further, the embassies of Mali and Zambia indicated that their records accounted only for the first migrating generation of their citizens.

Based on the information obtained from these officials, there are currently an estimated 1,613,157 Africans residing in the UK, accounting for 2.6% of the total UK population. The figures represent only estimates of the actual population of Africans in the UK, and numbers could be higher. For example, the 2001 Census listed 43,515 Somalis in the UK. Community leaders, however, estimate that there are currently around 110,000 Somalis living in the UK. However, as the Somali embassy could not be located, the figure of 1,613,157 African populations in the UK excludes Somalis. The largest numbers of African immigrants are from South Africa, Zimbabwe, Nigeria, Kenya, Somalia, and Ghana (See Table 1.2).

In 2012 statistics were released from the 2011 census, which reported that there were only 989,628 Africans living in the UK (Office for National Statistics (ONS), 2012). This difference of over 700,000 (1,613,157 + 110,000 – 989,628) could have a detrimental impact on decision-making relating to health services and to the design of culturally relevant preventative health promotion programmes.

Table 1.2: Estimated Number of African People Living in the UK-2011
Source: Telephone and Email requests Made by the Researcher for This Study

	Population			
Country	***2001 ONS***	***Embassy officials 2011***	***Community Leaders***	***Embassy based***
Algeria	10670	29000		London
Angola	5914	11000		London
Benin	239	1000		Paris
Botswana	2051	3000		London
Burkina-Faso	99	2000		London
Burundi	2022	4057		Belgium
Cameroon	3233	17000		London
Cape-Verde	328	1500		Liverpool
Central African Rep.	312	400		London
Chad	183	300		Belgium
Comoros	62	500		London
Congo	3266	6000		London
Congo, DRC	9000	11000		London
Cote d'Ivoire	2794	9000		London
Djibouti	237	300		Paris
Egypt	24700	27000		London
Equatorial Guinea	51	150		London
Eritrea	6561	22000		London
Ethiopia	7700	75000		London
Gabon	135	1200		London
Gambia	3924	4000		London
Ghana	56112	93000		London
Guinea	265	950		London
Guinea Bissau	x	1600		Kent
Kenya	129636	140000		London
Lesotho	331	6000		London
Liberia	1583	1800		London
Libya	9141	25000		London
Madagascar	789	2000		Paris
Malawi	12340	14000		London
Mali	121	3000		Paris
Mauritania	28	200		London
Mauritius	27078	50000		London
Morocco	12348	68000		London
Mozambique	3353	500		London
Namibia	1230	20000		London
Niger	96	200		Paris
Nigeria	88378	155000		London
Rwanda	2373	4000		London
Sao Tome	x	x		N/A
Senegal	723	1000		London
Seychelles	2905	4500		London
Sierra Leon	17048	20000		London
Somalia	43515	x	110000[1]	N/A
South Africa	141405	353000		London
Sudan	12,000	20000		London
Swaziland	863	500		London
Tanzania	32630	68000		London
Togo	553	1000		Paris
Tunisia	3070	1500		London
Uganda	55000	9000		London
Zambia	29000	4000		London
Zimbabwe	49524	320000		London
Total	**816919**	**1,613,157**		

[1] This figure is not included in the total sum as it was not obtained from embassy officials.

1.6 Caribbean people in the UK

Before the end of the slave trade, few people from the Caribbean settled in the UK. From 1948 onwards the numbers increased significantly with a mass immigration known as the '*Windrush generation*', named after the ship the Caribbean immigrants sailed on (Fraser, 1993). Smaje (1995) suggests that the colonial connection, the 1948 British Nationality Act, and recruitment to fill shortages in the labour market were the main factors for mass migration from the Caribbean islands into the UK. The 2011 Census currently estimates that 1,021,540 people of Caribbean heritage reside in the UK (ONS, 2012). While the 2001 census provided a breakdown of the numbers and origins of the Caribbean community in the UK, the 2011 Census has yet to provide data based on country of birth.

In 2001 (ONS, 2001), there were 565,876 people of Caribbean heritage living in the UK. More than half of these (304,950) were UK-born. The remaining 260,926 were Caribbean-born, with a large number from Jamaica (see Table 1.3). The near doubling of the Caribbean population in the UK from 2001 (565,876) to 2011 (1,021,540) is significant; however, it will only become clear whether this is a result of immigration or a native-born population increase once the 2011 census figures concerning country of birth are released. From a health provision perspective, healthcare professionals should be aware of this significant demographic change in order to provide relevant healthcare and health promotion services.

Table 1.3: Caribbean People Living in The UK By Their Country of Birth
Source: Office for National Statistics, 2001

Country of birth	*2001 ONS*
Anguilla	498
Antigua and Barbuda	3,891
Barbados	21,601
Dominica	6,739
Grenada	9,783
Guyana	20,872
Jamaica	146,401
Montserrat	7,983
Saint Kitts and Nevis	6,519
Saint Lucia	8,265
Saint Vincent and the Grenadines	7,091
Trinidad and Tobago	21,283
Total	**260,926**

1.7 Africa and the Caribbean: Population, Language, Culture, and Religion

1.7.1 Africa

The world's second-largest and second-most populous continent (Population Reference Bureau, 2011), Africa is home to at least 3,000 ethnic groups (Mbiti, 2003) and to a third of the world's spoken languages (Heine & Nurse, 2000). Christianity and Islam have the largest number of followers on the continent, with the Baha'i faith the third-most common religion practiced in Africa (Lee, 1997). Consequently, culture in Africa is diverse, with every African country divided into a mixture of tribes, each with its own unique language and practices. The continent’s best-known cultures include the Masai of east Africa, the Kalahari San Bushmen of southern Africa, and the Touareg of the Sahara (Mbiti, 2003).

Despite being rich in natural resources, Africa is the world’s poorest continent, with poverty, illiteracy, and poor healthcare affecting a large proportion of the population. The negative impact of communicable and infectious diseases on the continent's economic growth has been immense (The World Bank, 2008), as evidenced by the index of the

United Nations Development Program (2011), with 34 African countries listed under the low human development index.

1.7.2 The Caribbean

The Caribbean region is a collection of islands surrounding the Caribbean Sea, situated between North and South America. The region has strong cultural and historical connections to European colonisation, slavery, and the plantation system (Knight & Palmer, 1989). There are as many as 700 islands in the Caribbean and a total population of 39,169,962 (Population Reference Bureau, 2011). The majority of the population is black, but Chinese, white, Indian, and Arab populations exist in the region in large numbers. English and French are widely spoken languages in the region and Christianity is the predominant religion. Tourism and fishing represent the region's main economic resource (CIA World Factbook, 2013).

Following the abolition of slavery, the Caribbean region divided into a number of sub-regions, based mainly on colonial affiliation; e.g. the French West Indies, Spanish West Indies, and British West Indies (Knight & Palmer, 1989). In this study, "Caribbean" will refer to the major islands of the British West Indies, encompassing Anguilla, Antigua and Barbuda, Barbados, Dominica, Grenada, Guyana, Jamaica, Montserrat, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago. All the countries mentioned above were selected because immigrants from these countries can be found in most Caribbean communities in the UK (see Table 1.3) (Fraser, 1993).

1.8 Cancer in the Caribbean and Africa

1.8.1 Cancer in the Caribbean

Cancer is the third-leading cause of death in the Caribbean after cardiovascular and cerebrovascular disease (Phillips et al., 2007). Ecological factors and lifestyle changes have set cancer on course to become the main challenge for health services in the Caribbean in the coming decades (Aiken & Eldemire-Shearer, 2012; Phillips et al., 2007).

Prostate, breast, and lung are the most commonly diagnosed cancers and the leading causes of cancer mortality in the region (Ferlay et al., 2010b). In 2008, prostate and lung cancer accounted for 47.3% of the total cancer diagnosis among males. In the same year, 11,700 men died of these two types of cancer (Ferlay et al., 2010b), accounting for 44.7% of the total cancer mortality in males registered in the region. Jamaican men have the highest incidence rate of prostate cancer in the world (Phillips et al., 2007).

There are at least seven cancer registries in the region (Ragin et al., 2007); however, data on cancer incidence and mortality rates is not available from many of the Caribbean countries (Phillips et al., 2007), with a lack of adequate resources and expertise cited as the main reasons for inadequate data (Ragin et al., 2007).

Aiken & Eldemire-Shearer (2012) noted a trend of late cancer diagnosis in the black Caribbean community within the Caribbean, particularly among men. Since there has not been an investigation into the uptake of early detection and treatment programmes specific to black subgroups in the UK, it remains to be seen whether this trend, which is applicable to the UK black community as a whole, has also carried over to the Caribbean immigrant community .

1.8.2 Cancer in Africa

While cancer patterns throughout the world are well monitored, a lack of resources in Africa makes the tracking of the disease challenging, with few countries having the facilities to undertake cancer registration (Adebamowo, 2007; Parkin et al., 2003). Until recently, knowledge of cancer patterns in Africa was based primarily on the work of pioneering clinicians and pathologists as they encountered cancer sufferers (Ferlay et al., 2010b). For example, no cancer registers existed in Libya, Congo, Sudan, Ethiopia, Tunisia, and Liberia before 2003 (ACS, 2011b).

A number of reasons account for the difficulty in establishing cancer registers in African countries. For example, it is difficult to identify new cancer cases because they can only be registered when patients come into contact with health services, mainly referral hospitals; when resources are limited, the number of people who can access such institutions is restricted (Parkin et al., 2003). More recently, cancer registers have been established for most African Countries (Parkin et al., 2003), however they are not functioning efficiently (Adebamowo, 2007), making it difficult to obtain an accurate picture of cancer trends in Africa.

Although communicable diseases remain a focus for public health officials, cancer is now acknowledged as a critical health problem in Africa (UN, 2011). The ACS (2011b) points out that an increase in life expectancy and changes in lifestyle have contributed to the increase in cancer in Africa. Cervical, liver, Kaposi sarcoma, bladder, prostate, lung and breast cancer are the most common cancer types in the African continent (ACS, 2011b). In 2008, cervical cancer accounted for 21% of newly diagnosed cancers in females, and prostate and liver cancer combined accounted for 22.8% of new cancer cases in males (Ferlay et al., 2010a). The types of common cancers nonetheless vary in different parts of

Africa (see Figure 1.1). In eastern Africa, cancer of the oesophagus, Kaposi sarcoma, prostate, and non-Hodgkin lymphoma are the most frequently diagnosed cancers and the leading causes of cancer death in men. In contrast to eastern Africa, liver and prostate cancer were the most commonly diagnosed cancers and the leading causes of cancer death among males in western Africa (Ferlay et al., 2010a).

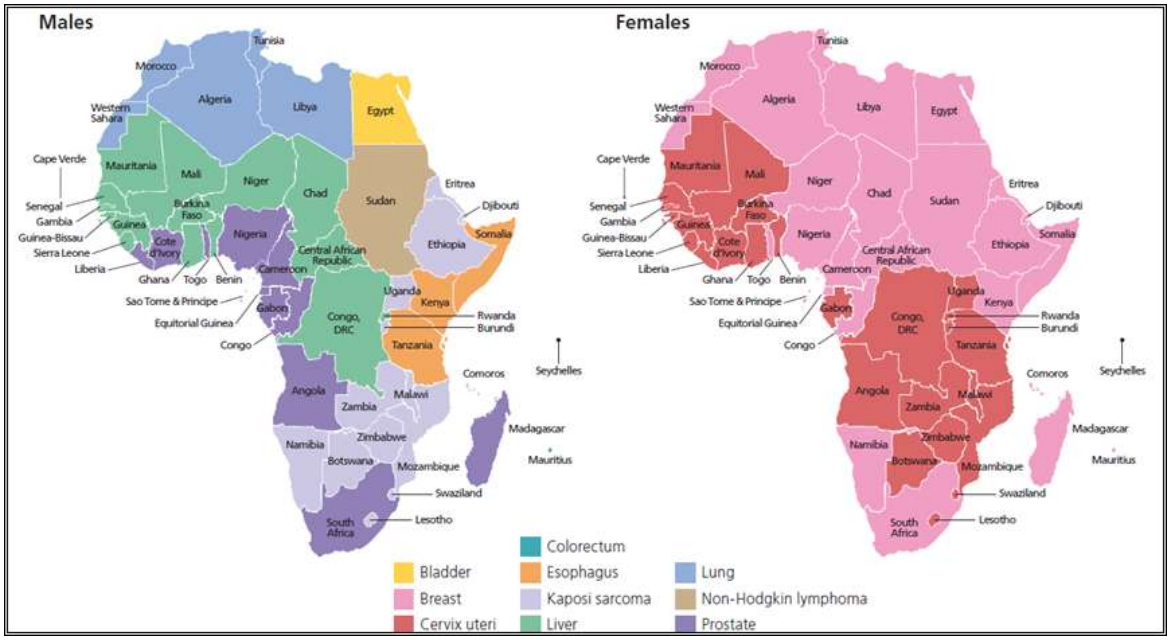

Figure 1.1: Most Common Cancer Sites in Africa by Gender, 2008
Source: Ferlay et al (GLOBOCAN), 2010b

1.8.3 Cancer prevention, treatment and care in Africa

In Africa, particularly in the sub-Saharan regions, healthcare priorities are dictated by infectious diseases like HIV. In combination with other factors, this makes it impossible for officials in the region to properly fund cancer care and treatment (Jemal et al., 2012). The majority of cancers (about 80%) in Africa are diagnosed at an advanced stage of the illness because of a lack of screening and early detection services, coupled with limited public health promotions about awareness of early signs and symptoms of cancer (Jemal et al.,

2012; Parkin et al., 2003). Stigma associated with a diagnosis of cancer also discourages people from seeking help early (ACS, 2011b).

Accordingly, African cancer mortality rates are very high and there is limited timely and standard treatment (Jemal et al., 2012). The availability of cancer treatment in Africa is also limited by a lack of a skilled workforce, surgical equipment, and radiation facilities (International Atomic Energy Agency, 2006). According to International Atomic Energy Agency (2010) data, 29 out of the 54 African countries have no radiation treatment centres. When countries do have facilities, many tend to be inadequate (ACS, 2011b). In 2002, cancer drugs were only available in 22%, and affordable in 11%, of 39 African countries (WHO, 2002).

The lack of exposure of Africans to adequate public health campaigns, early detection, and treatment programmes in their home countries might play a significant part in how African immigrants in the UK understand, explain and view cancer.

1.9 Black African and Caribbean men and cancer in the UK

Although a few studies have touched upon cancer incidence in the BA and BAC communities in the UK, in general, there are little data available specific to cancer morbidity and mortality within these subgroups (Cancer Research UK, 2009), making it difficult to minimise cancer care inequalities (DH, 2011).

An epidemiological study by Haworth, Raleigh & Balarajan (1999) shows high mortality from primary liver cancer among the African population in the UK. Evidence indicates that prostate cancer is more common among black men in the UK than any other ethnic group (Ben-Shlomo et al., 2008). Wild et al. (2006) conducted a cancer mortality rate review from

2001-2003, which found that mortality from prostate cancer was two-to-three times higher for men born in West Africa and the Caribbean than any other ethnic group.

A review of lung cancer mortality rates from 2001-2003 indicates that lung cancer deaths were higher in men than women for people born in Africa and the Caribbean (Wild et al., 2006). The same review found that while colorectal cancer mortality rates for Caribbean men were lower than the UK average, mortality rates for African men were higher than the national average (Wild et al., 2006); no reason is provided to account for these figures.

It has been suggested that these unaccountably higher mortality rates among BA and BAC men might relate to their cultures and to the way culture affects their views towards cancer, and accordingly their subsequent uptake of cancer-related services (DH, 2011; Pedersen et al., 2012).

Accordingly, this study aims to explore the influence of culture on the views of BA and BAC men living in the UK towards cancer, and to determine the role this influence may play on the low uptake of preventive healthcare services among these groups. It is hoped that the resulting evidence base could contribute to increased awareness of early symptoms and signs of cancer, through the design of effective culturally tailored public health campaigns, to which the African and Caribbean communities will be more likely to respond.

Chapter 2 **: Cancer Policy and Public Health Models**

2.1 Over view

This chapter provides an overview of public health and comprehensive information regarding public health in the UK in light of cancer policy documents. This information provides a policy framework for the study. The chapter will present the impact of cancer policies on cancer-related public health services, alongside how the current health and social care system reform is shaping these services with particular attention to black and ethnic minority groups. Section 2.3 of this chapter will focus on public-health promotion theories and models, presenting well-recognised and frequently used theories and models in public health promotion. It is important to mention that not all available public-health theories and models are included, only those that are considered to be potentially relevant to undertaking cancer-related health-promotion campaigns among black men. Limiting the number of theories and models included in this chapter was necessary for several reasons. Firstly, including all models and theories is not only impractical, but also does not bring any additional meaningful contribution to this study. Secondly, the aim of this chapter is not to examine the effectiveness of all public-health theories and models. Instead, the aim is to select those theories and models that could potentially be applied to cancer-related public health promotion among UK-based black men, and then to perform an initial assessment based on existing evidence about what is known in relation to black men in the area of interest. Further, the information in this chapter will become useful for discussing the most suitable model, based on the findings of this study, at a later stage of the research process (Discussion Chapter). The first section of the chapter, section 2.2 will commence below by defining the concept of public health.

2.2 Public health in the UK

The term ‘public health’ can be described as a discipline aiming to deal with wider health issues in society. Sir Donald Acheson defined public health as “*The science and art of preventing disease, prolonging life, and promoting health through organised efforts of society*." (The Facility of Public Health, n. d., p.7). Health improvement, health protection, and health-service delivery and quality are the three major domains of public health (Griffiths, Jewell, & Donnelly, 2005). While health improvement focuses on behavioural, socio-political and socio-economic influences of health, the focus of health protection includes environmental hazards and infectious diseases. The third domain, health service delivery and quality, focuses on issues including the planning, efficiency, effectiveness, and evaluation of health-related services (Griffiths et al., 2005). Accordingly, based on Griffiths et al.’s (2005) framework, cancer-related public-health policies and public-health promotions are mainly associated with the health improvement and health-services delivery and quality domains. While health improvement deals with the impact of individuals’ lifestyles and the impact of health inequalities, issues such as better cancer care, health promotion and early detection programmes fall under the health-services delivery and quality domain. However, the systems and strategies for carrying out tasks such as crafting health policy and health promotion are changeable, often based on the ideology of the government in office (Buse, Mays, & Walt, 2012).

In the UK, the last Labour government introduced two major cancer-policy documents: the ‘*Cancer Plan*’ (2000) and ‘*Cancer Reform Strategy*’ 2007 (DH, 2000, 2007). Policies in these documents recognised cancer-related inequalities faced by different groups of society, including black men. Despite good intentions, beyond recognition of existing inequalities, there was no substantial policy targeted at ethnic minorities to reduce inequality. However,

the '*Cancer Reform Strategy*' (DH, 2007) increased the emphasis and recognised that the lack of evidence on how to reduce cancer inequalities was a challenge. Consequently, in 2008 the National Cancer Equality Initiative (NCEI) and the National Awareness and Early Diagnosis Initiative (NAEDI) were established to tackle inequalities by providing evidence-based information to policy makers (DH, 2011).

Since the UK 2010 general election, the healthcare system within the UK has been undergoing some major reforms, in-line with the Health and Social Care Act 2012. Accordingly, the cancer policy documents '*Improving outcomes: A strategy for cancer'* and the public-health policy document '*Healthy lives, healthy people: Our strategy for public health in England*' have shaped the current public-health system (DH, 2010, 2011). '*Improving outcomes: A strategy for cancer*' is the main cancer policy document guiding the UK to successfully deliver cancer outcomes that match the best, or at least the average, survival rates in Europe by 2014 (DH, 2011). For the last decade, significant progress has been made in improving cancer services following the government's policies introduced in the '*Cancer Plan*' (2000), '*Cancer Reform Strategy*' (2007) and '*Improving outcomes: A strategy for cancer*'(2011). Referring specifically to cancer-related inequalities, the latter two documents identified the lack of evidence about the different causes of cancer-related health inequalities. In addition, the main challenge to combatting cancer-related health inequalities was a lack of evidence regarding the most appropriate and effective interventions to reduce them (DH, 2007, 2011). As a result, the current cancer policy document, '*Improving outcomes: A strategy for cancer*' particularly focused on cancer-related inequalities (DH, 2011), affirming the importance of NCEI and NAEDI for tackling inequalities by preserving these two public bodies as part of the new '*Public Health England*' (DH, 2011). There is, therefore, an expectation of improvement in cancer-related

services for minority groups, including black men, by engendering better understanding about minority groups, promoting more targeted health promotion, increasing the uptake of available cancer screening programmes and encouraging early diagnoses (DH, 2010, 2011).

The public-health policy document '*Healthy lives, healthy people: Our strategy for public health in England*' places local authorities at the centre of public health, by providing funding, alongside responsibility and freedom to improve local communities' health and to reduce health inequalities (DH, 2010). When the Health and Social Care Act 2012 came into effect in April 2013, several organisations, including the Health Protection Agency, Primary Care Trusts, the National Treatment Agency for Substance Misuse, and the Strategic Health Authorities were dissolved. The new '*Public Health England*' absorbed some of these organisations, including Regional Public Health Observatories and the Cancer Registries, which were responsible for cancer surveillance. These changes in the healthcare system and the NHS have brought about changes in the way that cancer-screening programmes and lifestyle programmes are commissioned. Cancer screenings are now mainly national programmes and include cervical, breast, and bowel cancers, for which commissioning responsibility has been transferred to the new '*Public Health England'*. Responsibility for commissioning lifestyle programmes, such as smoking-cessation services and alcohol-treatment services, designed to reduce cancer risks in the broader sense, has been transferred to upper-tier local authorities. However, at the local level, responsibility for public health lies with the Director of Public Health, who is employed by the local council. '*Public Health England'* does not have any authority over Directors of Public Health; it is there to support and oversee the Directors of Public Health in their work (DH, 2010).

Several local and national charities in the UK focus on cancer research, prevention, and care, including organisations like MacMillan Cancer Support and Prostate Cancer UK. As mentioned in the '*Healthy lives, healthy people: Our strategy for public health in England*' policy document, local authorities do not necessarily run health promotion campaigns, but they are responsible for commissioning them (DH, 2010). The commissioning of services is a complicated task since it includes contracting for what will be delivered and monitoring the contract to ensure adherence on the part of service providers. The services are run by a wide variety of organisations, some employed directly by the council, and some, including charity organisations, which are commissioned and funded by local councils. According to the DH (2010), such contracted services are local arrangements, based on local health-issue profiles, priorities, and needs. There are also some elements of cancer-related public-health promotion and prevention for which responsibility is held by the NHS, including general practitioner's (GP's) roles in cancer screening and increasing public awareness about cancer (DH, 2010). As a result of the current reform, cancer-related public-health responsibilities appear fragmented, making it unclear where certain responsibilities, such as improving cancer-related services for minority groups like black people, lie. Hence, not delegating the responsibility of commissioning or monitoring cancer-related services for all '*Black and Ethnic minority groups'* to one specific body could jeopardise the intention to reduce inequalities and to improve cancer outcomes as set out by the consecutive cancer policies '*Cancer Reform Strategy*' (2007) and '*Improving outcomes: A Strategy for Cancer*' (2011), and it could be argued that the absence of one designated body within current cancer policy and within the broader public health policies has made these policies less able to address black men's concerns.

Furthermore, according to Sir Donald Acheson's definition, effective public health requires '*organised efforts of society*' (The Facility of Public Health, n.d.), which emphasises the active participation of society. ONS (2012) statistics suggest that in total, black and ethnic minorities accounted for around 12 per cent of the UK population, of which the black population accounted for approximately three per cent of the UK population (Table 1.3). Hence, public-health policies need to give consideration to the views and participation of these black communities in society in order to improve the effectiveness of the policy. Consequently, the desire to reduce health inequalities could be more effective.

2.3 Public health promotion theories and models

In relation to the preferred ways of conducting public-health campaigns, there are an eclectic mix of public-health models to choose from, depending on the desired outcome required (Nutbeam, Harris, & Wise, 2010; US Department of Health and Human Services, 2002). The selection of a specific public-health campaigning model can also involve an ideological stance, ethical issues, and perceived effectiveness of the model (Local Government Association, 2013). The US Department of Health and Human Services (2002) classified frequently used health-promotion theories and models into three major categories: individual level, interpersonal level, and community level. By adding another category that focused particularly on health-related behavioural change in organisations, Nutbeam et al. (2010) classified health-promotion theories and models into four categories. After carefully reviewing the core concept of the most frequently used theories and models, those considered relevant for discussion in relation to this study were selected, namely the interpersonal-, individual-, and community-level categories used by the US Department of Health and Human Services (2002); (see Table 2.1 below).

Table 2.1: Most Frequently Used Health-promotion Theories and Models That May Be Relevant to Cancer-related Health Campaign among Black Men

Theories and models	Categories		
	Interpersonal Level	Individual Level	Community Level
	Social learning/social cognitive theory Theory of reasoned action Theory of planned behaviour	Stages of change/ transtheoretical model Health belief model Nudge theory	Organizational change theory Diffusion of innovations theory Ecological approaches Community organization model

2.3.1 Interpersonal level

The most common interpersonal-level public-health promotion theories and models are *social learning/social cognitive theory*, the *theory of reasoned action*, and the *theory of planned action*.

The '*Social Learning Theory*' assumes that behaviours are influenced by, or reflect, knowledge and attitudes; accordingly, people learn and obtain knowledge from the consequence of their behaviour (Bandura, 2001). This social learning theory concept demonstrates that behaviour is not only the practical reflection of knowledge, but is also one form of obtaining knowledge. Social learning theory suggests that people learn from one another by observation, imitation, and by regulating their action based on experience (Bandura, 1977). Hence, both direct experience and observation influence thought and behaviour (Bandura, 1977, 2001). Behavioural change is determined by the reciprocal interaction between people's environment and their individual personal factors, with great

importance of self-efficacy (Bandura, 1977, 2002; Nutbeam et al., 2010; US Department of Health and Human Services, 2002). Social learning theory is useful for explaining health-behaviour changes, by concentrating on individual characteristics (Nutbeam et al., 2010).

The concept of learning by observation or imitation from others in relation to the use of this particular theory to promote cancer-related health campaigns among black men could be problematic. Health-related knowledge in general revolves around an individual's awareness of a particular health condition, its symptoms, and available services and treatment options (St. Claire & Clucas, 2012). Based on this concept, since people's opportunities to access factual health information and their ability to use it effectively increases their health-related knowledge (Nutbeam, 2000); it can be assumed that rather than observation or imitation from others, cancer-related knowledge can be improved by increasing black men's access to health information and increasing their ability to use it effectively.

Introduced by Martin Fishbein and later developed by Fishbein and Icek Ajzen, the '*Theory of Reasoned Action*' focused on prediction of behaviour by 'measuring' the relationship between attitude and belief (Fishbein & Ajzen, 1975; Terry, Gallois, & McCamish, 1993). The core concept of this theory is that the combination of our belief about potential outcome and our evaluation of this potential outcome influences our attitudes towards particular behaviours. Consequently, our attitudes towards a particular behaviour (e.g., to avoid driving less than two miles) and our subjective norms (e.g., environmental and social norm not to drive) determine our intention to act (Fishbein & Ajzen, 1975; Nutbeam et al., 2010; Terry et al., 1993). As illustrated in Figure 2.1, the emphasis of this theory is that since humans are rational they make reasoned decisions, -but their reasoning is influenced by their attitudes and norm. Similarities can be noticed here with the Health Belief Model

(HBM) notion of perceived benefits encouraging people's health-related behavioural change.

Noticeably, the theory of reasoned action was applied in the 1980s to the development of health promotion targeted at reducing smoking among young people (Nutbeam et al., 2010); and reducing sexually transmitted infections including HIV (Nutbeam et al., 2010; Terry et al., 1993). The evaluation of the programme indicated that the outcomes were weaker than expected; instead the model has been useful in identifying factors that influence smoking-related behaviour that may need targeted intervention for better outcome (Nutbeam et al., 2010).

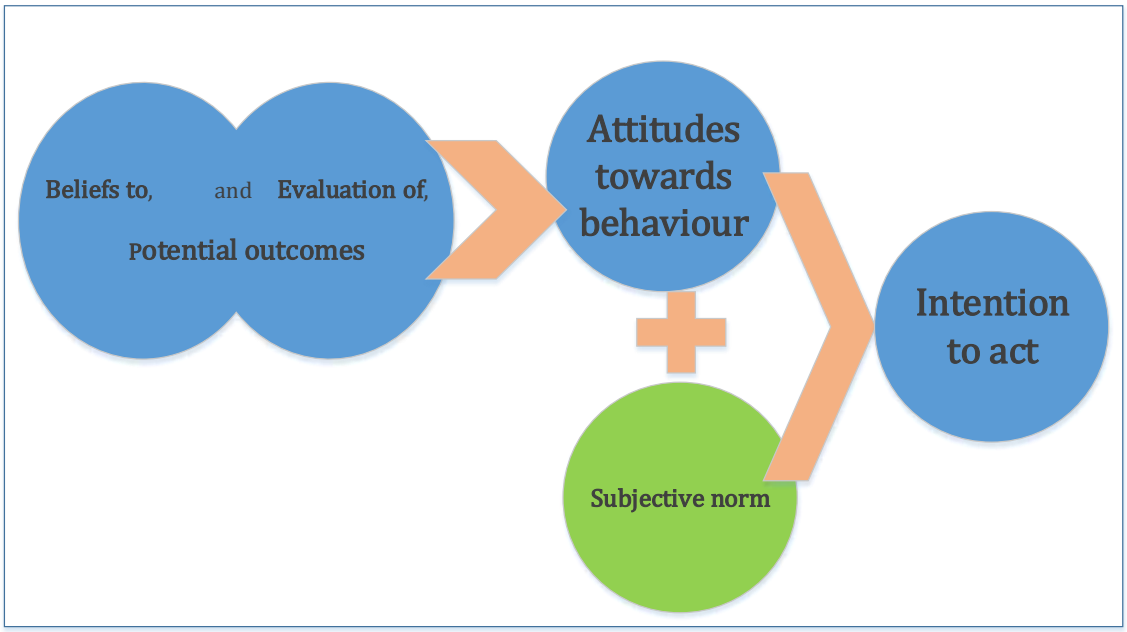

Figure 2.1: The Concept of the Theory of Reasoned Action

The '*Theory of planned behaviour*' is the refined product of the theory of reasoned action (Fazio & Petty, 2007). After recognising the complexity of the human decision-making process, Ajzen (1991) acknowledged that people's intentions to act are not only determined by attitudes and subjective norms, but also by what Ajzen defines as 'perceived behavioural

control' (Ajzen, 1991, 2002; Fazio & Petty, 2007; Nutbeam et al., 2010). Ajzen's concept of perceived behavioural control can be seen as similar to self-efficacy. The difference is that Ajzen's idea of 'perceived behaviour control' includes people's perceived power and control over opportunities and resources (US Department of Health and Human Services, 2002).

Accordingly, in relation to this present study, to develop cancer-related health promotion among black men based on the theory of reasoned action, it would firstly be vital to understand black men's views towards cancer, their beliefs about what the causes of cancer are, and their attitudes towards taking action to reduce the risk of cancer (attitudes towards a particular behaviour). It would be also important to identify the significant other and environmental factors that shape the decisions that could reduce the risk of cancer (norms). Furthermore, in light of the theory of planned behavior, black men's perceived behavioural control, such as perception of their control of opportunities and resources, is also important, and determines black men's intention to engage in activities that can reduce the risk of cancer such as unhealthy lifestyle and smoking. Based on the current available evidence, black men are less aware of cancer risk factors (Rajbabu et al., 2007). Thus, raising general cancer awareness needs to be the first phase of health promotion among black men. The 'theory of reasoned action' and 'the theory of planned behaviour' seem more appropriate for use during the second phase of cancer-related health promotion to maintain black men's awareness. These theories could be also used to encourage behavioural changes among black men by targeting specific behaviours using effective interventions gleaned from the past experiences of health-promotion programmes which applied these theories.

2.3.2 Individual level

As indicated in Table 2.1, '*Stages of change/Transtheoretical model', 'Health Belief Model*' and '*Nudge theory*' are included in this category. The Stages of change/transtheoretical model assumes that behavioural change is not an event, but rather a process of different stages of change, including maintaining the change of behaviour (Prochaska, 1984; Prochaska & DiClemente, 1982, 1984). Accordingly, there are six important stages of behavioural change: precontemplation, contemplation, preparation, action, maintenance, and relapse (Prochaska, 1984; Prochaska & DiClemente, 1982; Prochaska, Norcross, & DiClemente, 1994). This model recognises that since an individual's willingness to change is motivated by a number of factors, people can begin a behavioural change at any stage of these changes, so the model is circular (Nutbeam et al., 2010). As illustrated in Figure 2.2, the stage of change/transtheoretical model has two basic dimensions: stages of change and the process of change in each stage.

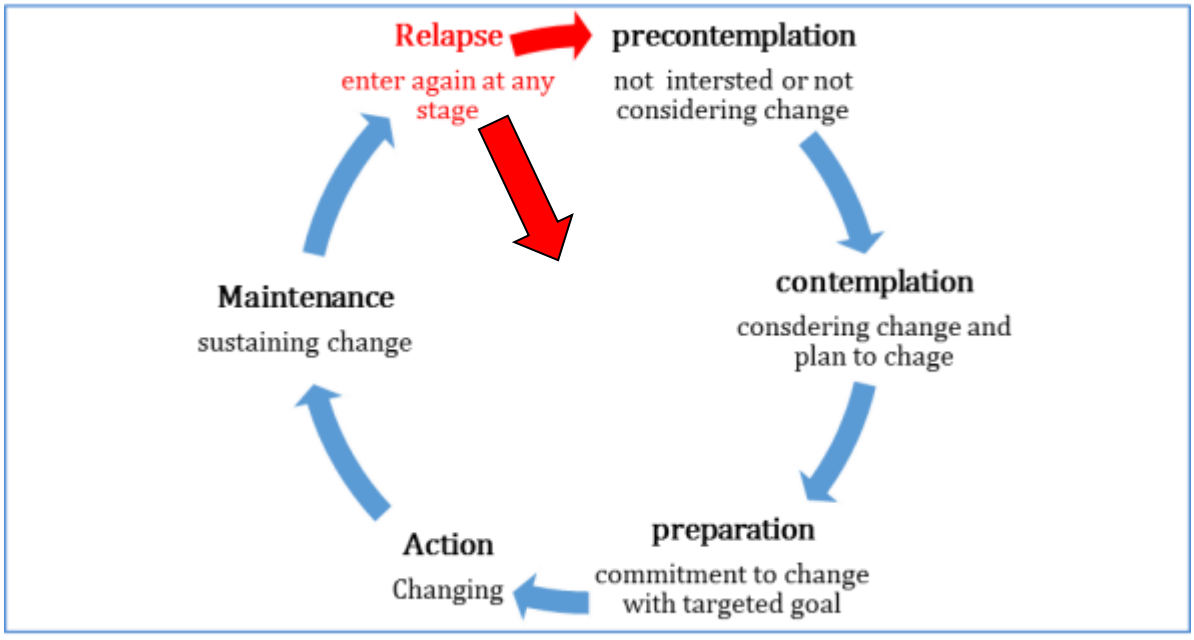

Figure 2.2: The Concept of Transtheoretical Model's Stages and Process of Behavioural Change

Source: Adopted from Prochaska and DiClemente (1982, p.283).

The stages of change/transtheoretical model can be applied across a wide range of health-promotion issues, including weight control, smoking, and other addiction habits (Nutbeam et al., 2010, US Department of Health and Human Services, 2002). As indicated in the systematic review by Bridle et al. (2005), the stages of change/transtheoretical model does not give enough attention to the 'complexity' of human behaviour change at different socioeconomic levels. Further, Bridle et al. (2005) suggested that this particular model is more effective in clinical settings, such as rehabilitation from addiction.

'The Health Belief Model' (HBM) is one of a wide range of models used to promote public health. HBM is a conceptual framework proposing that in order for individuals to protect themselves from a disease, they need to have knowledge, information, and the willingness to avoid health threats (Sheeran & Abraham, 2005; Zak-place & Stern, 2004). The HBM model assumes that knowledge is a predictor of action, i.e., if people become more aware and knowledgeable about a disease or health threat, they will consequently change their actions by calculating the health risks and the net benefit.

During the last two decades, many UK public-health campaigns, including cancer-related national campaigns (*Stop smoking*; *Obesity: watch your weight*; and *Healthy eating*) were based on a combination of the HBM and the '*Restricting Choice*' intervention, which focused on regulating and restricting people's choices, including banning smoking in public places and regulating the amount of salt that should be in a certain amount of food (Local Government Association, 2013).

More recently, the approach to dealing with public health, including cancer-related issues, has shifted from HBM and the restricting choice intervention to the '*Nudge Theory*' approach (Local Government Association, 2013). Based on the '*Healthy lives, healthy*

people: Our strategy for public health in England' document, a large part of public-health promotion is now the local authorities' responsibility. Using the nudge theory approach, local authorities are undertaking their responsibility to promote healthy lifestyles and to improve the local communities' health (DH, 2010; Local Government Association, 2013).

The nudge theory was introduced by Thaler and Sunstein (2008). Influencing people through subtle guidance to make a choice in a certain (default) direction is a core premise of the nudge model. It advocates liberalism over paternalism and encourages the government to act as a guiding hand for the public towards desirable behaviour, rather than restricting or banning individual choice (Thaler & Sunstein, 2008). This particular individual level model has attracted growing interest from a wide range of policy makers, from health to collecting tax revenue (Local Government Association, 2013).

All the above-mentioned models: the stage of change/transtheoretical model, the health belief model, and the nudge theory are often used to promote positive health behaviour at a personal, individual level (US Department of Health and Human Services, 2002). Although individual-level health promotion models are useful, they are not sufficient for understanding the multi-layered nature of people's cultural and religious views towards illnesses like cancer. After performing community-level health-promotion projects within the African-American community using an '*Afrocentric*' health-promotion model in her evaluation, Freeman, (2000) stated that using individual-level health promotion models (i.e. aiming the information at individuals hoping for a positive response) is counterproductive; because it reinforces in the victim the feeling they are being blamed and lacks the capacity to address multi-layered cultural meanings in African-American communities.

In contrast, community-level health-promotion models recognise multiple influences on health and health-related behaviour and offer a multi-level health promotion strategy (US Department of Health and Human Services, 2002). Hence, on the bases of this advantage, community-level health-promotion models were assumed to be more effective than individual level models in conducting cancer-related health promotions among black men.

Before providing detailed information about selected community-level health-promotion models, it is important to mention that the Afrocentric health-promotion model is not included among the selected community-level models for the following reasons.

The use of the community-level Afrocentric health-promotion model was effective in transforming the African-American communities' perceptions, using the '*whole village*' concept concerning HIV, stress, and nutrition (Freeman, 2000). In spite of Freeman's (2000) claim about the effectiveness of the Afrocentric community-level health-promotion model, there is very little evidence to suggest that the Afrocentric model is effective among black communities other than African-American communities, or indeed, communities outside the USA. Freeman, (2000) also pointed out that the Afrocentric model is a long-term process and measuring its outcome could be inconsistent from one community to another. Hence, the Afrocentric model was not considered a preferable option for application among UK-based black men and was excluded from the community level models listed below.

2.3.3 Community level

The '*Organizational Change Theory'*, '*Diffusion of Innovations Theory*', '*Ecological Approaches*' and '*Community Organization Model*' are the most commonly used models in community-level health promotion (US Department of Health and Human Services, 2002).

The organisational change theory advocates the involvement of institutions in public-health campaigns. Current USA-based studies suggest that black men preferred to access information from sources that were independent of healthcare institutes (Allen et al., 2007; Pedersen et al., 2012). Therefore, this particular model was assumed to be a less attractive option for influencing black men's interest in engaging with health-promotion programmes.

The diffusion of innovations theory revolves around the effectiveness of communication and innovations in spreading new ideas or a product gaining momentum, with the new idea or product being accepted over time. The momentum of the new idea or product impaled in the community will dictate whether, and to what extent, the community will change its behaviour (Rogers, 2003). There is no evidence to suggest any tangible reasoning for the diffusion of innovations theory to be considered as a possible model for effective health promotion among black men.

The *Ecological Approaches* assume that, as health is shaped by many environmental and social systems, such as family, community, finances, beliefs, traditions and social environments; effective health-promotion interventions must influence multiple levels (McLeroy, Bibeau, Steckler, & Glanz, 1988; US Department of Health and Human Services, 2002). Ecological approaches may be an ideal way of sufficiently enhancing cancer-health promotion, as they advocate minimised negative health behaviour, hand-in-hand with minimising environmental and social health hazards. A good example is educating young people about healthy eating; this is good health promotion to change behaviour at an individual level. However, if the school provides unhealthy meals, or if these young people live in an area where there are many fast-food outlets and both parents work full time with no time to provide healthy, fresh-cooked food, educating young people about healthy lifestyles would be a waste of time (McLeroy et al., 1988). The ecological

approaches recognise that to effectively promote public health, the strategy must be comprehensive to deal with wider social, economic, and environmental issues. However, when examined in relation to existing evidence about black men in the area of interest, this particular model appeared too broad, requiring extensive social, economic, and environmental reforms to be able to capture the views and concerns of black men in order to create effective cancer health promotion. Hence, although the model appears ideal in theory, it would require cooperation from different organisations, policy changes, and long-term ongoing monitoring. Moreover, it could create tensions within some beneficiary bodies, setting limits on its practicality. However, in theory this approach can be seen as one of the most relevant approaches that could be used to promote effective cancer-related health promotion among black men; subject to its compatibility to the findings of this present study.

The *Community Organization Model* assumes that active community participation is crucial to effective health promotion, ensuring that healthcare professionals, like public health workers, work together with the target community in identifying health and social problems, and in planning and implementing health promotion strategies (Braithwaite, Murphy, Lythcott & Blumenthal, 1989; WHO, 2009). The key factors in making the target community receptive to the health promotion are its willingness to share responsibility and authority. As the community organization model ensures communities' empowerment by including them in the health-promotion process, from planning to implementation, members of the community will have control over the health-promotion programme by sharing responsibility and authority (Braithwaite et al., 1989).

For the benefit of its community inclusiveness, a number of major public-health promotion programmes have been undertaken using the community organization model. For example,

in a number of sub-Saharan African countries, WHO and national public-health promotion packages using the community organisation model were implemented for HIV, maternal, and new-born health programmes (WHO, 2009). Braithwaite et al. (1989) also asserted that the community organisation model was an effective model of health promotion focused on healthy lifestyles within the urban black community in Atlanta, Georgia. In addition to its inclusiveness, as this particular model has been tried and tested in a number of geographical locations among different black sub-group communities, it is considered as potentially the most suitable model for use in promoting public health effectively among UK-based black men.

2.4 Summary

The purpose of this chapter was to explore and examine the most commonly used public-health promotion theories and models, in order to establish whether they could be effectively applied to public-health promotion among black men in the UK. Most common interpersonal, individual, and community-level public-health theories and models were examined. Based on the current available evidence regarding UK-based black men's knowledge of, and attitudes towards, cancer, a community-level approach to public-health promotion appeared more suitable than an interpersonal- or individual-level approach. From the four common community-level approaches, ecological approaches and the community organization model appeared to warrant further consideration. Based on the findings of this study, the most suitable community level approach will be discussed in Chapter 6 (Discussion).

Chapter 3 **: Literature Review**

3.1 Overview

In theory, pioneers and proponent grounded theorists have different views regarding whether a literature review should be undertaken before conducting the actual research or after finalising the data analysis process. Classic Glaserian grounded theorists, noticeably Glaser himself, reject the idea of conducting a literature review before completing data analysis in order to avoid discovering pre-conceived theory (Glaser, 2002; Glaser & Strauss, 1967). Although Strauss initially shared Glaser's view (Glaser & Strauss, 1967), later in his work with Corbin, he became more open-minded about issue of when the literature review should take place, as Strauss and Corbin (1990) focused highly on formulating the data analysis procedures of grounded theory. Charmaz (2006) realised the practical hindrance of attempting not to undertake the literature review before conducting the actual research (for example: gaining ethical approval, duplication of work), she also gives weight for Glaser's concern; and reconciles both thinking. Accordingly, she suggested that researchers walk into a research area with assumptions and cannot pretend to be a '*blank slate'*, but having an '*open mind*' is not the same as having an '*empty head*' (Charmaz, 2006).

Conducting a doctoral research study without carrying out an initial literature review is somewhat idealistic when considering the practical aspects of research projects such as funding, obtaining ethical approval, and the academic institution's policy to register a research project at a given time, and more importantly uncovering a knowledge gap, so that originality can be revealed in the final thesis. Hence, undertaking the literature review before data collection in this study is not a matter of inclination to a specific view but it has

been conducted for the practical reasons stated above. Also, at the outset of PhD study it is often not clear what methodological approach will be taken, as the research aims and objectives emerge from a literature review that identifies the gaps in our knowledge. Once the gaps in our knowledge have been identified and the unique contribution of the thesis has been established, a suitable methodological approach can be chosen.

The literature review aimed to systematically search the available literature for information about the views of black men living in the UK about cancer. It included significant past and current evidence on the topic. Starting with an outline of the objective of the literature review, this chapter will describe how the search was conducted, explain how the quality of included papers was assessed and, by synthesising the included papers, identify the knowledge gap in the current understanding of this study topic.

3.1.1 Aim of the review

The primary objective of this literature review was to extract papers that would identify the existing evidence base about BA and BAC men's views and attitudes about cancer including the causes of cancer, common risk factors, and awareness of early warning symptoms and early detection (screening). The literature review also attempted to present the current competent level of understanding about the subject area. Further, the literature included in the review would become a useful source for juxtaposing the results of the study when interpreting its findings.

3.2 Search strategy

Six medical and social science databases were searched to extract literature: Academic Search Complete, AMED, CINAHL, MEDLINE, Psyc Info, and Soc Index. After saving the search histories in these databases, weekly search alerts were created within each

database to ensure that new publications relating to the initial literature search were captured. However, since the initial literature review was conducted, no new relevant literature has been published that would add to the papers already included in this review. The search also included electronic journals, namely the Journal of Immigrant and Minority Health, Ethnicity & Health, and the European Journal of Public Health. In addition to that, the following sites were searched for healthcare policies and guidance, and evidence-based practice: ACS, Cancer Research UK, Cochrane library, DH, Gov.UK, NICE and Prostate Cancer UK. Cited references from the studies identified in the search were also used to extend the scope of the search. The search was limited to English-language studies. In order to increase the probability of including all relevant papers, the search was not limited by publication date.

Since the area of exploration was 'what are the views of black men in the UK regarding cancer?', with a focus on BA and BAC men's views and attitudes about the causes of cancer, common risk factors, and awareness of early warning symptoms and early detection (screening), relevant key words relating to the topic were used (Hek, 2006). Some of the terms included were: *African*, *African communities*, *African-Caribbean*, *black*, *black British*, *black African*, *Caribbean*, *minority groups*, *inner-city people*, *ethnic minority*, *cancer*, *cancer prevention*, *cancer screening*, *neoplasms*, *oncology*, *oncology care*, *screening programmes*, *views*, *culture*, *belief*, *social perception*, *delay in diagnosis*, *early diagnosis*, *knowledge*, *attitudes*, *behaviour*, *perception*, *awareness*, *health behaviour*, and *help seeking*.

The key words used to search for articles were further categorised into three groups: population, subject, and outcome (see Figure 3.1 and Table 3.1). This categorisation was carried out by adopting the concept of PICO (Population, Intervention, Control and

Outcome). PICO is a search technique recommended by Lewis et al. (2005) and Bhandari et al. (2002) in order to conduct effective searches that enable the literature review to cover a significant proportion of published works.

Table 3.1: Terms Used in Medline Ovid Database

Population	Subject	Outcome
Adult (MeSH)	Bowel Cancer (free text)	Attitude (MeSH)
Africa (MeSH)	Colonic neoplasms (MeSH)	Attitude of Health Personnel (MeSH)
African Americans (MeSH)	Colorectal neoplasms(MeSH)	Attitude to Health (MeSH)
African Caribbean (free text)	Colorectal cancer (free text)	Awareness (Me SH)
African Continental Ancestry Group (MeSH)	Lung Neoplasms (free text)	Belief (free text)
Black (free text)	Neoplasms (MeSH)	Culture (MeSH)
Black African (free text)	Prostate cancer (free text)	Comprehension (MeSH)
Black African Caribbean (free text)	Prostatic neoplasms(MeSH)	Health Behavior (MeSH)
Black British (free text)		Health Knowledge, Attitudes, Practice (MeSH)
Caribbean (free text)		Insight (free text)
Caribbean region (MeSH)		Knowledge (MeSH)
Emigration and Immigration (MeSH)		Social Perception (MeSH)
Ethnic Groups (MeSH)		Views (free text)
Minority Groups (MeSH)		
Minority Health (MeSH)		
Refugees (MeSH)		
West Indies (MeSH)		

As it was not the aim of this literature review to examine the effectiveness of any intervention, the use of terms relevant to '*intervention'* and '*control'* was not applicable and accordingly, the terms were replaced by '*Subject*'; population, subject and outcome (PSO) was adopted from the PICO concept. Table 3.1 shows the categorisation of MeSH (Medical Subject Headings) and free text terms used in the Medline Ovid online database, under the heading of population, subject and outcome. Likewise, Figure 3.1 shows the categorisation of keywords used to search literature in the remaining databases (Academic Search

Complete, AMED, CINAHL, Psyc Info, and Soc Index) by population, subject and outcome.

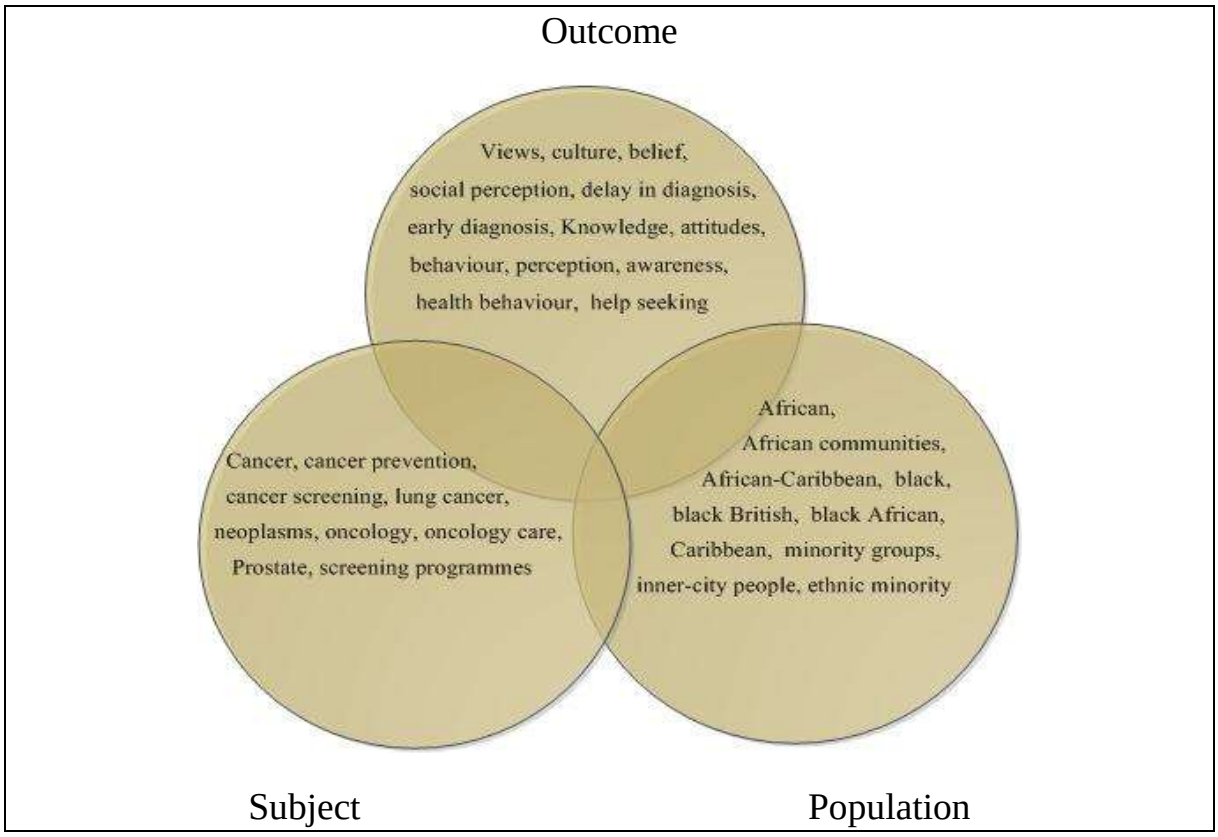

Figure 3.1: Key Words Used in Academic Search Complete, AMED, CINAHL, PsycInfo, and Soc Index Databases to Search Literature; Grouped into Three Categories (population, subject and outcome).

3.2.1 Inclusion and exclusion criteria for review

The inclusion and exclusion criteria used to select relevant papers is presented in Table 3.2. While most of the inclusion and exclusion criteria for the literature review are self-explanatory, the reason for excluding studies conducted among BA and BAC in Africa or Caribbean countries (the last exclusion criterion) might require clarification. As mentioned at the beginning of this chapter, the main objective of the literature review was to identify existing knowledge about the views of black men living in the UK, many of whom are

foreign-born[2] immigrants and their native born[3] descendants. As changes to geographical location (environment) and acculturation influence the formation of attitudes (Abraído-Lanza et al., 2006), studies carried out in Africa or in Caribbean countries among BA or BAC men are unlikely to explore the effects of acculturation or living in an adoptive country on participants' views towards cancer, making them irrelevant to the objective of this literature review. However, appropriate studies based in Africa or in Caribbean countries were used to establish the study background.

Table 3.2: Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Were written in the English language.	Focused on health issues other than cancer.
Provided an abstract (so that a decision could be made on content).	Focused on ethnic minorities in general or on other ethnic groups.
Abstract contained a substantial reference to Africans/BA men, or BAC men, or both.	Focused on cancer patients' and survivors' knowledge, attitudes, and experience.
Contained substantial references to views, knowledge, attitudes, and behaviour, or other similar terms, such as perception, opinion, and practice towards cancer.	BA men or BAC men mentioned 'in passing' but were not a significant focus.
	Black women and men were recruited but findings did not differentiate between genders.
	Concerned with study participants living in Africa or in Caribbean countries.

3.2.2 Search process and results

Using a combination of search terms (using Boolean operators including, 'AND', 'OR', 'NOT', '*', and '( )'), several search attempts were made to establish feasible initial search

[2] Foreign born refers to 1st generation immigrants who were born outside their adopted country.
[3] Native born refers to people who are 2nd, 3rd, or 4th generation descendants of immigrants.

results in the area of interest (see **Error! Reference source not found.** for an example of the search history).

Table 3.3: Example of Search History (Medline Ovid Database)

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present> Search Strategy:

	Search terms	Results (# of references)
1.	*Adult/	486
2.	*African Americans/	19761
3.	exp Africa/	170976
4.	African caribbean.mp.	391
5.	African Continental Ancestry Group/	29902
6.	Black.mp.	72938
7.	Black african.mp.	1146
8.	Black African caribbean.mp.	31
9.	Black british.mp.	35
10.	caribbean.mp.	8896
11.	exp Caribbean Region/	22158
12.	*"Emigration and Immigration"/	13385
13.	*Ethnic Groups/	17148
14.	*Minority Groups/	5528
15.	*Minority Health/	162
16.	*Refugees/	5027
17.	exp West Indies/	20108
18.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	**320426**
19.	*Colonic Neoplasms/	41005
20.	*Colorectal Neoplasms/	43506
21.	Colorectal cancer.mp.	50115
22.	*Neoplasms/	201644
23.	*Lung Neoplasms/	113717
24.	*Prostatic Neoplasms/	72555
25.	Prostate cancer.mp.	62915
26.	Bowel cancer.mp.	1407
27.	19 or 20 or 21 or 22 or 23 or 24 or 25 or 26	**493028**
28.	*Attitude/	18009
29.	*Attitude to Health/	34834
30.	*"Attitude of Health Personnel"/	42583
31.	*Awareness/	5991
32.	*Culture/	11147
33.	*Health Behavior/	15491
34.	belief.mp.	19961
35.	*Comprehension/	3250
36.	*Health Knowledge, Attitudes, Practice/	33655
37.	insight.mp.	98553
38.	*Knowledge/	2840
39.	*Social Perception/	8742
40.	views.mp.	46629
41.	28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40	**315863**
42.	19 and 27 and 41	**387**
43.	limit 42 to (male and humans and cancer)	**308**[4]

[4] This number [308] is reported as 296 in Figure 3.2 after omitting 12 duplicates references from this database. For a further explanation, see Appendix 1

After removing duplicate references, an initial search from all six medical and social science databases yielded a total of 654 references. The number of references yielded from each databases is shown in Figure 3.2. No empirical research papers emerged from the healthcare policies and guidance, and evidence based-practice websites (ACS, Cochrane, Cancer Research UK, DH, Gov.UK, NICE, and Prostate Cancer UK) search results.

Each of the 654 titles/abstracts were screened and assessed for their relevance on the basis of the inclusion and exclusion criteria. A total of 613 papers were excluded, as follows: studies were conducted among other ethnic groups such as Chinese, Latino and Haitian (98); studies focused on mixed ethnic minority communities and findings were reported as a representation of the views of ethnic minorities' as a whole (116); both black women and men were recruited but findings did not differentiate between gender (41); studies presented healthcare professionals' attitudes towards ethnic minority patients (61); studies were focused on access to healthcare service systems by minority groups and utilisation of healthcare such as mental health, drugs and alcohol (81); studies focused on other health issues, not on cancer (52); studies focused on religion and cancer and investigating how cancer patients view religion as a coping mechanism (19); studies focused on epidemiology and clinical practices, such as genetics tests (27); studies focused on cancer patients' and survivors' knowledge, attitudes and experience (31); papers presenting information on theories and models (25), and studies conducted in Africa or in Caribbean countries so participants were not perceived as immigrants (62). Hence, the remaining 41 papers were included in the review. Additional three papers were included in the review from hand searching, bringing the total number of papers to 44.

The breakdown of excluded and included papers from the search results is presented in Figure 3.2. Important information of each of these 44 papers such as research aim, method, sampling, number of participants and main findings are summarised and presented in Appendix 2.

Accordingly, the final stage of the search included 44 papers (24 quantitative, 16 qualitative, three mixed methods, and one systematic review). Most were conducted in the USA (n=39), with five conducted in the UK. Sample sizes of the target groups varied between studies, from 103 BA and BAC men out of 21,488 participants (Taskila et al., 2009) to all participants being BA men (Kumar et al., 2009; Odedina et al., 2009), depending on the studies' aims. Table 3.4 shows this variation by the frequency of studies.

Table 3.4: Participants' Demography by Ethnicity and Gender within Included Literature

Participants' demography	Number of studies	Note
African-American men	12	
African-American and white men	2	
African-American men and women	5	
African men	2	
African men and women	1	
Black men in general	4	
Black and white men	4	
Black, white and Hispanic men	2	
Men from different black subgroups	4	African American, Caribbean, Haitian, African men
Both genders, from different black subgroups	3	
Both genders, from different ethnic groups	3	White, Indian, Pakistani Bangladeshi, Chinese, mixed, Caribbean, African
Both genders, black and white	1	

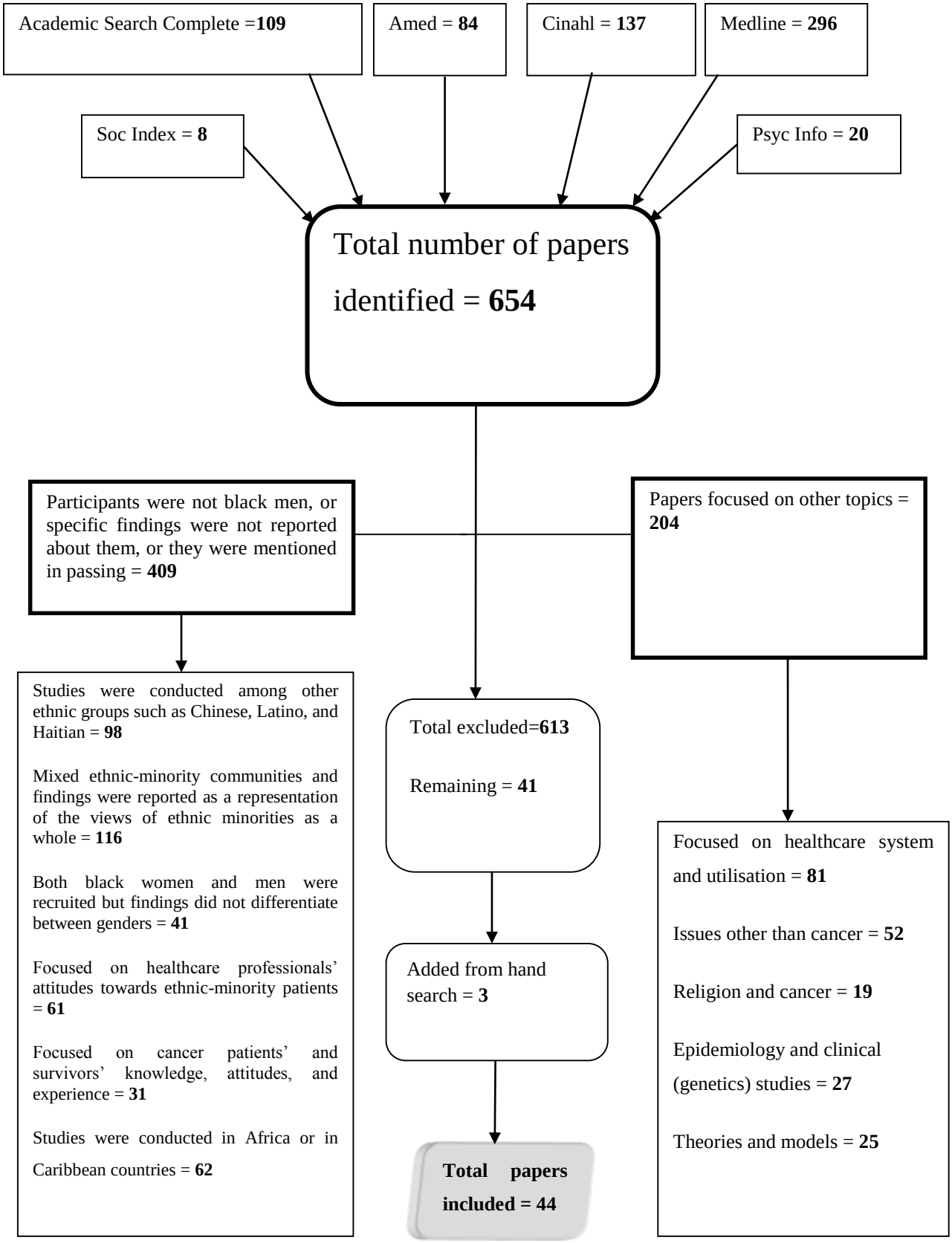

Figure 3.2: Breakdown of Excluded and Included Papers

3.3 Data extraction and quality assessment

A number of assessment tools were considered for assessing the quality of studies included in the literature review, including the Critical Appraisal Skills Programme (CASP), Consolidated Criteria for Reporting Qualitative Research (COREQ), and enhancing transparency in reporting the synthesis of qualitative research (ENTREQ). *Quality checklist for questionnaire surveys*, *Quality Assessment Tool for Quantitative Studies* and the *DARE Assessment Tool* were also considered for use in assessing quantitative research.

Ultimately, the system for mixed methods research and mixed studies reviews (SMSR) assessment tool by Pluye, Gagnon, Griffiths, & Johnson-Lafleur's (2009) was chosen to assess study quality, as it can be used to assess all research design types, including qualitative, quantitative, and mixed methods, thereby ensuring consistency. Assessment tools like CASP and *Quality checklist for questionnaire surveys* do not provide a rating system and there are no guidelines on how to comparatively rate studies, whereas the SMSR assessment tool gives a scoring and rating system (Pluye et al., 2009). The quality for all studies (43), excluding the systematic review (1), were assessed using SMSR's 15 core criteria. These 15 criteria are grouped into four methodological categories (see Table 3.5), allowing the quality of mixed method, quantitative, and qualitative studies to be assessed against each relevant criteria to the study design (Pluye et al., 2009).

The SMSR is based on a small number of basic quality criteria, listed in the unshaded section of Table 3.5, which all studies should fulfil. The shaded section of Table 3.5 is not a part of Pluye et al.'s (2009) original SMSR quality criteria table. It was added by the researcher of this study to show the limitation of the SMSR tool rating system, which requires the ordering of studies according to their total quality score (Pluye et al., 2009).

Based on Pluye et al.'s (2009) formula [# of yes/relevant criteria x100] for calculating the quality score, the results are always one of six numbers: 16, 33, 50, 66, 83, 100 (see shaded section of Table 3.5 below). For example, if a qualitative study paper has three 'yeses' for the presence of three relevant criteria out of six, its quality score will be 50% [(3/6) X 100]. Whereas a quantitative study paper that has the same number of three 'yeses' could score 100% [(3/3) X 100], as there are only three relevant criteria. Based on this scale, it is problematic to use the total quality score to classify whether the included papers were of poor, moderate, or high standard by ordering them in their sequence of total quality score. Therefore this concern was highlighted to Professor Pluye via email, (personal communication) with the possible solution of classifying papers with quality scores lower than 51% as 'low', between 51-70% as 'moderate' and greater than 70 % as 'high' quality studies. Professor Pluye agreed with this suggestion and granted the researcher of this study his endorsement to do so. Hence, the classifications were made accordingly (email exchange with Professor Pluye placed in Appendix 3). Professor Pluye also expressed his intention to look in depth at the issue raised above and subsequently informed the researcher of this study that funding had been secured for one of his students (Quan Nha Hong) to undertake work in this area (see Appendix 3).

Table 3.5: SMSR's 15 Criteria and Overall Quality Results Based on Pluye et al.'s (2009) Formula

Types of Study	Methodological Quality criteria	Quality score scale by %
1. Qualitative	• Qualitative objective or question • Appropriate qualitative approach or design or method • Description of the context • Description of participants and justification of sampling • Description of qualitative data collection and analysis • Discussion of researchers' reflexivity	With 1 yes = 16 With 2 yeses = 33 3 = 50 4 = 66 5 = 83 6 = 100
2. Quantitative experimental	• Appropriate sequence generation and/or randomization • Allocation concealment and/or blinding • Complete outcome data and/or low withdrawal/drop-out	With 1 = 33 2 = 66 3 =100
3. Quantitative observational	• Appropriate sampling and sample • Justification of measurements (validity and standards) • Control of confounding variables	• As above
4. Mixed methods	• Justification of the mixed methods design • Combination of qualitative and quantitative data collection-analysis techniques or procedures • Integration of qualitative and quantitative data or results	• As above

The quality of included qualitative, quantitative and mixed methods studies was assessed using the three steps for scoring and reporting recommendations in Pluye et al. (2009). The first step was assessing the presence or absence of each criterion in the paper, with the presence/absence of the criterion scoring 1 and 0, respectively. In the second step, a 'quality score' calculation was carried out, represented as a percentage [(number of 'yes' responses divided by the number of 'relevant criteria' for the research approach) X 100] For example, a good qualitative study that scored 1 for the presence of each six relevant criteria could score 100% [(6/6) X 100]. The final step was to classify the overall rate as 'low', 'moderate', or 'high' quality. Studies with a 'quality score' greater than 70% were classified as 'high', 51-70% were classified as moderate, and less than 51% were classified as low, as reported in Appendix 2. A detailed quality assessment scoring and the overall

'quality score' of each paper is provided in Appendix 4. (The heading of this table is colour coded to show which criteria are relevant to which type of study; green for qualitative, yellow for quantitative, and red for mixed methods study.)

As qualitative studies were included in this review, it is important and relevant to mention the hierarchy of evidence pyramid. According to the Centre for Reviews and Dissemination (2008), meta-analyses and systematic reviews of randomised controlled trials (RCTs) are the gold standards for top-rated quantitative research, followed by controlled trials. If information from controlled trials is not available, the hierarchy of evidence in the pyramid goes from cohort studies to case-control studies, cross-sectional surveys and case reports (Centre for Reviews and Dissemination, 2008; Rosner, 2012). Findings are considered more robust if the study is rated higher in the methodology hierarchy. Twenty-four quantitative studies were included in this review, all of which were surveys. Based on the evidence pyramid, the findings of these studies might be considered less robust than findings from RCTs (Rosner, 2012). However, it is important to note that the area of exploration was not concerned with the effectiveness of an intervention; rather it focused on experience and opinions, which do not lend themselves to an RCT study design.

As explained above, the quality of 43 out of 44 papers was assessed against SMSR criteria. Based on the SMSR assessment tool's parameters, 26 studies scored 'high' and 15 studies were of 'moderate' quality. Two studies scored as 'low'; however the participants (BA and BAC men) and the research findings of these low quality-rated studies were significantly relevant to this study. Thus, both low quality papers were included in the review.

The quality of one included systematic review paper was assessed as high quality using preferred reporting items for systematic reviews and meta-analyses (PRISMA), which is a

tool validated in healthcare research and reviewed constantly (Moher, Liberati, Tetzlaff, & Altman, 2009).

3.4 Syntheses of included papers

The findings of included papers were synthesised using a narrative synthesis approach; an approach considered best for the synthesis of findings from multiple studies when statistical meta-analysis or meta-ethnography analysis is not feasible (Dixon-Woods et al., 2004; Popay et al., 2006; Pope, Mays, & Popay, 2007). The narrative synthesis method was used based on guidance provided by Popay et al. (2006) which provides the tools and techniques for conducting narrative synthesis in systematic reviews.

Most of these tools and techniques are simple, but some require cross-referencing and/or in-depth understanding and experience in conducting systematic reviews (evidence-based healthcare), making them less appropriate for the less advanced reviewer. While having a choice of tools and techniques for each phase of the synthesis can be helpful, it can also be overwhelming as the reviewer must find convincing reasons to use or not to use a particular tool or techniques.

Popay et al. (2006) encourage assessing the robustness of the synthesis as the final stage, to make the systematic review a convincing piece of evidence for policy change. There are several tools and techniques for assessing robustness of the synthesis: 1) Weight of Evidence, e.g. the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI) approach; 2) Best Evidence Synthesis (BES); 3) Validity assessment, e.g. The Centres for Disease Control and Prevention (CDC) approach; 4) Critical reflection on the synthesis process; and 5) Checking the synthesis with authors of primary studies (Popay et al., 2006). Using these tools and techniques is time consuming, labour intensive, and

requires an established team of reviewers (Pope et al., 2007). As the objective of this literature review was not to produce a policy-changing systematic review, and this study has resource constraints, assessing robustness was challenging.

Narrative synthesis is open to bias and data exploitation (Pope et al., 2007). Particularly during the construction of a common rubric process, the practice of transforming quantitative results to qualitative or vice-versa is exposed to the reviewer's subjective judgment. For example, if 45% of participants demonstrated positive attitudes towards cancer screening services, this result can be transformed into qualitative (textual) statements in different ways, making the approach open for quantitative data exploitation. Nevertheless, Pope et al. (2007) argue that applying different statistical techniques exposes quantitative study results to exploitation anyway, so this weakness is not unique to the narrative synthesis approach.

Narrative synthesis is a useful tool for undertaking a systematic review on a wide range of questions. It also allows for conducting literature (evidence) reviews from a variety of research designs on a given topic (Pope et al., 2007). As this literature review included a variety of research designs, a mixture of a systematic review, mixed method, qualitative, and quantitative studies, using narrative synthesis appeared the most suitable approach.

The guidance provided by Popay et al. (2006) particularly focused on how to carry out narrative synthesis in reviews of evidence on the effectiveness of interventions, and evidence concerning the factors influencing the implementation of interventions. However, the approach can also be adapted to review evidence from other types of review questions; for example, the health needs preferences of particular section of society (Popay et al., 2006).

The first task in the approach is the selection of the specific tools and techniques provided in the guidance. This selection is determined mainly by the nature of the review question and resources such as time, expertise and human power (Pope et al., 2007). With the help of the description provided for each available tool and technique and after cross-checking the recommendation in Dixon-Woods et al. (2004); Popay et al. (2006); and Pope et al. (2007), the following tools and techniques were selected for undertaking the synthesis process.

Groupings and clusters: This tool was selected to conduct the first stage of the process. Studies were grouped based on the nature of the results being reported, such as knowledge about prostate cancer and attitudes towards digital rectal examination. Next, findings in the studies relevant to the review question were highlighted and initial coding performed. At this stage some study findings had a single code and some had multiple codes.

Transforming data to constructing a common rubric: As qualitative, quantitative and mixed method studies were incorporated in this review, it was necessary to transform qualitative findings into quantitative form, or vice-versa, to construct a common rubric for the synthesis (Popay et al., 2006). In this phase of the synthesis, quantitative findings were transformed into qualitative findings. For example, the findings of the Jones et al.'s (2005) quantitative study showed that only 10% of black participants perceived their risk for prostate cancer as high. This was transformed to a majority of black participants were unaware of the high risk of prostate cancer in black men. Then, based on the initial coding, findings were re-arranged and a list of sentence and/or phrases was written separately under the given code in order to conceptualise common headings. Thus, broader headings were created.

Exploring relationships within and between studies: The main focus in this stage was to explore the frequency of findings, the recurrence of idea across studies, different presentations of findings that might interlink, or contradictory findings on the same topic. This process led to the development of an overall picture of descriptive synthesis about black men's views towards cancer. The major emerging themes were established on this basis.

Exploring the influence of heterogeneity: to identify and examine the potential sources of variations and then to provide context for the major themes and factors that could magnify the diverse findings. This included differences in methodology, data collection methods, and the kinds of questions asked. More focus was given to participants' socio-demographic, cultural and origin variances, which could affect participants' views towards cancer. At the end of the process, five important themes emerged from the literature synthesis: knowledge about cancer, attitudes towards cancer screening, knowledge and attitudes towards cancer according to participants' country of origin, mistrust, and culturally sensitive information needs.

3.4.1 Knowledge about cancer

The literature review indicated that there were differences in research findings regarding black men's knowledge of cancer. The majority of the studies indicated that overall, black men had low levels of knowledge about causes of cancer, hereditary cancer and available screening for cancer (Agho & Lewis, 2001; Bloom et al., 1989; Chan et al., 2003; Clarke-Tasker & Wade, 2002; Ford et al., 2006; Forrester-Anderson, 2005; Friedman et al., 2009; Green & Kelly, 2004; Jones et al., 2005; Richardson et al., 2004; Waller et al., 2009; Weinrich et al., 2007; Woods et al., 2004). Four papers indicated that the sample group, black men, had adequate knowledge about common cancer types and identified some of the

risk factors of cancer (Blocker et al., 2006; Forrester-Anderson, 2005; Magnus, 2004; Odedina et al., 2009).

However, a result of one study carried out by Fearing et al. (2000) to investigate health beliefs and practices among African-American men regarding prostate cancer screening reported that participants had a high level of prostate cancer knowledge. One significant factor unique to the study's participants was that a majority, 86% of the 59 participants, visited private physicians on a yearly basis; the majority of them were comfortable with discussing health problems with their doctor and had screening during their visits (Fearing et al., 2000). Conversely, participants of the Green and Kelly (2004) survey, who were in a similar age group to that of the participants in Fearing et al. (2000), demonstrated low levels of knowledge about cancer. The design for both of these studies was a survey. The main difference in participant characteristics was that Green and Kelly (2004) recruited their participants from a low-income background. More importantly, participants in Green and Kelly (2004) study did not think their doctors helped them in gaining information about cancer and cancer screening.

One of the common characteristics of these two studies was that they were conducted in the USA, where healthcare is provided mainly by the private sector, with higher-income participants more likely to have the ability to pay and to utilise the healthcare system than lower-income participants, resulting in very different experiences and perceptions regarding cancer. In contrast, individuals from low-income backgrounds had limited financial resources for utilising the healthcare system (Bloom et al., 1989; Parchment, 2004). As a result, there were fewer interactions and opportunities to form meaningful doctor-patient relationships, which are vital for informing participants' knowledge regarding cancer and for accessing cancer screening programmes (Odedina et al., 2011a; Oliver, 2007; Woods et

al., 2004). Thus, it can be argued that income could affect participants' relationships with their doctors. Consequently their chance of acquiring cancer-related information was minimal.

Participants' age was another important influencing factor concerning the variation of black men's knowledge about cancer. Bloom et al. (1989) conducted a survey by randomly selecting 1,137 black participants. Although the overall findings suggested participants demonstrated a low level of knowledge, in comparison, older participants were more knowledgeable than younger participants. The same pattern was also reported among participants in the qualitative study carried out by Clarke-Tasker and Wade (2002) using focus-groups. Hence, the participants' age, income and doctor-patient relationship were possible factors accounting for variations in black men's knowledge about cancer.

The findings of studies that assessed cancer-related knowledge among black and white men showed that the knowledge difference between these two groups changed over a period of time. A 1995 survey of 1,504 black and white men showed that there were similarities among black and white men regarding knowledge of prostate cancer (Demark-Wahnefried et al., 1995). However, relatively recent surveys suggested that African-American men (Chan et al., 2003) and non-Hispanic black men were less knowledgeable than white men about prostate cancer, its risk factors and screening for it (Jones et al., 2005). A UK-based study carried out among black and white men also suggested that black men had poorer knowledge of prostate cancer than white men, but after receiving 'targeted educational information' as part of the study, there were significant improvements in their knowledge, risk awareness, and attitudes towards prostate cancer (Rajbabu et al., 2007).

3.4.2 Attitudes towards cancer screening

Black men's negative attitudes towards cancer screening were a major barrier to prostate and colorectal cancer screening (Consedine et al., 2011). Black men perceived screening as a threat to their masculine identity, associated with homosexuality (Allen et al., 2007; Blocker et al., 2006; Clarke-Tasker & Wade, 2002; Oliver, 2007), and considered it a painful and undignified procedure (Allen et al., 2007; Fyffe et al., 2008). The findings of one USA based study indicated that, although awareness of cancer screening tests and risk perception were low across all black subgroups, native-born participants had better awareness compared with foreign-born participants (Gwede et al., 2011).

Studies carried out among black and white male participants suggested variation regarding which ethnic groups associated screening with a greater degree of embarrassment. In some studies embarrassment and fear of prostate cancer screening were higher among black men (Chan et al., 2003; Lee et al., 2011). However, another USA based qualitative study conducted among African-American and white men suggested that fear of prostate cancer was not associated with race; rather, it depended on the participants' education level (Winterich et al., 2009).

Studies comparing attitudes towards cancer screening between different ethnic minority groups reported that BAC participants had high levels of fear and embarrassment about colorectal cancer screening (Austin et al. 2009). When a comparison was carried out between black subgroups, levels of fear, embarrassment, and profound violation of norms, which could in turn be taken as evidence of homosexual behaviour, were higher among BAC participants, and particularly among Jamaican men (Consedine et al., 2009; Consedine et al., 2011). This seemed to indicate that while BA and BAC men share certain attitudes towards cancer screenings, a micro level analysis shows that there are differences

in the degree to which BA and BAC men perceive cancer screenings. The inference within the literature suggests that this is related to their upbringing, culture, and social norms.

3.4.3 Knowledge and attitudes towards cancer and cancer screening by place of origin

The review showed differences between native-born[5] and foreign-born[6] black men's knowledge about cancer, in perceptions of curability, and in preventive practices. Native-born black men had the highest knowledge of cancer when compared with African-born and Caribbean-born black men (Odedina et al., 2011b). Further, the same study indicated that African-born black men's knowledge was lowest among the three groups, but they were most likely to discuss prostate cancer risk reduction and early detection with African doctors (Odedina et al., 2011b). The Odedina et al. (2009) study, using participants recruited in the USA and Nigeria, showed significant differences in knowledge and attitudes between Nigerian men in the USA, Nigerian men in Nigeria and African-American men in the USA. Although African-American men had higher levels of knowledge about prostate cancer, the Nigerian men in the USA showed a positive attitude by being more willing to attend prostate cancer screening than the two other groups (Odedina et al., 2009). It is interesting that while African-American men had better knowledge levels, their knowledge did not inform their attitudes; but the reason for this was not reported in the study. Odedina et al.'s (2009) study employed a survey questionnaire, which was not a suitable method for exploring the underlying causes of such findings.

Cancer-prevention practices differed by place of origin. Foreign-born black men reported using specific herbs, bush tea, body cleansing products such as laxatives (aloe vera, castor oil), and fasting as means of preventing cancer. This was not practiced by native-born black

[5] Native born refers to people who are 2nd, 3rd, or 4th generation descendants of immigrants.
[6] Foreign born means refers to 1st generation immigrants who were born outside their adopted country

men (Gwede et al., 2011). This difference in cancer-prevention engagement can be viewed from different perspectives. Firstly, foreign-born black men's engagement in supposedly preventative activity could be a reflection of positive attitude, as it is evident from the Odedina et al. (2009) findings that Nigerian men in the USA were more willing to attend prostate cancer screening than native-born African-American. Secondly, it could also be the lack of information about early detection programmes or preference towards alternative preventative measures over conventional medical practices.

3.4.4 Mistrust

Mistrust of the healthcare system and health professionals emerged as a main issue of concern for black men. Regardless of their place of origin, black men appeared to mistrust the healthcare system (Pedersen et al., 2012). Nearly 40% of respondents in Woods et al. (2004) study perceived that the healthcare system did not help black men, and 75% of Parchment's (2004) black participants believed that their doctor did not encourage them to attend regular screening. Black male participants reported this concern in many studies and believed the healthcare providers lacked responsiveness to black men's needs (Allen et al., 2007; Clarke-Tasker & Wade, 2002; Ford et al., 2006; Janz et al., 2003; Odedina et al., 2011a). The historical mistreatment of blacks in the USA healthcare system, as detailed in the Tuskegee Syphilis Study, continues to be a major source of mistrust (Allen et al., 2007; Forrester-Anderson, 2005; Oliver, 2007). Tuskegee Syphilis Study is one of the highly controversial longitudinal clinical study conducted among black American men lasted for 40-year. Researchers intentionally withheld Syphilis treatment and information about it from their participants who assumed they were granted free healthcare from the government (Brandon et al., 2013; Savitt, 1981).

Black men believed that it was the intent of the government to deliberately distribute cancer to the black community (Forrester-Anderson, 2005). One obvious explanation is that, as a result of the betrayal involved in the Tuskegee study where treatment was purposely withheld from black men while they thought they were receiving free healthcare funded by the USA government, black men now hold a very suspicious view towards the authorities and authority figures. Furthermore, the tendency to view healthcare professionals as the authority (Allen et al., 2007) could make black men's mistrust even more profound. Consequently this could influence the desire to seek and access information from doctors and other healthcare professionals, as well as negatively influence the low uptake of cancer screening in the USA by black men, thus potentially resulting in a high level of morbidity and mortality. In the UK context there is no evidence of a similar event triggering such mistrust. Thus the evidence from the USA cannot fully explain the reason for low uptake of cancer screening by black men in the UK, although there is the potential for UK black men to be aware of such unethical studies have taken place within Western healthcare systems.

3.4.5 Culturally sensitive information needs

Black male participants reported media outlets such as TV and radio and doctors in primary care to be their main source of information with regard to cancer (Allen et al., 2007; Gwede et al., 2011; Woods et al., 2004). Black male participants in the Gwede et al. (2011) and Woods et al. (2004) studies reported that most of the information presented to them about cancer through these sources was not presented in a manner that would make them take the information seriously. In particular, the presenters used and the manner in which they presented the information were considered by black men to lack relevance. Lack of culturally tailored linguistic and symbolic information available to black men was reported as one of the main reasons behind black men's poor knowledge of cancer (Agho & Lewis,

2001; Woods et al., 2004). Findings from the majority of studies suggested that black men were willing to learn more about cancer (Carter et al., 2010; Elmubarak et al., 2005; Green & Kelly, 2004; Gwede et al., 2011; Odedina et al., 2011a; Powe et al., 2009); however, as black men had an inherent mistrust of the healthcare system, black men showed their desire to access information from other sources that were independent of the healthcare system (Allen et al., 2007). Churches and barbershops were noted by black men as preferable locations for acquiring cancer information (Ford et al., 2006; Friedman et al., 2012). As to the format, they preferred verbal rather than printed information (Woods et al., 2004), or DVDs (Friedman et al., 2012; Gwede et al., 2011). These preferences can be seen as good indicators of whether the healthcare system is behind or ahead of society's needs and also offers suggestions for making the necessary adjustments to meet user needs.

3.5 Discussion of literature synthesis

Evidence from the included papers showed, with few exceptions, a low level of knowledge about cancer risk factors, cancer illness, and available cancer screening services across all black subgroups, particularly in BA and BAC men. Black men—and particularly BAC men (especially from Jamaica) frequently demonstrated negative attitudes towards prostate and colorectal cancer screening, mainly due to perceptions regarding masculinity and sexual orientation, embarrassment, and the discomfort of the procedure.

Mistrust of healthcare professionals was noted in a number of studies as a major issue across all black subgroups, with a possible explanation for these views being the lack of culturally tailored factual information relevant to black men on the common risk factors of cancer, warning signs, symptoms, and early detection. When cancer-related information

was channelled to the black community, who delivered it and how it was delivered was important.

Although previous studies provided insights of BA and BAC men's views towards cancer, there were a number of limitations. Nearly half (21) of the studies' target groups were African-American men. This black subgroup has cultural similarities and differences with other black subgroups such as BA and BAC. These differences or similarities were determined by whether the researcher wanted to approach the subject of cultural background from a macro or micro level. At the macro level, for example, Odedina et al. (2011a) carried out a cross-sectional survey by recruiting 3,430 black men without attempting to differentiate between black subgroups. The study explored the personal factors related to prostate cancer risk reduction and detection behaviours among black men in general. Conversely, at the micro level, in their (2011b) paper, Odedina et al. used the same data with a different analysis focus, exploring the ethnic variations among USA-born, African-born and Caribbean-born black men in relation to prostate cancer risk reduction behaviours. These two publications demonstrate that grouping people under one umbrella term on the basis of similar characteristics (in this case skin colour) or obvious differences (place of origin) generates knowledge that cannot be applied cross culturally. Therefore, the findings of studies that were focused only on African-American men may not be applicable within the UK context.

From 44 included papers, only 14 studies included participants who were BA or BAC men, or both. Of these 14, the majority of studies presented the target groups' views towards cancer in a comparison with other ethnic groups (see, for example Austin et al., 2009; Consedine et al., 2011; Waller et al., 2009). This comparison was made by recruiting small BA and BAC samples, for example, 29 BAC men out of 245 participants in Consedine et

al. (2011) and 20 Africans among 528 participants in Magnus (2004). As a result, the intention to investigate thoroughly the views of BA and BAC men's about cancer was compromised and the information gathered from these studies about BA men's and BAC men's views was minimal.

Moreover, very little work has been done in the UK, with most research conducted in the USA. These findings from the USA may not be applicable to the UK-based black community, for the following reasons. Firstly, healthcare provision in the UK is mostly available as a public service, rather than through the private sector as in the USA. This difference is likely to impact on findings, as unlike in the USA-based studies by Fearing (2000) and Green and Kelly (2004), ability to pay may not be a major barrier to accessing public healthcare service in the UK. Secondly, African communities in the USA were established as an outcome of slavery, while in the UK they were established as a result of settlement following immigration from the commonwealth nations to meet workforce shortages. This factor interlinks with acculturation, nativity, acceptance and rejection; it could significantly affect the formation of attitudes by BA and BAC men about their place in the healthcare system and the way its provisions relate to them (Abraído-Lanza et al., 2006; LaVeist & Isaac, 2013; Savitt, 1981).

Thirdly, the review demonstrates African participants in the US studies were limited to Nigerian and Sudanese men. Whereas Africans in the UK come from more than 50 countries (see Table 1.2). Thus, the previous studies' findings do not apply to the majority of African people living in the UK. Finally, some researchers specifically noted that their findings may not be suitable for making generalisations or transferability across differing healthcare systems (Consedine et al., 2011; Elmubarak et al., 2005; Magnus, 2004).

3.6 Research Purpose

The Cancer Reform Strategy (DH, 2007) acknowledged that a lack of evidence and information presented a major challenge to the reduction of inequalities and the improvement of cancer prevention, treatment and care that people from all types of backgrounds receive. To address this challenge, a National Cancer Equality Initiative (NCEI) was established in 2008. The main mission of NCEI is to bring together key stakeholders such as healthcare professionals, the voluntary sector, academics, and equality groups to develop evidence-based knowledge on cancer inequalities and advice on the development of wider policy (DH, 2007, 2011). In order to maximise the effort and effectiveness of primary cancer prevention strategies and access to services among BA and BAC men living in the UK, an understanding of their social, cultural values, beliefs, and existing views concerning cancer need to be identified. The purpose of this study is to explore the views of BA and BAC men living in the UK about cancer in order to contribute to the knowledge evidence base in this area and to consequently reduce the information deficiency.

3.7 Overall aim and specific objectives

The overall aim and specific objectives of the study are presented below.

Aims

To explore the influence of culture on views of cancer held by BA and BAC men living in the UK.

Specific objectives

1- To explore the understanding of UK-born and African/Caribbean-born black men living in the UK regarding cancer risk factors, signs, and symptoms;

2- To explore these men's views and beliefs towards cancer and cancer screening;

3- To elicit lifestyle behaviours in relation to cancer risk factors;

4- To explore health-related cultural similarity and difference between BA and BAC men in relation to their views towards cancer

3.8 Significance of the study

Few studies have been conducted in Africa or in western countries, including the UK, on attitudes towards cancer among BA and BAC men. Hence, the knowledge and understanding of how these factors, which may predispose BA and BAC men to poor health outcomes in the UK, is limited (Cancer Research UK, 2009; Grulich et al., 1992; National Audit Office, 2005).

Furthermore, in order to identify unmet needs and to inform policy makers, charitable organisations in the UK aiming to address cancer-specific problems among ethnic minority populations have recommended the need for an urgent investigation into whether there are differences in the specific needs of black communities to be able to readily access information, treatment, or care for cancer (Breast Cancer Care, 2005; Lodge, 2001; The Prostate Cancer Charity, 2008; Waller et al., 2009).

This study will provide a better understanding about the target groups' views towards cancer. As the study focuses only on black men it will add new evidence to the current

literature (which is very limited in the UK) and has a potential to be used as a resource for researchers who would like to conduct further study on the topic. Moreover, it has a potential to inform healthcare professionals, policy makers, and other organisations working in cancer care so that service provision includes strategies for BA and BAC men to increase awareness, lifestyle change, and recognition of early symptoms and signs of cancer.

Chapter 4 : Methodology and Working Methods

4.1 Overview

This chapter discusses the core concepts of social science research philosophy, ontology, epistemology and theoretical prospective, and outlines the reason for choosing the interpretivist paradigm for this study. After discussing the theoretical account of grounded theory, the chapter will then explain why grounded theory was considered the most suitable methodology for achieving answering the study's aim and objectives. The chapter then presents the working methods for the study; providing a rationale for the method chosen and presenting detailed information on the research process, including sampling, recruitment, data collection, ethical issues, and the data analysis process.

4.2 Ontology and epistemology

The primary aim of scientific research is to acquire knowledge based on empirical evidence. Social science research acquires this knowledge following a structured pattern or model, technically referred to as a paradigm (Gergen, 2009). A given paradigm comprises three basic concepts: ontology, epistemology and methodology (Denzin & Lincoln, 2005). According to Crotty (1998), the social research process contains the chain of ***Ontology*** > ***epistemology*** > ***theoretical prospective*** > ***methodology*** > ***method*** (Crotty, 1998). Thus, ontology and epistemology are the core principles for guiding a social inquiry into any study aiming to gain knowledge (Crotty, 1998; Jupp, 2006).

The core concept of ontology is about identifying reality; the knowing of the existence of reality or being (Crotty, 1998). Epistemology, however, is concerned with providing a philosophical ground for making a judgment, for what kind of knowledge can be obtained,

and more importantly, for how the 'knower' ensures the adequacy and legitimacy of the acquired knowledge (Maynard, 1994). Crotty (1998) describes it as the way of understanding; how we know what we know. Epistemology is therefore mainly about the process of knowing and the philosophical explanation of the known. The formation of epistemology is a state of paradigm that leads researchers to their inclination of theoretical perspective, and consequently the type of methodology they choose will depend on it (Crotty, 1998). Objectivism and constructivism are the two major stances of epistemology, respectively invoking quantitative and qualitative research methodology.

Objectivist epistemological philosophy is based on objective reality and the concept that reality exists as an objective absolute; this means that reality or meaningful reality exist independently of consciousness. In this philosophy, the formation of knowledge follows the hierarchy of entity (the concept of existence), identity (knowledge of uniqueness, differentiation, and similarity), and unit (knowledge of measuring entity, a certain way of regarding things) (Rand, 1990). The axiomatic (undeniable idea) concept is core for this epistemology. Typical examples of axioms are that existence exists, or that A is always A, whether it is defined as a letter or as a combination of three straight lines. Objectivist epistemology correlates with quantitative research methodology (Crotty, 1998; Denzin & Lincoln, 2005).

Constructivist epistemology rejects this objectivist philosophical explanation and argues that the formation of knowledge is dependent on interaction and mind. Without consciousness there is no meaning. We do not discover meaning, but rather, we construct it (Rockmore, 2005). According to the constructivist philosophy, the 'knower' does not think of truth in terms of a match to absolute reality. Instead, it is based on experiences and interactions with the environment; the knower interprets and constructs a reality (Fosnot,

2005). This infers that humans develop knowledge through interaction with their environment. The interpretation of this knowledge will form awareness and attitude, which contain multiple truths (Rockmore, 2005). An ideal example of this is that people in different places or cultures may construct different meaning for the same situation; or the same person constructs different meanings for the same phenomena in different areas. The second concept that strengthens the constructivist epistemology explanation: 'the *formation of knowledge is dependent on mind and interaction*' extracted from Rand's (a pioneer objectivist philosopher) description of 'Definition'. Rand argued that a ''*Definition is a statement that identifies the nature of the unit subsumed under a concept... A word is merely a symbol used to represent a concept; and words have no meanings other than those of the concept they symbolise*'' (Rand, 1990, p.40). Hence it can be seen that the concept of definition is subjective. To illustrate this in context, upon hearing the word 'table' in a room where there is no table, individuals will imagine an object and define it as a 'table'; but do all individuals imagine the same table, despite all these people knowing what a table is by definition? Since experience can be different for different individuals, they construct different meanings and description for any given topic. Accordingly BA and BAC men could have their own reality regarding cancer which constructed based on their interaction to, and meaning of their environment. The researcher of this study embedded within this study that there is ['no single external reality'] as his ontology, and [constructivism] as his epistemology stance (detail justification provided in section 4.3). Researchers with a constructivist epistemological stance (excluding phronesis) predominantly justify the use of qualitative methodology to conduct research based on their theoretical perspective (Crotty, 1998; Denzin & Lincoln, 2005).

4.2.1 Theoretical perspective

In many social science publications, the terms *theoretical perspective*, *philosophical approach*, *paradigm*, *epistemology*, and sometimes *methodology* are discussed interchangeably or in an ambiguous way. For example, Denzin & Lincoln (2005) describe ontology, epistemology, and methodology as three basic concepts of a paradigm; they then list positivism, critical theory, constructivism and post-positivism as paradigms. Whereas, Crotty (1998), described the chain of social research as; *ontology* > *epistemology* (Constructivism, Objectivism and subjectivism) > *theoretical perspective* (post-positivism, positivism, phenomenology, interpretivism, symbolic interactionism, etc.) > *methodology* (survey, ethnography, phenomenological research, grounded theory, etc.) > *method* (questionnaire, observation, interview, etc.). While Denzin & Lincoln categorise constructivism as a paradigm, Crotty categorises it as epistemology; with the exception of constructivism, Crotty (1998) refers to all paradigms as theoretical perspectives. In this PhD study, the researcher found Crotty's logical sequence clearer. Thus, by treating the terms paradigm and theoretical perspective as comparable, the discussion and selection of theoretical perspectives will follow in line with Crotty's (1998) social research chain.

As noted, Crotty (1998) describes post-positivism, positivism, phenomenology, symbolic interactionism, and interpretivism as theoretical perspectives in social science. The term theoretical perspective is defined as the researcher's '*set of beliefs and feelings about the world and how it should be understood and studied*' (Denzin & Lincoln, 2005, p, 22). Accordingly, our theoretical perspective shapes and reflects the way we look at the world and make sense of it. Therefore, when researchers choose a paradigm, it is directly influenced by their beliefs about the nature of reality and their stance on how reality should be understood (Crotty, 1998). The selection of a paradigm should be compatible with the

researcher's preferred way of knowing reality (Denzin & Lincoln, 2005; Mills, 2006). The next section (4.3) will explain why the research of this study has chosen the interpretivist paradigm, with specific interest in symbolic interactionism.

4.3 Choosing a paradigm

Interpretivism is a generic sociological paradigm (Williams, 2008) with pluralistic characteristics. It embraces many sub-branch paradigms that advocate for the interpretation of the nature of knowledge, such as social constructionism, symbolic interactionism, phenomenology, and hermeneutics (Crotty, 1998; Denzin & Lincoln, 2000). The interpretivist looks for culturally derived and historically situated interpretations of the social life-world (Crotty, 1998; Williams, 2008). Interpretive sub-branch paradigms, such as symbolic interactionism and phenomenology, view the concept of culture very differently, with the former placing great emphasis on culture and the latter viewing it as less significant (Crotty, 1998). As a baseline ontological perspective, interpretivists believe that natural reality and social reality are different kinds of reality so there is no single external reality. Human experience is therefore a process of interpretation of interaction with the world (Weber, 2004; Williams, 2008). From the interpretivist's epistemological point of view, knowledge is what results from socially constructed concepts and meanings (Weber, 2004), and research is socially constructed with the aim of seeking to understand a specific context of the topic under investigation (Weber, 2004; Williams, 2008). In the interpretivist paradigm, therefore, researchers themselves are the most important tool. In this way, the researcher and the research participant are interdependent (Avis, 2005).

From an ontological perspective, the researcher of this study believes that the research participants' knowledge is constructed from their understandings of the meanings of the

world, and the interactions of the meanings. Within the context of this study, for example, what is the meaning of National Health Service (NHS), or cancer, or healthy eating, or cancer screening to black men? How are these meanings interpreted/ understood in the community? The researcher is also epistemologically inclined to think that knowledge is built through interpretation of the surrounding world, in that human knowledge is highly influenced by the surrounding environment. People's decision-making process (in this case *view*) is dependent on their knowledge. Finally, the human decision-making process (*view*) is expressed by activities and practices (*behaviour*). Thus, in broad terms (as illustrated in Figure 4.1) it was assumed that BA and BAC men's interaction with their surrounding environment (this includes healthcare service) will influence their interpretation of meaning, from which knowledge will be constructed. Based on this knowledge, they formulate attitudes that are reflected by action. Hence, the interpretivist paradigm with specific interest in symbolic interactionism is the paradigm chosen for this study, as it is compatible with the paradigm for the research topic and with the researcher's personal ontological and constructivism epistemological inclination. Therefore, the philosophical chain of this study is established as follows: - ontology (no single external reality) > epistemology (Constructivism) > theoretical perspective (Interpretivism) > methodology (Qualitative Study). Although employing a qualitative approach as methodology is obvious in line with the ontology and epistemology stances explained so far; further justification is provided in section 4.5 for choosing qualitative approach.

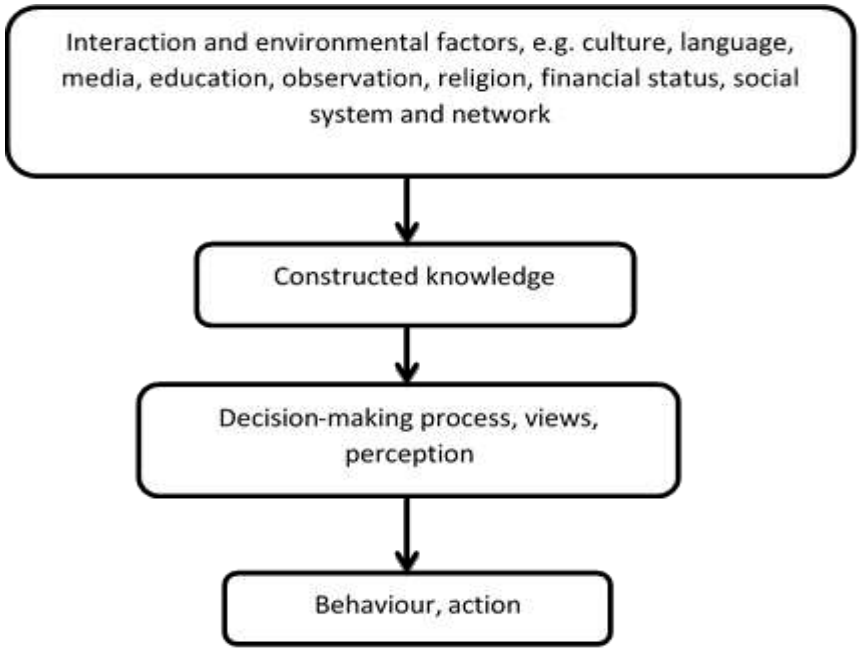

Figure 4.1: Conceptual Assumption of How Individual Could Construct Knowledge

4.4 Symbolic interactionism

Symbolic interactionism is a theory that emphasises the significance of people imposing meaning on symbols (events, characteristics and objects) in order to understand their individual role and relationship with society (Crotty, 1998); it is frequently associated with grounded theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). This perspective has its roots beginning with Max Weber and, George H. Mead. Mead emphasised the subjective meaning of human behaviour, the social process, and pragmatism (Etzrodt, 2008). Herbert Blumer is responsible for inventing the term 'symbolic interactionism', and for articulating the theory of symbolic interactionism (Blumer, 1969).

Blumer (1969) developed his theory based on three core concepts: meaning, language, and thought. These core concepts led him to set out three basic grounds of symbolic

interactionism theories of perspective. The first core principle of meaning is that humans act toward people and entities based upon the meanings that they have given to those people or entities; secondly, language gives humans a means and ability by which to negotiate meaning through symbols; and thirdly, thought modifies each individual's interpretation of symbols (Blumer, 1969). The main principle in Blumer's theory of symbolic interactionism is that thought, based on language, is a mental conversation or dialogue that requires role taking, or imagining different points of view by giving meaning through symbols (Etzrodt, 2008).

Symbolic interactionism stresses the notion that meaning is changeable and therefore individuals' actions could be changed in accordance with how they define the changing of situations (Etzrodt, 2008). Hence, in human behaviour people consider events and entities as significant, and individuals encounter and take action on the basis of their interpretations of these events and entities. Although Etzrodt's notion that meaning can be changed based on an individual's interpretation of a given situation puts a greater emphasis on 'time' rather than 'place', this concept of symbolic interactionism is relevant and appropriate to this study, since the majority of the papers included in the literature review were based in the USA, and participants in the USA and in the UK encounter and experience different entities, such as the healthcare system. Consequently, formation of meaning and role taking (action) vary accordingly. Symbolic interactionism focuses on a dynamic link between meanings with actions; meaning arises from action, and as a result, meaning then influences action (Charmaz, 2006). As noted, symbolic interactionism is widely associated with the grounded theory methodology, and it is useful for studying aspects of social interaction, and individuals' meaning and actions in the social realm (Creswell, 2007; Gray, 2010).

4.5 Choosing qualitative methodology

The researcher's constructivist epistemological inclination, as mentioned in section 4.3 above, has led him to choose a qualitative research methodology. Further, the aim of this study is to explore the influence of culture on views of cancer held by BA and BAC men living in the UK; in order to identify ways of providing information to this group that it finds acceptable, understandable and appropriate. A qualitative approach has the advantage of undertaking in-depth examination of phenomena (people's views) and collecting rich data without strictly defined variables (Neuman, 1999), thus a qualitative approach is the most appropriate approach for achieving the aim and objectives of this study in light of the interpretivist theoretical perspective (Crotty, 1998).

4.5.1 Why grounded theory was appropriate methodology

Phenomenology, ethnography and grounded theory were all methodologies and approaches considered for this study. The primary intent of the phenomenological approach is to describe phenomena or to describe how phenomena are interpreted (Cohen, Kahn, & Steeves, 2000). It is a classic approach that explores the lived experience of individual or groups of people with common experience (Creswell, 2007; Crotty, 1998); moreover, it explores the lived experience as it is understood by those experiencing it (Cohen et al., 2000). As the target groups for this study are healthy BA and BAC men who have a common experience based on their cultural upbringing, but not a lived experience as cancer patients, the phenomenological approach was rejected for this study.

Ethnography aims to understand and explain the value, behaviours, beliefs and way of life of people who share a common culture (Creswell, 2007). As the target groups meet this cultural categorisation, ethnography could have been a suitable approach. However,

observation is an important data collection method in ethnographic studies (Neuman, 1999). The issues which the researcher would need to observe, including attitudes towards cancer, healthcare, and knowledge of cancer; are not tangible things with which the participants are likely to engage physically unless they are situated within a relevant setting, such as interactions with medical staff at a hospital or clinic. Observation was not a practical data collection method in this study as there were no guarantees that there would be an action to observe, given that participants in this study were not cancer patients. While data collection in ethnographic studies can also be conducted using interviews while foregoing observation (Spradley, 1979), the essence of Spradley's ethnographic interview is to understand the meaning of '*actions and events to the people we seek to understand*' (Spradley, 1979, p.5) and to learn what a specific event or action really means to participants within the context of their culture. Hence, the researcher would still need to observe the participants and identify the action or event he/she would like to explore more. While this level of observation need not be extensive, the researcher must conduct a primary observation before conducting the interview, which, as noted, would be difficult as there is no guarantee of such an action or event occurring during the observation.

In ethnographic research, *action* and *interaction* of the people we seek to understand are vital elements to be explored using observation and/or interviews. Hence, there must be an action and interaction to be observed, in which participants collectively engaged for a length of time in a certain place. In the context of this study, a classic example would be receiving treatment for the same medical condition or accessing services from the same or similar providers. However, as mentioned above, the target population of this study were non-cancer patients who were neither situated in the same geographical or clinical location, nor engaging in action or interaction that could be observed or explored through interview.

Accordingly, for pragmatic reasons, ethnography was also rejected as an unsuitable methodology for this study.

Grounded theory method is an approach that allows an exploration of experiences by individuals who shares a common culture (Creswell, 2007). It is a recommended approach for understanding social problems or conditions to which people must adapt and to explore how social circumstance could influence individual or group experiences and behaviours (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Assuming black men share similar social circumstance and are often categorised as one target group in health research (e.g. see Pedersen et al., 2012; The Prostate Cancer Charity, 2008); grounded theory method was selected as the most appropriate approach to explore black men's view towards cancer in this study. The grounded theory method and grounded theory are two distinct entities that need to be clearly understood by researchers, but which are often mixed up leading to epistemological ambiguity (Bryant & Charmaz, 2007). The grounded theory method is one of the methodological approaches in qualitative study, used to study processes (Charmaz, 2005), while grounded theory is the theory developed using the grounded theory method (Charmaz, 2005; Bryant & Charmaz, 2007). This difference and another vital issues of grounded theory approach will be discussed in more detail in the next section (section 4.6).

4.6 Grounded theory

Grounded theory methodology is categorised within the interpretivist research paradigm (Crotty, 1998). In this study, grounded theory, which is influenced by symbolic interactionism, will help the researcher to understand BA and BAC men's social constructs and views towards cancer. Prior to detailed discussion of grounded theory, the history of

grounded theory and the philosophical underpinning of grounded theory, located in symbolic interactionism, is discussed below.

4.6.1 History of grounded theory

Barney Glaser and Anselm Strauss developed the grounded theory methodology in the early 1960s, while collaborating on studies focused on people dying in hospital (Glaser & Strauss, 1967). Glaser and Strauss explored analytical ideas for the data they gathered through interviews, observation, and field notes; they constructed systematic methodological strategies that social scientists can adopt for studying many other topics (Glaser & Strauss, 1967). In this methodology, theory is discovered from—or grounded—in data, making it an inductive approach (Glaser & Strauss, 1967). The emergence of grounded theory significantly affected the methodological shift in social science research. In the 1960s, qualitative research in the sociological discipline was losing ground to the dominance and popularity of quantitative research (Charmaz, 2006). Glaser and Strauss's (1967) book, '*The Discovery of Grounded Theory*,' offered systematic strategies and momentum for qualitative research (Charmaz, 2006).

4.6.2 What is grounded theory?

Grounded theory is now one of the leading and probably most common and popular analytic techniques in qualitative studies (Cohen & Crabtree, 2006, Thomas & James, 2006; Titscher & Jenner, 2000), resting under constructivist epistemology and interpretivist theoretical perspectives (Crotty, 1998). It is worth noting that according to Charmaz (2000), classic grounded theory does not fit with constructivism epistemology; rather, it has an objectivist epistemology stance. This will be discussed in more detail in the Charmaz constructivist grounded theory section (see 4.6.3.3).

Returning to the previous point of interpretivist theoretical perspectives, there is a philosophical underpinning that people impose their internal perceptions and ideals on the external world and, in so doing, actively construct their realities (Suddaby, 2006). From this perspective, the key variables of interest are internal and subjective, and the purpose of grounded theory is to elicit understandings about patterned relationships between social actors and how these relationships and interactions actively construct reality, rather than to make statements of absolute truth about their reality (Glaser & Strauss, 1967).

Among the defining components of grounded theory method is discovering theory from data, which provides an insight and explanation into the phenomenon being studied; it is also concerned with the whole process of theory generation and sampling aimed toward theory construction, not for its representativeness (Glaser & Strauss, 1967). Another key feature of grounded theory is that the process is facilitated through an interaction between the participant and the researcher, as well as the data collection and analysis process (Charmaz, 2006; Glaser, 1998, 1978; Glaser & Strauss, 1967).

Overall, grounded theory stresses both the research process itself and the results of the research process (Bryant & Charmaz, 2007). It is a systematic qualitative research process that believes in conceptualising dominant emergent data based on the beliefs of symbolic interactionism, where theory is generated from the ground up and is built upon the constant comparative method, which requires simultaneous data collection and analysis (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967).

4.6.3 The three versions of grounded theory

After Glaser and Strauss parted ways, both developed their own perspectives on grounded theory. Kathy Charmaz, an eminent contemporary proponent of grounded theory, also

developed her own perspective on this methodology. The three versions of grounded theory are discussed below.

4.6.3.1 Glaserian grounded theory

From Glaser's (1992) perspective, grounded theory is a study of concept and conceptualising meaning patterns. The researcher's aim should be to know what is really going on. The core question for Glaser is '*what do we have here*?' (Glaser, 2001). Another well-known Glaser's statement is that '*All is data*,' which is to say that data is not only what is being told, how it is being told and the conditions of it is being told, but also all the factors and issues arising as it is being collected (Glaser, 2001). Although the Glaserian version seems to be a qualitative research approach with an interpretivist stance to inquiry, the concept of 'discovering theory from data' is more inclined towards objectivist epistemology than towards constructivist epistemology, which advocates that we construct meaning rather than discover it (Charmaz, 2000, 2009). Because the Glaserian version is embedded objectivist epistemology, it assumes that researchers are unbiased observers (Charmaz, 2009; Glaser, 1978, 2001). Researchers need to maintain this unbiased position by avoiding activities which bring a bias to the research; such as the use of a topic guide during interviews. Rather, Glaser encourages researchers to conduct unstructured interviews and be passive listeners during the interviews so as to ensure the research will be free from bias (Glaser, 1978, 2001). Also to undertake grounded theory research Glaser advocates researchers should be open minded, so as to be free from preconceptions and the literature review should be carried out after discovering the theory. This present study embraces constructivist epistemology which assumes meaning is constructed through active interaction between the participant and the researcher. The conclusion being that the

Glaserian version of grounded theory appeared less appropriate in the undertaking of this study.

4.6.3.2 Strauss and Corbin grounded theory

Strauss and Corbin (1990) developed their own detailed systematic way to conduct grounded theory research. They ask a '*what if?*' question which has a futuristic tendency to forecast and control the link between cause and effect, and particularly focuses on the process of analysing data (Corbin & Strauss, 2008; Strauss & Corbin, 1998, 1990). This version of grounded theory appears to emphasise a highly complex but systematic process of data analysis. Strauss and Corbin formulated a more prescriptive approach to grounded theory research, which arguably hinders the creation of an inductive and more flexible theory as advocated in the Glaserian style. This version of grounded theory has been criticised as '*programmatic and overformulaic*' (Melia, 1996, p.370). Glaser also argues that Strauss and Corbin's version should be called 'full conceptual description' (Glaser, 1992).

The Glaserian and Straussian versions share the same fundamental belief that knowledge might be increased by generating new theories rather than analysing data within existing ones (Heath & Cowley, 2004; Melia, 1996); but the two versions differ slightly in epistemological issues, including induction, deduction and verification (Heath & Cowley, 2004). Concerning the debate about literature reviews, during Strauss and Glaser collaboration, Strauss shared Glaser's view of delaying the literature review until completing the data analysis (Glaser & Strauss, 1967). Whereas in his later work with Corbin, Strauss takes a more liberal position concerning the role of literature in the research process, maintaining that the literature could be used at the beginning of the study (Strauss & Corbin, 1990).

Despite the above mentioned differences both the Glaserian version and Strauss & Corbin version are referred to as classic grounded theory (Charmaz, 2005, 2009, 2014). In these classic grounded theory versions, 'grounded theory method' and 'grounded theory' are not recognised as two distinct entities. These two parts are inseparable so the ultimate goal of using the grounded theory method is the discovery of data to create theory (Glaser, 1967, 2002; Strauss & Corbin, 1990).

Charmaz described Strauss & Corbin version of grounded theory as '*pragmatist*'; since '*what if*' is its central interest of inquiry, it views reality as fluid and somewhat indeterminate, and has a tendency to be used as a problem-solving approach (Charmaz, 2005). The primary aim of this present study was to explore the influence of culture on views of cancer held by BA and BAC men living in the UK, which was not interested to speculate by putting '*what if*' question as its central interest of inquiry. Rather it puts the understanding of black men's views as the central interest of inquiry. Hence Strauss & Corbin *pragmatist* version also appeared as less appropriate approach to undertake this study.

4.6.3.3 Charmaz's constructivist grounded theory

For Charmaz, grounded theory needed to move on from its positivist origin and to be incorporated into the methods and questions posed by constructivist thinkers over the past twenty years, to become a more reflexive practice (Charmaz, 2006). A student of Glaser and Strauss, Charmaz has emerged as the leading proponent of constructivist grounded theory.

This contemporary version of grounded theory rejects the idea of discovering theory as emerging solely from data gained independently of the dynamic between researcher and

participants, as an objective entity. Rather, constructivist grounded theory claims that theories are constructed through the researcher's own involvement and interaction with research participants (Charmaz, 2000). Further, Charmaz (2000) argues that because classical grounded theory does not recognise the vital role of interaction between the researcher and research participants in the formation of meaning and interpreting data, it lacks epistemological clarity.

According to Charmaz (2000, 2006), constructivist grounded theory is tackling the fundamental criticisms of grounded theory's ambiguous epistemological stance. She agrees (2005) with the critics of the grounded theory epistemology stance, stating that it 'provide[s] a template of doing qualitative research stamped with positivist approval' (p.509). The mix-up between 'the core aspects of the method' and 'historical context within which the method developed' causes this situation, in philosophical terms; Charmaz refers to these two versions of grounded theory as objectivist and constructivist, respectively (Bryant & Charmaz, 2007; Charmaz, 2000). She urges a re-positioning of the grounded theory epistemological landscape. Re-positioning of the epistemological landscape helps grounded theory to address its criticisms. Furthermore, it also helps to ease off its complexity in the form of over-formulated data analysis processes and the authoritarian reach of over-generalisation (Bryant & Charmaz, 2007; Charmaz, 2000, 2005, 2006).

Constructivist grounded theory reshapes the interaction between the researcher and participants in the research process and emphasises keeping the researcher close to the participants by keeping participants' words intact in the process of data analysis, and writing the findings to maintain the presence of participants throughout (Charmaz, 2000). Charmaz's Constructivist grounded theory assumes that reality is multiple and socially constricted; epistemologically it takes a middle ground between postmodernism and

positivism (Bryant & Charmaz, 2007; Charmaz, 2000, 2006). However, Glaser (2002) argues that constructivist grounded theory remodels grounded theory from a conceptual theory to a conceptual description method with full coverage of the interactive interpretation. Furthermore, Glaser expresses doubt about the existence of constructivist data and argues that even if it exists, grounded theory is not constructivist (Glaser, 2002).

In relation to the debate concerning the right timing for conducting the literature review, Charmaz realised the practical difficulty of attempting not to undertake the literature review before conducting the actual research, also giving weight to Glaser's concern, and reconciling both approaches by heightening the difference between being an 'open minded' and an 'empty head' (Charmaz, 2006, 2009). Charmaz suggested that, rather than the timing of conducting literature review, researchers need to mindful about the purpose of conducting it and to use the literature review to strength the grounded theory without letting it supress the creativity of the researcher or strangled the developing of theory grounded on the raw data (Charmaz, 2006, 2014).

The researcher of this study endeavoured to explore in great depth the similarities and differences among the above mentioned three versions of grounded theory by utilising a verity of resources and opportunities. Conversely, to enhance his research skills and knowledge, particularly in Constructivist Grounded Theory, he attended a Workshop at the University of Huddersfield facilitated by Professor Kathy Charmaz. As she is the pioneer figure in this specific version of Grounded Theory, the researcher of this study gained invaluable benefit by having a one-to-one conversation with her. More importantly, he had an opportunity to show her the section of this methodology chapter that focused on Constructivists Grounded theory and received positive feedback from Professor Kathy Charmaz confirming that he understand the concept of her version of grounded theory:

Constructivists Grounded theory. Having an opportunity to meet Professor Kathy Charmaz and receiving feedback, as well as the additional resources she provided concerning Constructivist Grounded Theory (see Appendix 5), was an amazing opportunity and an uplifting experience which convinced this researcher to conduct this study using the Constructivist Grounded Theory in addition to the justification provided below in Section 4.6.4 to select this specific version.

4.6.4 Choosing a specific version of grounded theory

There are grounded theory proponents who advocate different ways of undertaking the methodology as discussed in section 4.6.3 (e.g. Charmaz, 2006; Glaser, 1992; Strauss & Corbin 1990). The researcher acknowledges that all versions of grounded theory methodological frameworks can produce sound work and probably overlap with each other. However, every researcher must be clear as to precisely which method is being used to avoid methodological slurring (Melia, 1996; Stern, 1994). In this study, the researcher decided to adopt Charmaz's constructivist grounded theory, for the following reasons.

This particular version takes a middle ground that has the advantage of being less restrictive than the classic (Glaserian and Straussian) versions. For example, the classic grounded theory aims to achieve context free generalisation by assuming the researcher as neutral and passive; whereas the constructivist version assumes the researcher's values, positions and actions affect the research (Charmaz, 2005). The researcher of this study strongly believes that reality is constructed based on meaning, and interaction between the researcher and participants impacts on the interpretation of meaning, which is to say that how both the researcher and participants perceive each other influences their relationship and interaction. Thus, the interpretation of meaning by the researcher and the participants could be perceived differently by each. More importantly, as the researcher is a native of Africa, the

constructive grounded theory notion of constructive reality between researcher and participants seems most appropriate for the researcher, particularly in terms of interaction with BAs, but also in terms of a common understanding between the researcher, a black male, and BAC male participants.

In constructivist thinking, grounded theory is a method to study processes, assuming the mutual emergence of data through interaction between the researcher and research participants; theory might be constructed but not always as a necessary priority as it is in classic grounded theory (Charmaz, 2005). This particular version has the advantage of less restriction than the grounded theory versions proposed by Glaser, Strauss and Corbin. Secondly, Charmaz's grounded theory advocates 'a social constructivist perspective that includes emphasizing diverse local worlds, multiple realities, and the complexities of particular worlds, views, and actions' (Creswell, 2007, p.65). Furthermore, this study's ontological (*multiple external social reality exist*) and constructivist epistemological (*seeking to understand specific context*) stances were more compatible to the constructivist grounded theory. This allowed the researcher to use constructivist grounded theory to explore the views of BA and BAC men in the UK towards cancer by constructing data rather than discovering data. As constructing data involved placing participants' meanings and action at the centre of the process, it was effective to show the connection between participants' views at the micro and macro levels (Charmaz, 2005). Based on the explanation given above, in this study, Charmaz's constructivist grounded theory was considered the most suitable approach.

4.7 Working Methods

This section will present the working methods used to undertake this constructivist grounded theory study in order to achieve its overall aim and specific objectives. The aim of this constructivist grounded theory study was to explore the influence of culture on the views of BA and BAC men living in the UK towards cancer.

In this constructivist grounded theory study, like all versions of grounded theory, data collection and data analysis were carried out simultaneously, applying the key components of grounded theory techniques: constant comparison, theoretical sampling and data saturation (Charmaz, 2006, 2009, 2014; Corbin & Strauss, 2008; Glaser, 1978, 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1998, 1990). However, in order to provide a much clearer account of the research process, the process of data collection and data analysis will be presented separately under different sub headings.

4.7.1 Sample technique

A convenience sampling method advertising was initially used to recruit suitable participants for interviews. As data analysis commenced, using constant comparison techniques; theoretical sampling was used to work towards data saturation of emerging categories. In grounded theory, any kind of initial sampling is a starting point for the research, whereas theoretical sampling directs the researcher how to proceed further data collection, how to refine and develop emerging categories, when to reach data saturation, and how to develop theoretical categories (Charmaz, 2006).

4.7.1.1 Inclusion criteria

- African-born black men living in the UK;
- UK-born black-African men;

- Caribbean-born black men living in the UK;
- UK-born black Caribbean men;
- Aged 18 years and over;
- Able to communicate in the English language.

4.7.1.2 Exclusion criteria

- Black men who are unable to communicate in English;
- Black men under the age of 18;
- Non-black African men (Asian, Arab and white African);
- Non-black Caribbean men (white, Hispanic, Asian);
- Previously diagnosed with or treated for cancer.

Men previously diagnosed with or treated for cancer have been excluded from this study, as they would already be exposed to cancer services and would be familiar with access to those services. Data gathered from such participants could be useful for comparing the difference between non-cancer patients and cancer patients, although it would detract from the primary focus of the study. As noted in section 3.8, the findings from this study have the potential to inform healthcare professionals, policy makers, and other organisations working in cancer care to enable them to provide services that are relevant and acceptable to BA and BAC men in the UK in relation to increasing awareness, lifestyle change, and recognition of early symptoms and signs of cancer. Inclusion of black men who had already experienced a cancer diagnosis and subsequent treatment would introduce bias as well as it would detract from the primary aim and objectives of the current study.

4.7.2 Sample size

Sample sizes in qualitative research are usually small for three main reasons: data management, contribution to new evidence, and nature of the qualitative approach (Ritchie, Lewis, & Elam, 2003). Firstly, the quantity of raw data that could be collected in qualitative research is vast, so collecting and analysing data by conducting hundreds of interviews

becomes unmanageable in terms of time and resources. Secondly, a large sample size does not guarantee new evidence in qualitative research: ‘‘Very little new evidence is obtained from each additional fieldwork unit… increasing sample size no longer contributes new evidence” (Ritchie et al., 2003, p.83). Thirdly, it is not the nature or concern of qualitative research to show the frequency and pattern of evidence to support the argument; hence, there is no need for a large number of participants to determine statistically significant discriminatory variables to secure generalisability (Ritchie et al., 2003).

As is the case in all qualitative research approaches, sample size in grounded theory is not aimed at generalisability or representativeness of the study population (Patton, 2002). Sample size is all about obtaining a sample that can inform the researchers adequately about the phenomena they are exploring and ultimately reaching data saturation (Charmaz, 2006, 2014; Corbin & Strauss, 2008; Glaser, 1998; Mason, 2010). Data saturation can be described as the point at which data collection can be stopped as there are no new ideas emerging from the raw data that would add something new to the emerging category so data collection can be stopped. Data saturation is a debatable concept. There are arguments to suggest that data saturation can never really be achieved in an absolute level (Mason, 2010, Saumure & Given, 2008). However researchers need to decide the point at which no more data needed to be collected that is relevant to the emerging theory (Saumure & Given, 2008). The data saturation point in this study was referred to as the point at which the completeness of emerging categories without unexplained gaps within it, to construct robust theory, was achieved (Charmaz, 2014, Saumure & Given, 2008). In grounded theory, data saturation can be achieved with small sample sizes, varying from seven (Charmaz, 2006) to 30 interviews (Creswell, 2007). There are no strict criteria for what constitutes an acceptable sample size in grounded theory (Patton, 2002). The sample size

for this study was 27 participants which was determined by the emerging findings of the interviews and securing data saturation.

4.7.2.1 Study location

The study was conducted in Yorkshire, the North West, the Midlands and the London areas, where large populations of BA and BAC communities reside. In addition to the fact that large populations of the target population were resident in these areas, black community organisations, based respectively in the major cities of Leeds, Manchester, Birmingham, and London, agreed to support this study mainly in the participant recruitment process.

4.7.3 Gaining access and participant recruitment

To gain access to BA and BAC men, the researcher approached BA and BAC community organisations in Leeds, Manchester, Birmingham, and London to explain the purpose of the study. These included the Afro-Caribbean Millennium Centre & radio station, the Moss Side & Hulme Community Development Trust, community organisations representing Cameroon, Congo, Eritrea, Ethiopia, Ghana, Guinea-Bissau, Ivory-Cost, Nigeria, Sierra Leone, Somalia, South Africa, Sudan, Zambia, and Zimbabwe.

All the community leaders who were contacted agreed to support the study by explaining it to their community members, and also agreed to identify potential participants. The manager of the Afro-Caribbean Millennium Centre & radio station agreed to advertise the recruitment on air free of charge until the required number of participants were secured. The script for the radio advertisement was prepared based on the manager's suggestion that needs to be informal and the use of day-to-day vocabulary and slang commonly used by black men. (Please see Appendix 6: The Script for Radio Advertisement). The

advertisement was put out twice a day for two months. At the same time, with the agreement of all community leaders, recruitment posters (Appendix 7) and participant information sheets (Appendix 8) were disseminated in each community organisation. The community leaders distributed participant information sheets and the researcher's UCLan contact details to those who expressed an interest. Volunteers who contacted the researcher through community leaders were given more detailed information, as well as answers to any questions they had. From these potential participants, volunteers who showed an interest in participating were then asked for a postal or email address to which a consent form could be sent. Receiving a copy of the consent form in advance of scheduling an interview allowed the volunteers to understand what they would be expected to sign and allowed them an opportunity to change their mind about participating if they were uncomfortable with the terms to which they were asked to consent.

Any volunteers who contacted the researcher directly after reading the invitation poster or hearing the radio advertisement received an explanation about the study and had their questions answered. Only potential participants who were still interested in taking part in the research after these explanations and clarifications were asked to provide a postal or email address to which the participant information sheet and consent form could be sent. As with volunteers reached through community leaders, these forms were sent in advance of scheduling an interview to allow the volunteers to understand what they would be expected to sign and to allow them an opportunity to change their mind about participating if they were uncomfortable with the terms to which they would be asked to consent. Once volunteers had an opportunity to read the participant information sheet and the consent form, the researcher contacted all potential participants by phone to receive their verbal

consent to proceed, and then made arrangements for an interview at a mutually agreed place and time. Accordingly, 27 participants were recruited and interviewed in this study.

Out of a total of 27 participants, 70 per cent were recruited by disseminating recruitment posters and participant information sheets in black-community organisations, in collaboration with community leaders. The remaining 30 per cent were recruited through a radio advertisement. The radio advertisement was put out on the Afro-Caribbean Millennium Centre & Radio station which is based in Birmingham. The radio station's service mission is to give people of the African and Caribbean community a voice by providing reflective programmes that are specific to African Caribbean culture and aspiration (The Afro Caribbean Millennium Centre, 2013). Since this radio station's target audience is the black community, its programmes are predominantly oriented to the black-community's culture and tradition. Hence, in terms of sampling this was a very targeted approach and may have yielded interest primarily from individuals with strong traditional beliefs. It may be assumed that the majority of the audience would consist of black people seeking to listen to radio media that targets a black audience. It could consequently be assumed that participants who had heard the radio adverts and agreed to participate in this research could have contained a group of people who were interested in preserving their culture, traditional values, and set beliefs.

4.7.4 Methods of data collection

Data can be collected in qualitative research through various methods, predominately one-to-one interviews, focus groups, and observation (Arthur & Nazroo, 2003; Kvale & Brinkmann, 2009). Participants in this study would not be located in one area or institution at the same time, making observation an ineffective data collection method. Focus groups

are often used as a quick and convenient way to collect data from several people simultaneously, and explicitly use group interaction as part of the method (Krueger & Casey, 2000). This study aims to explore in detail the influence of culture on the views of BA and BAC men living in the UK towards cancer. Comparing data from different focus groups is problematic as it is more likely that certain views or issues will be lost across groups (Sim, 1998). Additionally, it is the nature of the chosen methodology (grounded theory) that the generation of data for gaining in-depth information is achieved by using theoretical sampling, which mainly involves consecutive interviews (Charmaz, 2006). Theoretical sampling is one of the core elements of grounded theory, helping to collect data in order to complete the emerging ideas and to generate the full conceptual category. It involves constant comparison of data already collected to decide what data to collect next and from where/whom to find it, including contacting research participants again to enable saturation of emerging categories (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1990). The one-to-one interview method offered ample opportunity to contact participants repeatedly, allowed more detailed questions to be asked and had the advantage of enabling investigation of issues in-depth, exploring how individuals think and feel about a topic and why they hold certain opinions (Gubrium & Holstein, 2002). Therefore one-to-one interviews were selected as the most appropriate data collection method which allowed access to the phenomena under investigation.

4.7.5 Interviews

There are three kinds of interviews: structured, unstructured, and semi-structured (Kvale & Brinkmann, 2009; Legard, Keegan, & Ward, 2003). All three types of interview methods provide different advantages; however, researchers choose to use one or a combination of

any of these methods based on their flexibility, interactive nature, the ability to achieve the required depth, and the ability to capture data in its natural form (Legard et al., 2003).

In structured interviews, the interviewer asks the same questions in the same way and gives interviewees little option to express their views, not allowing the researcher to explore in depth the subject under investigation. Structured interviews are therefore more suitable to quantitative research (Arthur & Nazroo, 2003; Kvale & Brinkmann, 2009). Consequently, structured interviews would not offer an opportunity to explore black men's view in detail. Moreover, given the unique nature of grounded theory, theoretical sampling is used to further explore and complete the emerging categories, by asking participants appropriate questions; structured interviews would not provide flexibility to ask different participants different questions, and accordingly, the structured interview technique was rejected as an unsuitable interview method in this study.

Unstructured interviews are mainly used by experienced researchers (interviewers). Researchers who prefer to conduct unstructured interviews may use one or two general questions to stimulate the interview (Legard et al., 2003). Unstructured interviews involve the researcher wanting to know or to find out more about a specific topic without there being a structure or preconceived ideas (Kvale & Brinkmann, 2009). This appears comparable with Glaser's view about what interviews should be in a grounded theory study. According to Glaser (2002), interviewing is a very passive listening activity free of preconceived thoughts; this then helps develop more focused questions during theoretical sampling. Glaser further argues that interview guides impose interactive bias; instead, unstructured interviews with passive listening are key to avoiding bias in grounded theory (Glaser, 2002).

Unstructured interviews would provide flexibility but considering the researcher's experience level and the practicality of exploring the target group's views towards cancer by asking one or two questions, it was also considered inappropriate. Besides, despite Glaser's (2002) argument that passive listening without using interview guides is key to avoiding bias, the researcher of this study considered the concept of being a passive listener without preconceived thoughts for conducting a good level of unstructured interviews very challenging. The researcher in this study is a black man; it would have been dishonest to pretend not to have any preconceived thoughts about the participants and about the topic being studied. For example, as a cultural insider the researcher understood the importance of developing personal rapport before delving into the interview questions, waiting until the participant showed trust by using the acceptable and recognised language used by black men. Further, the trust between the researcher and black men needed to be maintained through active conversation not by passive listening; this would ensure participants would not be apprehensive if they were expected to provide a monologue. Moreover, constructivist grounded theory assumes that the interaction between the researcher and participants is one important factor in the research process as it influences the interpretation of meaning that develops from interviews. As a result of this assumption, constructivist grounded theory recognises *value* and *facts* as an inseparable part of reality (Charmaz, 2009). Therefore, mainly for pragmatic reasons but also partially for its compatibility with constructivist theory ethos, the unstructured interview technique was also rejected.

Semi-structured interviews can be seen as the middle ground between unstructured and structured interviews. A semi-structured interview style enhances the researcher's ability to establish rapport and earn participants' trust, generate data, and gain deeper understanding of the topic under study (Arthur & Nazroo, 2003). It is common practice for the interviewer

to use an interview guide, often containing open-ended questions that allow research participants the freedom to express their views in their own preferred way (Arthur & Nazroo, 2003; Legard et al., 2003). In semi-structured interviews, discussions between the interviewer and interviewee may diverge from the interview guide, and the interviewer needs to have skill to bring the discussion back to the topic (Kvale & Brinkmann, 2009; Legard et al., 2003). It is highly desirable and recommended practice to audio-record interviews and later transcribe these recordings for analysis. This allows the researcher to take few notes during the interview, so he/she remains engaged with the interview at an optimal level. As a result, the researcher devotes full attention to the participants and is able to probe in more detail (Legard et al., 2003). Accordingly, for practical reasons and due to its benefits of flexibility, interactivity, and the ability to achieve the required depth, a semi-structured one-to-one interview method was employed to collect data.

4.7.6 Interview questions

Interviews using semi-structured open-ended questions were conducted to collect data. A topic guide was constructed on the basis of the literature review and was used for early initial interviews, prior to the commencement of data analysis when the topic guide was amended in line with emerging themes. The topic guide contained seven main sections (see Appendix 9). In the first section, '*Welcoming participant and introduction*', the researcher welcomed participants, thanked them for their participation, explained the research briefly again as a reminder, answered any question that participants may have, and obtained written informed consent. There were four main sections to the topic guide:

- General questions about cancer,
- Explore how and from where information is accessed and its accessibility,
- Explore general views and opinions, and

- Explore awareness of risk factor and public health campaigns

The first section of the topic guide was used to direct the initial stage of the interviews. This section was focused mainly on asking participants general questions about cancer which included how cancer was perceived in the participant's home country and how it was likely to be talked about in the participant's community here in the UK. The purpose of this section was to introduce participants to the interview topic in the easiest way possible.

The second section focused on information provision. In this section questions were asked which aimed to explore the participant's views about the provision of cancer related information for black men here in the UK. Participants were also asked if they would like to obtain information about cancer, where they might get it, and whether the information was accessible and useful.

Questions listed in the topic guide to explore participants' general views and opinions about cancer were more personal such as asking participants if they would like to know if they had got cancer and what would be their reaction if they were diagnosed with cancer. In this section participants were also asked in what way their views and perceptions about cancer was formed as a result of living in the UK.

As a starting point for exploring participants' understanding of cancer risk factors, signs, and symptoms, the interview questions in the fourth main section of the topic guide (explore awareness of risk factors and public health campaigns) were designed on the basis of current scientific knowledge on the subject. Well-known risk factors, signs, and symptoms of major cancer types common among black men, such as prostate, lung, and bowel cancers, were drawn from the Cancer Research UK, DH, NHS, and Prostate Cancer UK websites. These cancer risk factors, signs, and symptoms, identified by modern medical

scientific investigations and endorsed by responsible and respected governmental and charitable organisations, were used as a stimulant and a reference for exploring participants' understanding of the subject from a perspective of scientific knowledge. However, this study did not aim and was not designed, to assess or examine the scientific knowledge of the participants. It aimed to explore what participants understood, from their own perspective, to be cancer risk factors, signs, and symptoms. Hence, as the interview progressed, the questions were shifted from the perspective of scientific knowledge to that of points raised by participants such as religious beliefs.

After commencing initial coding of the data (the beginning phase of data analysis process), the interview questions were shaped more by participants' responses and emerging themes. As simultaneous data analysis and data collection were carried out (constant comparison), the interview questions were modified accordingly. This nature of modifying interview questions during data collection in grounded theory method is common practice (Charmaz, 2014) as it allows the researcher to explore the phenomena fully by completing any unexplained gaps within the emerging categories.

Towards the end of the interview participants were asked socio-demographic questions and were asked if there was anything else they wished to discuss that had not been covered during the interview. The researcher showed his appreciation to each participants and thank them again for their participation at the closing stage of the interviews.

4.7.7 Service user group involvement

The Cancer, Supportive and Palliative Care Research Group at the host institution works closely with a user and carer research advisory group. A meeting was arranged for the researcher of this study to meet the above mentioned service user group. This group

provided valuable feedback about the design of the study and suggestions on the questions that might be asked during the interviews. Subsequently, the service user's suggestions were taken into account during the development of interview topics guide.

4.8 Data collection

Interviews were carried out from the end of June 2013 to the beginning of February 2014. A total of 27 participants were involved in this study and each participant was interviewed on at least one occasion. Some individuals were interviewed on more than one occasion and a total of 34 interviews were conducted. Sixteen initial in-depth interviews were conducted with 17 participants. Two participants were interviewed together on one occasion and this was counted as one interview. This had not been intentional. A black female healthcare professional, who had been mentioned by a previous participant, was recruited as part of theoretical sampling in order to explore the health-promotion approach within the black community, particularly in relation to her role of educating black men about prostate cancer and Sickle Cell disease. This female healthcare professional arrived at the interview with another black female individual without informing the researcher. This individual was considered a useful informant by the female healthcare professional as she [the second female] was involved in a number of public campaigns and was willing to participate in the research study. The second female participant was not a healthcare professional, but was involved in a number of public health campaigns including Sickle Cell disease health promotion among black communities. Therefore, the researcher decided to interview both participants in a joint interview; written consent was obtained from both individuals. Following the initial 16 interviews, theoretical sampling was employed and a further 18 interviews were conducted; 10 of these were first interviews with new participants and

eight were repeat interviews; more detailed information about research participants is provided in Appendix 10.

The sampling frame used in this grounded theory study was both convenience and theoretical sampling. In grounded theory, sampling is usually directed by the emergent theory (Charmaz, 2014; Glaser, 1978; Strauss & Corbin, 1990) and the size of the sample is not chosen before the study begins but evolves as the theory emerges, thus informants are not selected for their representativeness, but rather because of their knowledge of the phenomena under scrutiny and the emergent categories.

The process of recruiting and interviewing participants was carried out by going backwards and forwards throughout the different stages of the data collection and analysis process (constant comparison) and by following the new ideas emerging from previous data. As data collection and analysis progressed and categories started to emerge, participants were targeted who were able to provide information about the evolving theory.

The recruitment of potential participants was decided upon by a combination of two factors: from whom and from where the next/subsequent data could be obtained. The first factor concerned recruiting the right person who had knowledge of the phenomena, while the latter focused on recruiting further individuals to the study as the categories were being identified and the theory of 'cancer through black eyes' was starting to develop. This theoretical sampling technique ultimately strengthened the findings by saturating the emerging categories. Accordingly, if it was possible to obtain the information (data) from participants who were already interviewed, a decision was made to re-interview them as a theoretical sample in subsequent interviews. Based on this procedure, eight participants were interviewed for a second time. If the information (data) could not be elicited from

participants already recruited to the study, then new participants were targeted, consented and recruited to the study. Thus, this involved interviewing new individuals rather than people who were already recruited to the study. For example, the two female participants who were interviewed were part of a theoretical sampling approach, having been identified as valuable informants in the study due to their involvement in public-health campaigns among black men. Interviewing these participants helped to saturate emerging categories by providing an explanation to the properties of emerging categories related to public health campaigns. For example, why black men perceived that cancer was not their disease while they recognised Sickle Cell disease as a major health concern for themselves as well as the black community. Again, participant number 25 was recruited to complete the emerging ideas about an Islamic explanation of what cancer means in a religious context. This participant was an Islamic cleric (Imam), and was able to provide information to aid saturation of the category 'Religious beliefs' by exploring how cancer can be seen as a sign of forgiveness for sins committed. Altogether, 18 of the participants recruited to the study directly were related to a theoretical sampling strategy. This helped in yielding a greater understanding of developing categories and emerging theory, and ultimately informing data saturation.

The interviews were conducted in participants' own homes and in various community centres across the study locations, mainly located for the convenience of participants. Out of the total 34 interviews, 22 were conducted in participants' homes (some of the follow-up interviews were conducted over the telephone). The remaining 12 interviews were conducted in different community centres based on the participant's location (Leeds, Sheffield, Manchester, Birmingham, and London). In each community organisation where interviews were conducted, a separate room was provided for use during the interview. In

addition, interviews were scheduled for timeframes when community organisations had fewer scheduled events and visitors, to ensure that the interviews would not be interrupted and to ensure that the privacy of participants was maintained. The duration of interviews varied from 14:56 minutes to 114:11 minutes (nearly two hours).

During the interviews, the researcher endeavoured to create a relaxed environment for participants by showing interest in, and attention to, what they had to say, and by trying not to interrupt too often while they were talking, and encouraging participants with verbal and nonverbal gestures. Furthermore, the interviews were carried out in an informal, conversational manner to ease the pressure of 'being interviewed,' which can be stressful (Charmaz, 2006; Legard et al., 2003). When all interview topics had been covered and the interview was coming to an end, each participant was asked if there was anything that they would like to add. Participants were also asked for their agreement to be contacted for a follow-up interview in case clarification of issues that had arisen during the interview was necessary. All 27 participants indicated that they would be willing to be contacted should the research need to conduct further interviews. The researcher showed his appreciation and thanked his research participants during the closing stage of all interviews. All interviews were audio-recorded using an Olympus WS-813 digital voice recorder to ensure that participants' full accounts were captured. Immediately after leaving the interview venue, verbal reflective dairy accounts about each interview were audio-recorded. Twenty-two audio data files were transcribed by a professional interview transcription service, in keeping with UCLan's data protection and data management policy and regulation. The researcher himself transcribed the remaining 12 audio data files to further familiarise himself and to aid immersion into the data, which is in-keeping with a grounded theory approach.

4.8.1 Ethical issues and approval

This study involved healthy individuals who had not been diagnosed with cancer. None of the participants were members of vulnerable groups within the research context. Ethical approval had been sought from the University of Central Lancashire (BuSH) Research Ethics Committee and was obtained on June 11, 2013 (please see Appendix 12). Some of the ethical issues related to this study are discussed below:

Confidentiality: The identity of all participants' remained confidential. All identifiable information was removed from interview transcripts. Each individual who consented to participate was given a unique identifying number and this number was used on all research records. Interviews remained confidential. Only the researcher and the supervisory team had access to interview transcripts. The digital recordings of interviews were kept on a password-protected computer at the University of Central Lancashire, and transcribed recordings were kept in a locked filing cabinet once all identifying features had been removed. Identifying features were also removed from any quotations that were used to illustrate and /or present the findings of this study. All audio and transcribed documents will be destroyed after five years, following the completion of the study in accordance with UCLan's data protection and data management policies and regulations.

Exclusion: The study design (interview) required all participants to be able to speak and comprehend English. Hence, it was recognised that certain groups may be excluded from this study by this requirement. However, as all BAC and the majority of BA speak English (Owen, 2009; Heine & Nurse 2000), this exclusion criteria may only affect a small proportion of African-born black men potential participants. During the field work there were only two BA French-speakers potential participants who approached the researcher

affected by this exclusion criteria. During the initial contact with these two BA men, each of them suggested that they would articulate better their thoughts through interpreter. Due to this exclusion criteria (participants to be able to speak and comprehend English) the two BA men who were mentioned above were withdrawn from participating in this study.

Sensitivity and distress: At the outset of the data collection, it was acknowledged that some participants may have felt uneasy in a face-to-face interview (Legard et al., 2003). However, in this study, participants had complete autonomy in determining whether they would like to take part and were reminded of this throughout their involvement in the study. During interviews, if the researcher suspected that participants may not be comfortable, he asked if they would like to continue or to would like to stop the interview, and ensured that participants did not feel obliged to continue if they did not feel comfortable doing so. There were two young second generation participants (one BA aged 26 years, one BAC aged 19 years) who were concerned about their ability to answer questions, particularly about the risk of common cancers, and needed reassurance that they were not expected to have clinical knowledge about cancer and that the researcher was interested to hear what they thought about cancer and the risks of cancer from their point of view. Apart from these two young men, all participants appeared comfortable during the interview and no incidents arose subsequently that would indicate distress. Furthermore, as the majority of the interviews were conducted in the research participant's homes, participants had greater control of the environment, thus contributing to their comfort during the interview.

There was also a precautionary plan in place should participants have become distressed or concerned about aspects of cancer as a result of their involvement in this study. This plan included directing participants to appropriate services where they could get support and

information according to their concern. The researcher was a qualified nurse and felt able to provide appropriate information in this respect. For example, if participants had concerns about their own health they would have been advised to consult their general practitioner (GP) or to seek advice from the Macmillan helpline (telephone 0808 808 0000, web www.macmillan.org.uk), Mind helpline (telephone 0300 123 3393, web www.mind.org.uk/help), or Cancer Research UK (telephone 0808 800 4040 web http://www.cancerresearchuk.org/cancer-help/). If participants' had subsequent concerns about their involvement in this study, they could have contacted the researcher directly, the researcher's Director of Studies, or the Dean of School of the host institution; these contact details were included in the participant information sheet. However, there were no concerns reported from any of the 27 research participants.

Informed consent: Written consent was obtained from each participant prior to the commencement of each interview and a signed copy of their consent form was given to each participant. The consent form is presented in Appendix 13. Participants who were involved in follow-up interviews (as a theoretical sample and/or to clarify issues which were raised during their first interview) were not asked to sign an additional consent form. This was because, as they had consented to the first interview, their verbal agreement to the follow-up interview and willingness to meet the researcher was considered as informed consent. In addition, some of these follow-up interviews were conducted over the telephone, thus participants' willingness to answer the questions was again taken as informed consent.

Participants' absolute right to give or withdraw their consent to participate in this research was considered to be of paramount ethical importance. It was acknowledged that some participants may have had reservations about signing a formal document (consent form).

Some of the participants in this study were expected to be immigrants from Africa, and it could be assumed that some of these potential participants may not wish to sign the consent form as a result of their previous difficult experiences (torture, ill treatment, imprisonment and destitution) related to signing documents in their home countries (McGee, 2006). If this situation had arisen, subject to participants' permission, then a process of establishing verbal consent would have been initiated. Participants who preferred to give verbal consent rather than written consent would have been asked to confirm their agreement to each statement (items) listed in the written consent form and this verbal consent would have been audio-recorded. However, none of the participants requested this alternative, so all informed consent was obtained using written consent forms.

Throughout the research process all ethical requirements were met in accordance with the University of Central Lancashire (BuSH) Ethics Committee and the University of Central Lancashire (UCLan) research governance guidelines.

Researcher Safety: The researcher was working alone during data collection time. Interviews were take place in a mutually agreed place including participant's homes. Based on the UCLan Lone Working policy, safety measure were applied to minimise any risks for the personal safety of the researcher. The researcher notified his Director of Studies or one of the second supervisors the time, location and anticipated completion time of interviews before each interview; after the successful completion of the interviews, the researcher also notified a member of the supervision team that the interview has been completed. The researcher also carried a mobile phone as an additional safety measure and he could have been contacted within an hour of the anticipated end time of the interview if he failed to report to one of his supervisors. During the data collection time there was no single events

that needed to make an emergency contact between the researcher and his supervisory team.

4.9 Data analysis

This section provides an account of how data were analysed within this study. The section is divided into different sub-sections corresponding to the different stages of the data analysis process, mainly based on different stages of data coding. All stages of data storing, management and coding were performed both manually and using NVivo-10 software, a Computer Assisted Qualitative Data Analysing Software (CAQDAS) package (additional information on NVivo-10 is provided in Section 4.9.5). NVivo-10 was used to manage the entire data analysis task, to assist with creating categories and themes, and to extract reports throughout the data analysis process.

In grounded theory, a constant comparison method is used, which involves comparison of data with other data within the same interview, as well as with data from other interviews; data is also compared with categories, and categories with other categories. Finally, as a key characteristic of the data analysis process, categories are compared with abstract concepts (Charmaz, 2006; Corbin & Strauss, 2008; Glaser, 1978; Glaser & Strauss, 1967). This analytical practice continued throughout the data analysis process, with data collection and analysis being performed simultaneously (Charmaz, 2006; Corbin & Strauss, 2008). Because of this unique characteristic of grounded theory, it was not appropriate to complete all data collection tasks first and then analyse all collected data as a whole. Accordingly, after each interview, the audio files were uploaded into NVivo-10. When transcribed data were received from the transcription service, they were also uploaded into NVivo-10. A copy of each participant's interview transcript was provided to each participant to confirm

that what was transcribed was an accurate account and that they still agreed with the views they expressed during the interview. Participants provided their feedback via email or telephone and all participants agreed that the transcriptions were an accurate account.

Before starting the technical tasks of the data analysis process, it was important to become familiar with the raw data; audio data were listened to several times and the hard copy of each transcribed interview was read. Memos were written for each interview and kept separately, to be referred back to at the end of data analysis as a counter-checking tool for emerging categories. The researcher also had an opportunity to attend three health-promotion events within the black community. These opportunities were valuable in becoming familiar with the targeted group in their own environment in relation to health-promotion issues, including cancer, in the community. This familiarity aided understanding of the reasoning and meanings attached to participants' responses during interviews and data analysis. Creating 'intimate familiarity' with the data and targeted group in their own setting positioned the researcher on firm ground for strong data analysis that went beyond simplistic interpretation of participants' responses (Charmaz, 2006). The first step in the technical task of data analysis was performing initial coding.

4.9.1 Initial coding

Initial coding is the first step of the analytical task in grounded theory, which involves understanding what a section of data is about, interpreting it, identifying concepts to stand for the section of data, and labelling it with a single word or phrase (Charmaz, 2006; Corbin & Strauss, 2008). When undertaking initial coding, it is important that researchers remain open to exploring every possible theoretical direction that is discerned in the data (Charmaz, 2006; Corbin & Strauss, 2008; Glaser, 1978); because of the importance of being open when performing initial coding, the term initial coding is also referred to as

open coding. For example, Charmaz predominately uses the term ‘initial coding’ in most of her relevant publications; yet when she wants to emphasise the importance of being open-minded during this stage of coding, she uses the term ‘open coding’ (see examples in Charmaz, 2008, 2014). Other well-known names in grounded theory, including Corbin, Glaser, and Strauss, also prefer to use the term ‘open coding', (Glaser, 1978, Corbin & Strauss, 2008). For reasons of preference alone, in this study, the term *initial coding* was used.

Initial coding can be performed in three different ways: word-by-word, line-by-line, or incident-by-incident. Word-by-word initial coding is preferable when data is gathered from historical documents, personal letter or artefact. As its name suggests, incident-by-incident coding is preferable when comparing an incident with another incident within the same data source (e.g., interview), or with an incident in a different data sources. Line-by-line initial coding is useful for understanding in-depth interview data; it also assists in identifying participants’ implicit concerns and explicit statements (Charmaz, 2006). Using line-by-line initial coding, the researcher benefits from being able to compare data with data, identifying gaps in the data, and being more focused in subsequent interviews (Charmaz, 2006, 2014).

Data obtained from the participants in this study was coded initially using line-by-line coding. Initial coding was performed both manually and using NVivo-10 software. The term ‘node’ in NVivo has similar meaning to code (Beazley, 2007). As undertaking initial coding involved labelling data with a single word or phrase, it did help to categorise participants’ similar concepts, implicit concerns, and explicit statements under one code (node) (Charmaz, 2014). Wherever possible, an effort was made to use participants’ own words to label the code. During initial coding the connection between data was also

identified and used to systematically categorise the raw data in more analytically connected meanings. For example, one code (node) was called '*avoiding Babylon'* reflecting participants own words and their views towards a healthcare system as oppressive; 147 similar references from 12 sources (interviews) were categorised under this one code (node). After completion of the initial coding, there were a total of 308 initial codes (nodes) produced for further second-phase coding: focused coding.

4.9.2 Focused Coding

Focused coding, rather than 'axial coding' was undertaken as a second stage of coding. Until recently, axial coding was considered a significant stage of data analysis in grounded theory, and many grounded theorists who adopt the earlier versions of analysis as advocated in Strauss & Corbin's (1990, 1998) texts use axial coding as a second stage analytical coding procedure. However, the difference between initial coding and axial coding is almost insignificant. Corbin herself, who was the most known advocate of axial coding as a significant stage of the grounded theory analytical method, asserted in the most recent edition of her book that ''open coding and axial coding go hand in hand. The distinction made between the two types of coding are 'artificial' and for explanatory purpose only … after all, the connection comes from the data'' (Corbin & Strauss, 2008, p.198). Thus, tasks undertaken during initial coding included the main aspects of axial coding, which include sorting, synthesising, and organising a large amount of data and rearranging it in new ways (Creswell, 1998, 2007). According to Charmaz, in the contemporary grounded theory data analysis method, focused coding is the second phase of data coding, and involves assessing the initial codes and reassembling them in more analytically focused meanings (Charmaz, 2006, 2014).

The focused coding technique was used to undertake the second phase of coding in this study. During this stage, the main tasks involved systematically searching for the links or similarities between initial codes and categorising them by labelling them with one common analytical code/phrase, leading to themes then properties, and then to the construction of categories. The whole process of focused coding was carried out in two stages. First, initial codes were collapsed, by grouping them into themes (multiple initial codes). Multiple initial codes that were characteristically similar and/or could be included under one umbrella label were collapsed to create a theme, categorising the 308 initial codes into 113 themes. Second, these 113 themes were analysed to established properties (multiple themes); that are the characteristics of, and give specificity to, categories (Corbin & Strauss, 2008). During this process, multiple themes with overriding significant and common themes were combined, rearranged, and labelled with more conceptual terms to construct properties. Next, multiple properties were combined based on their characteristics and potential to give specificity to a category, constructing the categories. This stage of focus-coding properties was constructed by interpreting the meaning of the themes within analytical concepts, in order to transform the data analysis process from the descriptive to the conceptual level (Charmaz, 2014).

At this stage of analysis, it was as important to concentrate on what the initial codes were saying about the research participants' concepts, implicit concerns, and explicit statements, as this stage was focused on interpreting the meaning of collective themes and then giving them more conceptual labels, based on researcher's interpretations. According to Charmaz (2014), as the researchers themselves are a part of data analysis, this interpretation and defining the meanings of codes relies on the researchers' perspective and analytical skill, which is one of the ways in which the difference between classic and constructivist

grounded theory is evident. Before finalising the focused coding, the individual memos that were written before the commencement of the technical data analysis task and were stored separately, were referred to as a counter-check to ascertain whether the emerging properties and categories captured the essence of each participant's views. By the end of the focused coding stage there were 99 properties under 14 categories.

The entire data analysis process to this point, from initial coding to the constructing of 14 emerged categories, was captured as follows. Line-by-line initial coding was performed and produced 308 initial codes (nodes). Then multiple initial codes with characteristic similarity were combined to create 113 themes; in the same way, multiple themes combined to create 99 properties, and based on their conceptual meaning, specificity, and close relationships, multiple properties combined to construct 14 categories. Figure 4.2 below illustrated this process. Further, after the third and final stage of coding, theoretical coding (Section 4.9.3) based on a combination of multiple categories was used to develop the theory of this study.

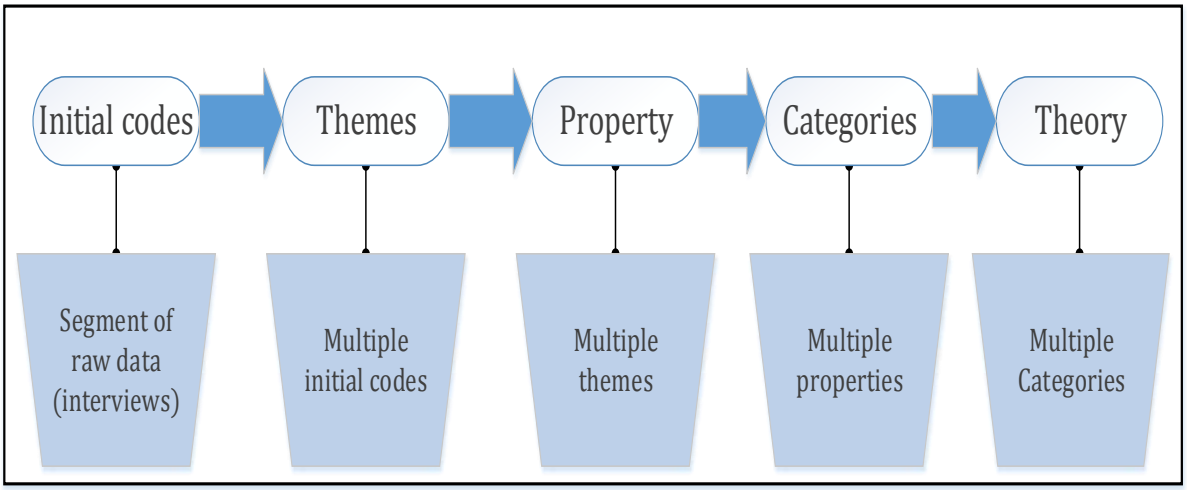

Figure 4.2: Process of Data Coding From Initial Coding to Constructing Categories

4.9.3 Theoretical coding

The purpose of theoretical coding is to theorize the data that has been produced by the completion of the focused coding (Charmaz, 2006, 2014). Theoretical coding was applied first by further refining the 99 properties that emerged as the result of focused coding. This was conducted by integrating the properties to construct more clear and coherent contributor properties of a category. Accordingly, each property in a given category was able to tell a fractured story of the category. The theoretical coding task involved making emerging categories and their properties more conceptual and theory-sensitive (data theorisation), which leads to developing an analytical story in a theoretical direction (Charmaz, 2006). At this stage, the relationships between each of the categories were examined, and accordingly, categories were interlinked with each other to construct a comprehensive, coherent analytical story about black men's views towards cancer. As a result, 30 properties under eight categories emerged. The next step was to select the core category out of these eight emerging categories. The core category was selected based on its capability to capture the studied phenomena at a more conceptual level, its interlinking with all remaining categories, and its level of explanatory power of the major concept (Corbin & Strauss, 2008). Finally, the data analysis process was completed by identifying one core category (cancer through black eyes) and seven sub-categories. These are presented in the Findings chapter (Chapter 5).

4.9.4 Developing theory

One of the unique characteristics of the grounded theory method is discovering theory from, or grounded in, data (Glaser & Strauss, 1967, Charmaz, 2006; Corbin & Strauss, 2008). However, there are different opinions among researchers as to what grounded theory should actually look like and how to conduct it; this remains a topic of on-going debate

ranging from classic grounded theory to situational analysis of grounded theory (see, for example, Bryant, 2003; Burawoy, 2000; Charmaz, 2000, 2006, 2009; Clarke, 2003; Glaser, 1978, 2001, 2002; Glaser & Strauss, 1967). These disagreements are manifested in the ways used to present (report) theory in grounded theory research publications. Charmaz (2006) classified these variations of presenting theory into nine categories:

1. An empirical generalisation,
2. An explication of a process,
3. An explanation,
4. A category,
5. A predisposition,
6. A relationship between variables,
7. An abstract understanding,
8. A description, and
9. A theory-resolving concept of the main concerns of participants.

The root source of these variations of views regarding what theory means in the grounded theory method relates back to the ambiguous and unclear epistemological stance of classic grounded theory (Charmaz, 2006, 2014; Kearney, 2007). Hence, based on the researcher's epistemological stance, the variation of reporting grounded theory can be distinguished into two major theoretical perspectives: positivist and interpretivist (Charmaz, 2006, 2009).

From the positivist theoretical perspective (mainly associated with classic grounded theory), theory is a statement of relationships between abstract concepts that cover a wide range of empirical observation, and treats concepts as variables (Charmaz, 2006, 2014). The objectives of theory in the positivist theoretical perspective are to reach hypostatical generalisation of a certain phenomenon and proposed predictions based on the relationships of variables (concepts) (Charmaz, 2006; Glaser, 1978, 2001; Kearney, 2007). The interpretive theoretical perspective advocates theory as the imaginative understanding of a

certain phenomenon, by emphasising facts and values as inseparable and accepting realities as multiple (Charmaz, 2006, 2009).

As the positivist theoretical perspective is associated with objective epistemology and the interpretivist theoretical perspective is associated with constructivist epistemology, the theory of this constructivist grounded theory study relied on an interpretivist theoretical perspective. The theory in the constructivist approach is the researcher's interpretation of the studied phenomena (Charmaz, 2006, 2009). Hence, based on this study researcher's interpretation of the emerging categories, the theory of cancer through black eyes was conceptualised through the process of data analysis, developing categories, and constructing a theoretical story, as presented in the Discussion Chapter (Chapter 6).

4.9.5 NVivo-10 CAQDAS

There are a number of computer software products to support the qualitative data analysis process, with slightly differing capabilities, differences in how complicated they are to operate (different level in their user friendliness) and differing compatibility with computer operating systems (e.g., Microsoft Windows, Mac OS, Linux, or Android). NVivo-10 is one of the latest versions of computer software to assist qualitative data analysis, tracing its roots back to 1979 as the first computer-assisted software to analyse qualitative data (Beazley, 2007; Richards, 2005). NVivo-10 was chosen to assist in the data analysis process for the following main reasons:-

NVivo-10 enabled data management and it was easy to import, store, organise, and keep track of multimedia raw data, including text-based data and audio data in different formats, as well as relevant information from different sources, including published research,

websites, databases, and social media. This gives the researcher the added advantage of being able to import, store, and access all data and relevant documents in one place.

NVivo-10 has a broad range of capabilities, from simple coding to matrix coding, and coded items can also be tracked back with referenced text and source data. This can be seen for each interview code (or another source of data) separately and/or for each code in the whole interviews (source of data) simultaneously. In data analysis, this was very useful for observing progress of data analysis, theoretical direction, developing categories, and, if needed, re-coding or un-coding or labelling multiple codes on one selected section of data. This flexibility especially gives much control over the codes and referenced text when undertaking the constant comparison process of grounded data analysis.

Querying data and managing ideas are other useful tools in NVivo-10. Searching from a simple question like a frequent word or phrase to complex ones by setting criteria and limitation for an answer helps to provide a close relationship with the data and also to allow further interrogation of coded data and categories. As a result, it serves as one additional indicator whether a further interview is needed, for example, for theoretical sampling. Alongside querying, initial or emerging ideas can also be managed by accessing a conceptual or theoretical memo that has been entered in the course of data analysis, by utilising the '*classification*' and '*models*' facilities of the NVivo-10 software. This is particularly useful for performing theoretical coding and data theorisation (the process of making raw data theory-sensitive).

Generating a report at any stage of data analysis is a helpful tool for monitoring the progress of data analysis. Summarised reports can be generated in eight different ways, based on the researcher's preference, including by data source (for each interviews), by

code (node), or by summary of the entire process. This gives a detailed insight into the process and content of the data analysis process for the raw data and the ideas and knowledge obtained from it.

The researcher of this study undertook basic training on how to operate NVivo-10 at his institution, UCLan. Furthermore, he attended an advanced-level workshop held by CAQDAS at Surrey University, which enhanced his knowledge of the software by providing the skills and confidence to utilise it effectively at an advanced level.

4.9.6 Research rigour

One of the major criticisms of qualitative research is that it lacks scientific rigour, putting into question the scientific merit of qualitative research (Angen, 2000; Creswell, 2007; Silverman, 2010). The question is particularly pertinent in healthcare research, where biomedical quantitative research using experimental methods has a strong tradition and dominance, making qualitative research appear less scientific (Sandelowski, 1986). To address the critics of the rigour of qualitative research, qualitative researchers generally outline a number of methods that can be used to evaluate the accuracy and validity of qualitative research findings (Creswell, 2014; Guba & Lincoln, 2005; Lincoln & Guba, 1985). Epistemological, methodological, and theoretical perspective differences in qualitative research are the main reason that it is difficult to produce a single universal rigour method (Angen, 2000; Creswell, 2007; Rolfe, 2006; Silverman, 2010). The debate is ongoing and seems to be no closer to establishing a consensus on quality criteria for qualitative research (Rolfe, 2006; Sandelowski & Barroso, 2002).

The most widely used standard quality criteria to evaluate the robustness of qualitative research findings was produced by Lincoln and Guba (1985), evaluating its trustworthiness

using four criteria: credibility, transferability, dependability, and conformability. Lincoln and Guba (1985) describe a total of 13 techniques that can be used to conduct qualitative research evaluation under the four criteria they outline (seven techniques for credibility, one for transferability, one for dependability, and four techniques for conformability). These four criteria, credibility, transferability, dependability, and conformability, are a mirror of the criteria for judging quantitative research: *internal validity*, *external validity*, *reliability*, and *objectivity*, respectively (Silverman, 2010; William, 2008). Including Lincoln and Guba's (1985) trustworthiness standard criteria, Creswell (2007) identified nine different existing standards of evaluating the robustness of qualitative research findings. Creswell also added that in all of these perspectives, a standard to evaluate an interpretivist perspective, such as grounded theory, is missing (Creswell, 2007). In his recently published book, *Research Design, 4th edition* (2014), Creswell recommended eight strategies to evaluate the robustness of qualitative research findings. Creswell's eight strategies are not new; they are extracted from Lincoln and Guba's (1985) 13 trustworthiness standard criteria. However, Creswell rearranged the most frequently used criteria in a more flexible manner for researchers to assess the accuracy of their research findings. Creswell (2014) recommended that the use of multiple of his eight strategies (*triangulate different data source, use member checking, use thick description, clarify the bias, present negative or discrepant information, spend prolonged time in the field, use peer debriefing, and use an external auditor*) enhances the process for evaluating the robustness of qualitative research findings (Creswell, 2014). Four of the above strategies were not selected as been applicable to evaluate the findings this study for the following reasons.

- The use of an external auditor is uncommon practice when undertaking a PhD research project.
- The research design and data collection method selected to conduct this study did not include the triangulation of different data source.
- There were some informal discussion with fellow PhD students about this research from time to time; these were not robust enough to be validly used as peer debriefing.
- The finding of this study endeavour to include wide-ranging participants' views about cancer and cancer related issues. However Creswell (2014) did not clearly explained what the meaning of negative or discrepant information is in interpretivist perspective. As a result the researcher of this study preferred not to use this particular strategy for evaluating his findings.

However the remaining four strategies were considered relevant and these were as follow.

Use member checking - This technique requires the researcher to provide the preliminary or final findings (not an interview transcript) to research participants to check that they agree with the findings' accuracy (Creswell, 2014); which means cross-checking with participants the findings of the study. Neither the preliminary nor final findings of this study were provided to the research participants with the intention of requesting their feedback on the accuracy of the findings. It is important to mention here that the notion of seeking agreement from research participants either in the preliminary or final findings contradicts the concept of the interpretivist perspective, which accepts multiple realities and seeking consensus is the least significant. Seeking confirmation from participants that what they said was accurately transcribed is more significant to the interpretivist perspective than seeking confirmation of findings. This is not to say that confirmation of the findings by

participants or by other people who share the same circumstances as participants is undesirable (Charmaz, 2006, 2014); but absence of consensus is assumed to be one way of manifesting multiple realities. Moreover, one particular participant could have completely opposite views to another. Hence, if a research participant discredited the findings that contradict his own views and beliefs, could it mean that the research findings were not robust enough? This question also leads to another of the strategies: *present negative or discrepant information.* The main idea of presenting negative or discrepant information is that real life is a collection of different perspectives. Thus, if the research findings reflect these contrary perspectives, the accuracy of the findings is more convincing (Creswell, 2014). This inconsistency may be seen as evidence as to why it is challenging to set one standard criteria for all qualitative research with its different theoretical perspectives. Returning to the initial point using the member checking strategy, for the reasons mentioned above, the findings of this study were also not given to the research participants for cross-checking in the spirit of this strategy.

However, during the data collection process, particularly while interviewing participants recruited using theoretical sampling, questions were asked based on early emerging preliminary findings. Participants did not mention that they were in disagreement with the early stage findings. For example, in the first few interviews of this study, the participants mentioned that there is a cure for cancer in modern Western medicine that is not available to black people; they also mentioned that the cosmetic industry uses black people's blood to extract melanin. In subsequent interviews, none of the participants who were asked about this disagreed; rather, they provided additional information and asserted to the researcher that ‘you did your research’.

In addition, the findings chapter of this research was provided to four black men who did not participate in this study. These four men (two African and two Caribbean) were originally meant to participate in this study, but were unable to due to scheduling difficulties. Nonetheless, these potential participants were very interested in being interviewed and contacted the researcher several times via telephone and text messages. The researcher asked these four men if they would be willing to read the findings chapter of the study when it was ready and to provide their feedback. Since these men were not interviewed, but shared the same circumstances as the participants who were, the thought was that they [the four men] could evaluate the findings freely without being in an interview situation, and could provide feedback to indicate whether they agreed or disagreed with the findings. There was also an element of being ethically fair to these four men in the decision to involve them in the research given their interest in being part of this study. Upon their agreement, the four men were asked to read the findings of this study and to provide feedback as to whether the findings made sense to them or represented unfamiliar views within their respective community, and the extent to which they agreed or disagreed with the findings. All four of them provided their feedback over the telephone. The feedback gathered from these four men confirmed that the findings made sense to them; stated that '*it is true*' and participants were '*very open*'.

Use a rich, thick description – This technique aims to provide a descriptive account of the research process from the start through to producing the findings (Creswell, 2014), providing enough information to the reader to show the process of how the research has been conducted to generate its findings. In the Methodology Chapter of this study (Chapter 4), particularly from Section 4.7 onwards, all research procedures and the justifications for their use are provided. This includes the geographical location where the study was

conducted, accessing target groups, the sample recruitment methods, the sample size, the venues where interviews were conducted, the data collection method, and how the data was analysed.

Clarify the bias - Creswell (2014) suggests that providing an open and honest narrative about how the researcher's personal background, such as culture and gender, shapes the findings is a sign of good qualitative research. First, this study was conducted by adopting a constructivist grounded theory, which assumes that the meaning of the world in the research is constructed together by the research participants and the researcher. Thus, the researcher's interpersonal factors, as well as his background, affect the process of constructing meaning, as they influence his interpretation of participants' responses. Based on this constructivist grounded theory concept, the potential influence of the researcher is clearly mentioned in section 4.6.4 of this chapter, where justification was provided for selecting constructivist grounded theory to undertake this research. Furthermore, as the researcher of this study is a cultural insider among the study's participants, the aforementioned section also discusses his personal and cultural influence on the research while evaluating the strengths and weaknesses of the study process as whole in Section 6.5.

Spend prolonged time in the field - It has been recommended that researchers who develop an in-depth understanding of the phenomena under study and the target population can produce more accurate, valid, and credible findings (Creswell, 2014). As mentioned above, the researcher is a cultural insider, and had an advantageous position of being familiar with the target study population. Furthermore, the argument that spending prolonged time in the field contributes to sound research findings (Creswell, 2014; Lincoln & Guba, 1985) has similarity with Charmaz's (2006, 2014) argument that 'intimate familiarity' with the participants in their own social setting enhances the quality of data

analysis and the quality of the findings. The researcher spent ample time in the field, speaking with a range of people and developing relationships with members of black-community organisations, including community leaders. He also attended health-promotion activities presented by black men to black men in their own setting. Hence, the interpretation of participants' responses was conducted based on all of these experiences and not only by reading the words in the transcripts, and accordingly, the findings were the result of a comprehensive process.

Chapter 5 **: Findings**

5.1 Introduction

This chapter presents the findings of the study. Background information on research participants will be provided, followed by an overview of the findings. The overview section contains a short summary of data analysis to show how the main findings emerged. The findings will then be illustrated in two diagrams. The first diagram (Figure 5.1) provides an overview of the findings and presents the core categories and sub-categories, while the second diagram (Figure 5.2) contains detailed information about each category. The main headings and sub-headings used to present the findings are directly extracted from Figure 5.2 and accordingly, some elements of the diagram (Figure 5.2) will be discussed before presenting the findings. This is mainly to clarify issues early on that will become clear in the main body of the findings, but also to provide general background information to explain the process by which these categories emerged from the data. The findings will be illustrated through quotations extracted from the participants' interviews.

5.1.1 Research participants

Twenty seven individuals took part in the study. The demographics of the participants are presented in Table 5.1 below. There were 17 BA and 10 BAC participants. Eighteen of the participants were first generation (14 BA and four BAC) and nine were second generation (three BA and six BAC). First and second generation participants were not recruited from the same family. Initial consideration was given to recruiting first and second generation participants from the same family in order to make comparisons. However, since African immigrants tend to be mostly young, single and relatively new to the UK (De Haas, 2008; Owen, 2009), the opportunity to recruit the required number of first and second-generation

African participants from the same family for the study was unlikely. Thus, proposing to recruit two generations of participants from the same family was considered a possible hindrance in the recruitment process. The youngest participants were 19 years old, whereas the oldest was 69 years old, accounting for a 50-year age range. The mean age of participants was 43 years; and the mode was 38 years old and 54 years old (each appearing three times).

Twenty five participants were male and two were female. The two females were recruited using a theoretical sampling approach to refine and elaborate emerging categories (Charmaz, 2014) in the early stage of data analysis. Of the 25 male participants, two of the participants were qualified nurses. A further two participants were care assistants. Out of 27 participants, 16 participants had obtained a university first degree qualification. 14 of these were BA men (12 first generation BA, two second generation BA) and the remaining two participants were both second generation BAC (one female and one male). Detailed socio-demographic characteristics data on participants is provided in Appendix 10. The basic demographic characteristics are summarised in Table 5.1, below.

Table 5.1: Demographic Characteristics of Participants

Characteristic	Number of participants
Study area (where participants reside)	
North West	8
Midlands	7
London	7
Yorkshire	5
Participant's background	
First generation black African	14
First generation black African Caribbean	4
Second generation black African	3
Second generation black African Caribbean	6
Age Range	
19-30	4
31-39	8
40-49	4
50-69	11
Education level	
No qualification	2
High school	2
A-level	1
Vocational	4
Certificate	1
Diploma	1
Degree	16
Employment status	
Student	4
Unemployed	1
Full time	19
Part time	3
Length of time residing in the UK by years	
4-10	4
11-20	10
21-30	5
Over 30	8

In the main body of the findings, direct quotations extracted from participants' responses are used to illustrate the findings. Text in brackets [], are used to clarify patois, slang or informal words used by participants during the interview.

At the end of each quotation, the participant's identification code is used to maintain confidentiality; a key for these codes is provided in Table 5.2. Each code is followed by

participant's identification number, assigned in sequence from 01-27. For example (FBA, 01) refers to participant number one, and the participant is a first generation black-African male; the suffix 'F' is used to indicate quotations from the female participants.

Table 5.2: Participant's Identification Code

Participants				
Generation	First	Second	First	Second
Background	Black African	Black African	Black African-Caribbean	Black African-Caribbean
Gender	Male	Male	Male	Male
Code	**FBA**	**SBA**	**FBAC**	**SBAC**

It was common for study participants to use the term 'black' rather than 'black African' and 'black African Caribbean' when referring to their particular communities. Hence, in the presentation of the findings the terms '*black', 'black men', 'black people' and 'black community/communities'* have been used as umbrella terms that refer to both BA and BAC.

5.1.2 Overview

The diagrams in Figure 5.1and Figure 5.2 were produced on the basis of eight emerging categories (one core category and seven sub-categories), in order to develop an analytical story leading to a theoretical direction (Charmaz, 2006, 2014). '***Cancer through black eyes***' was identified as a core category and placed in the centre of the diagram (see Figure 5.1). The remaining seven categories: '*Cultural views'*; '*Religious beliefs*'; '*Avoiding Babylon*'; '*Alienation*'; '*Suspicious mind*'; '*Advertisements and information influence very little*', and '*Gap in service provision (Bridging the gap)'* were classified as sub-categories and placed as satellites around the '*Cancer through black eyes*' category in Figure 5.1.

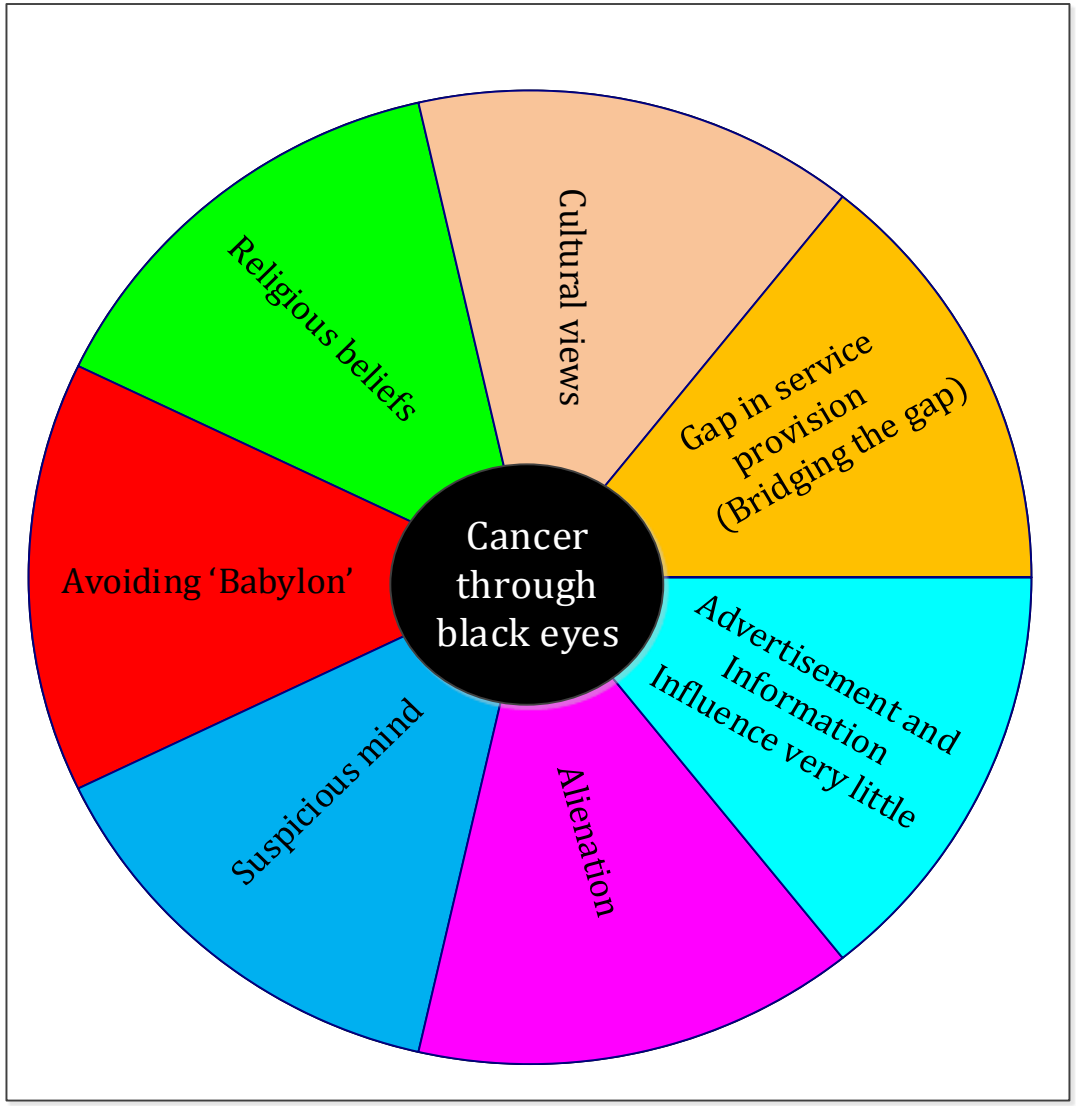

Figure 5.1: Core and Sub-categories

While Figure 5.1provides an overall view, Figure 5.2 shows the core category and sub-categories in detail with their contributor properties. There are direct or indirect interlinks among all seven sub-categories, and some of the sub-categories also overlap. For example, '*cultural views*' and '*religious beliefs*' could have been merged into one sub-category. However, doing so would compromise or weaken the ability to identify some significant issues and particularities at a micro level. Merging categories would also hinder the process of identifying similarities and differences between the views of BA and BAC participants. For example, '*We do not go to hospital*' is one property under '*Cultural views*'. Although this property emerged under the cultural views of both communities, the explanations as to why they did not want to go to hospital differed. This demonstrates that despite occasional overlap, there is justification for keeping the categories separate. As shown in Figure 5.2, the strong links and overlaps apply to all sub-categories. For example, the '*Alienation*' and '*Suspicious mind*' categories have more components in common, and significant sections of these categories were embedded from participants' cultural views. Furthermore, the '*Avoiding Babylon*' and '*Alienation*' categories seem to reflect similar feelings of disfranchisement. However, based on participants' explanations, in the former, it is a voluntary choice to avoid what is perceived as '*harmful*'; while the latter emphasises the feeling of '*being pushed or rejected*'. Hence, despite the fact that these sub-categories obviously feed one another, they were maintained as separate categories as the distinct nature of each was important for meeting the study aims and objectives. As a result, some of the views presented will recur in the main body of the findings, within different contexts and under different headings and sub-headings.

As mentioned earlier, '*Cancer through black eyes*' was identified as the core category, and opens the main body of the study findings.

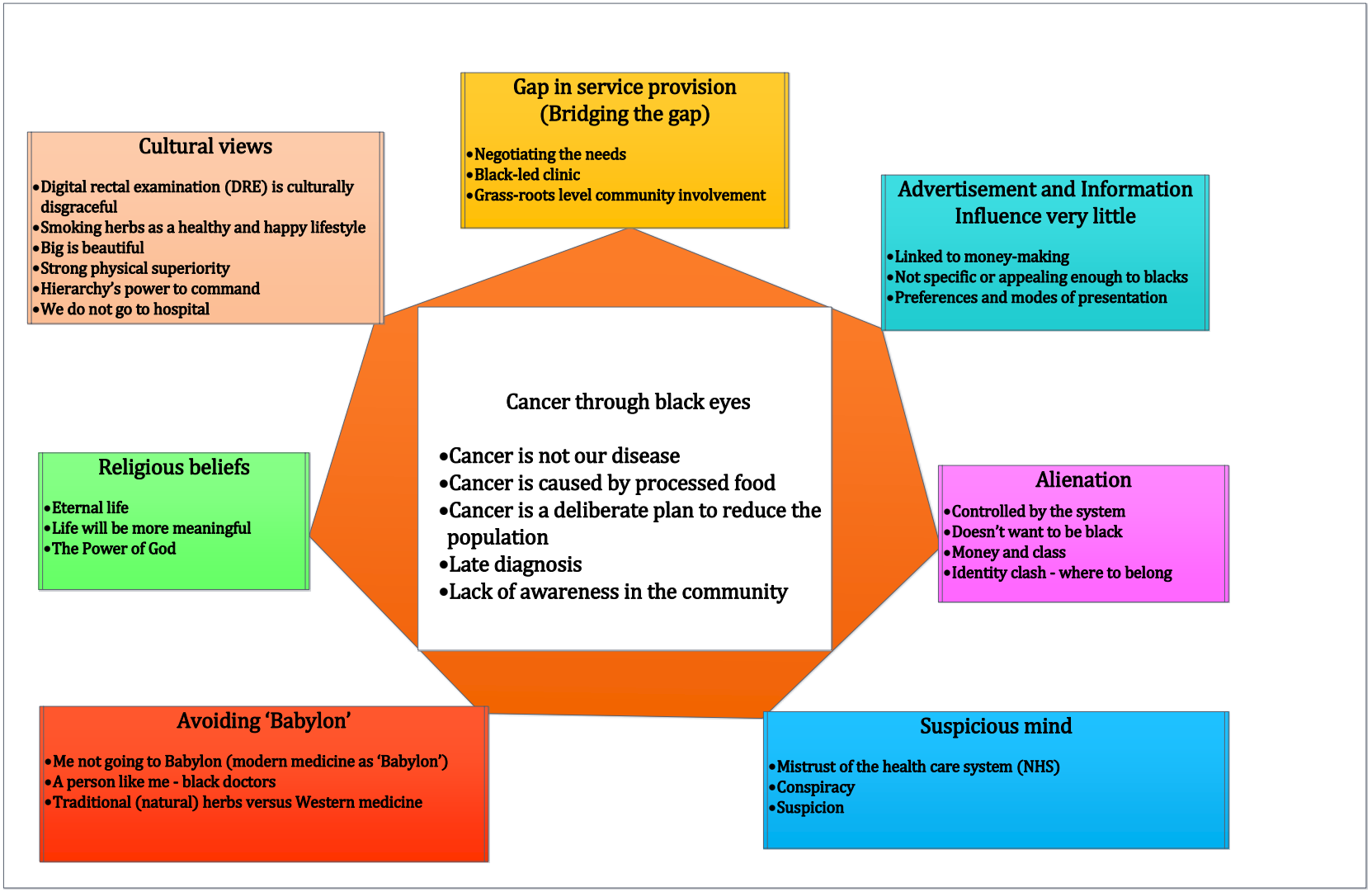

Figure 5.2: Core and Sub-categories Including their Properties

5.2 Cancer through black eyes

The core category, cancer through black eyes, highlighted participants' views of how black men see cancer in general. It became apparent that black men had their own way of looking at the subject of cancer and illness as a whole. The views of the participants are presented below under sub-headings that use the following main contributing properties: Cancer is not our disease; Cancer is caused by processed food; Cancer is a deliberate plan to reduce the population; Late diagnosis; and Lack of awareness in the community. Once these properties have been presented, the seven sub-categories that revolve around (feed) the main (core) category will be presented.

5.2.1 Cancer is not our disease

The data from this study suggests that black men do not see cancer as an illness that affects black people. Most participants mentioned that there is a lack of identification of cancer as a "*black peoples' problem*" in the way that other specific illnesses such as Sickle Cell disease and HIV have been associated with this community. Regardless of the participants' background, whether BAC or African, and whether first or second generation, they did not consider cancer to be a major health concern for black men. All BAC participants mentioned that they recognised Sickle Cell disease as a major health concern. These participants also reported that continued health promotion and education campaigns within the black community helped them to become more aware of Sickle Cell disease. The findings of this study suggested that, in contrast to Sickle Cell disease, participants felt that recognition among black men of any cancer type as a problem, including prostate cancer, is minimal. Unlike their African counterparts, the BAC research participants repeatedly mentioned that community-based health campaigns supported by the NHS helped them to recognise Sickle Cell disease as a black person's

illness. Two BAC participants from different generations, one first-generation and the other one second-generation, illustrated this perspective by stating:

> 'So when people realise this Sickle Cell is our disease they kind of homed into it and were made aware of it, because of all the things and the NHS as well, because of all the publicity around it so you could do the same thing for cancer for prostate cancer' (SBAC, 04)

> 'Sickle Cell awareness started a few years ago here in the UK, particularly within the NHS where it's an Afro-Caribbean type illness right…One of the important things is awareness, identifying and recognising it, cancer is a problem for black people; this is vital. Black men have to believe this first' (FBACF, 16)

For African participants, HIV/AIDS was more of an issue than cancer. African participants also highlighted that HIV-related intensive and large-scale public-health campaigns in their home countries made them familiar with HIV but not with cancer, making cancer a new phenomenon for this group.

> 'Cancer is new for us, this cancer thing, and when we knew it, it is incurable diseases that we know it as it is, like it was AIDS before, nowadays AIDS is okay because at least you can sustain your life for long, so we are not exposed enough for cancer for long, that's why we don't know it' (FBA, 13)

Participants were asked if they worried about cancer in general and prostate cancer in particular. Most reported that they did not worry about cancer, including prostate cancer, and believed that it affected white people more than black people.

> 'I wouldn't worry about prostate cancer or any cancer to be honest, that's me personally well, well as I say you live your life, no one knows when you're gonna go, so I'll enjoy my life until I go regardless. To be fair I know a white man, nice chap, died from prostate, yeah his dad also died from cancer, I am not sure, I think prostate, … if you see it, cancer is a white men thing, man' (FBAC, 01)

> 'It's just my thinking. I don't think for me black people are that much vulnerable for cancer for some reason. I don't know what reason it is, when you see the percentage… The media information where you see blacks are less likely to have a

> cancer than the white people, yeah, the reason why, I don't know, that's what my thinking is.' (FBA, 03)

Although most did not worry about cancer, three participants responded in a different way. One first-generation BA participant stated that as he suffered from skin irritation and had worried about skin cancer before he visited a dermatology clinic. Another first-generation BA participant reported that he worried about getting a brain tumour because he knew someone who had died of a brain tumour recently; he was concerned that brain surgery was complex and his chances of survival would be low.

> 'I worry about brain tumour because one person has died recently from a brain tumour, yeah … cos it's not, you cannot operate the brain easily and once you are diagnosed of brain tumour your survival chance is very, very low yeah, yeah' (FBA, 13)

The oldest participant, a BAC man aged 69 years, responded that he was not worried about cancer but was aware of it and took preventative measures, mainly by monitoring his food intake. By highlighting age as a risk factor this particular participant presented his view as follows:

> 'I'm not worry or afraid of cancer, not an actually specific one, but I know there is a connection between age and cancer, that is because as the older we get our organs work less right, but here's what I do, I'm not afraid of cancer though, this is my thing, I take more things to protect myself against cancer, I do take a lot of anti-cancer foods, not just because I'm afraid of cancer, but they keep my immune system up, like for example shitake mushrooms, I think this is a better thing, you know, because obviously the dinner table is the main site of WMD's [weapons of mass destruction], you know'(FBAC, 09)

How participants perceived the connection between food consumption and cancer will be presented in the next sub-heading of this category (section 5.2.2). To remain focused on participants' views towards cancer as an illness, the majority of participants echoed that cancer is not a black people's illness. Participants were asked specifically about prostate cancer and reported that they were unaware of black men's increased

susceptibility to prostate cancer over any other racial and ethnic group. Participants were not aware of any reasons why black men would be more susceptible to prostate cancer than any other ethnic group, and used slightly different reasoning to consider '*what makes black men different than other'* (SBAC, 18).

> 'Well, no, I don't think… Because why? If you think about it why black men' (SBA, 26)
>
> 'As a black man, I think, I don't think the risk is any higher than anyone else, yeah it's not, it's not any higher than anyone, I think it all depend on your lifestyle, really, isn't it?' (FBA, 02)
>
> 'To be honest I don't know and again I, I don't have any reason to think that or to reach to that generalisation because of… just, based on colour' (FBA, 22)

The perception that 'cancer is not our diseases' was strong among both African and BAC participants; most referred to consumption of processed food as one of the reasons for this belief, as presented next.

5.2.2 Cancer is caused by processed food

One of the contributing factors to participant's views about cancer was their belief that there is a connection between processed food and cancer. This explanation offered by both African and BAC participants was strongly linked to the reason black men did not see cancer as a concern. Many participants believed that the main cause of cancer was unnatural human activities connected to a modern lifestyle. Participants predominantly perceived that consuming processed food was the main cause of cancer and its unpleasant consequences. African participants specifically mentioned that, as they grew up in Africa consuming a natural and homemade diet, cancer was not their problem to worry about. In contrast, they argued that, in the Western world, people consumed processed food from a very early age and, as a result, suffered from cancer on a large scale. Likewise, BAC participants also believed that, as they were mostly vegetarian and consumed natural herbs while living in Caribbean islands and/or in the UK, cancer

was not their problem. BAC's also strongly believed that consuming processed and/or less natural food that was contaminated with chemicals was the root cause of cancer. Participants used the terms '*processed food'* and '*non-organic*' as synonyms for all mass-produced foods. Although the BACs' explanation was more detailed than their African counterparts, both communities believed that processed food and non-organic food was the main cause of cancer. Hence, there was a strong general belief among participants that since they grew up consuming organic food, the problem of cancer was especially associated with the Western indigenous Caucasian population rather than the black community.

> 'From where we come … we used to eat organic food, when you come to this country, in Europe or in a Western place there are a certain kind of food, all processed inorganic food, so if you are eating those kind of foods from your early age, your risk to getting cancer may be higher, so the black people for those reasons, because they've been, you know, in Africa or some Caribbean countries and then eat those unprocessed food, they are less likely to get cancer. In my belief cancer is a white people thing…' (FBA, 02)

> 'I don't think cancer is a big problem for us, Africans, I think, yeah, Africans eat healthy, they eat healthy natural food, because they don't eat processed, full of chemicals food, back home we don't have the warming from the microwave, you need to cook the food and when that's, yeah, you don't eat food which has been prepared by someone in factory and you just buy it in the shop, you need to cook from the scratch yeah, so we eat home cooked yeah, so, that's why I prefer to eat the cooked meal rather than the warmed microwaved meals'(FBA, 06)

Participants also reported perceptions on a number of other causes of cancer, such as, age, genetics, religion (see Section 5.4.3), engaging in too much sexual activity, and also masturbation. The latter two causes were mentioned by participants as specific to the causation of prostate cancer.

> 'I wouldn't say it's genetic no, if you have bad sexual behaviour, remember this is overactive, you get damage, so you're always sleeping with women, or you're playing with

> yourself all the time, you're going to damage it, … your prostate get damaged, you get cancer' (FBAC, 05)

One first-generation BAC participant stated that there was no convincing explanation for the cause of cancer. However, he felt that traditional herbs and foods were important to minimise the risk of getting prostate cancer and cancer in general.

> 'People are confused about the cause, but most people wouldn't just link it to only smoking you know so, but … I think there hasn't been any good explanation, you know, proper explanation of what, you know, what things can actually be effective against cancer, so that says there's still the belief and I think it's a good one that only traditional herbs and food, you know, can help cancer' (FBAC, 09)

Most participants, particularly BAC's, repeatedly mentioned this lack of proper explanation for what causes cancer, using phrases like '*cancer is bigger than smoking*' and '*they do not tell us the truth*'. Building on these statements, participants expressed their views that cancer was a deliberate plan with a hidden agenda such as population reduction. The findings on this view are presented under the next sub-heading.

5.2.3 Cancer is a deliberate plan to reduce the population

There was a strong belief among BAC participants that cancer was a deliberate and well-designed strategy by social engineers to reduce the world's population. They questioned why, given the amount of money spent on cancer research, an enormous number of people were still affected by cancer. Considering the length of time cancer has been recognised as a major illness, they felt that there was no sufficient explanation as to why it was taking such a long time to eradicate the problem, other than that cancer was being used as an instrument to reduce the population. To emphasise that cancer is a social-engineering project, participants used terms like '*deliberate*', '*they know what they are doing*', and even included the extreme term '*Genocide*'. For example, two BAC participants from different generations (first and second) stated that:

> ‘Genocide is going on really, it’s deeper than the cigarette, the cigarette is minor, you look at the skies, you see the aeroplanes, what they doing they’re spraying you and giving you cancer, they’re spraying out the sky and we’re breathing it in and that is it, that’s what they’re doing, it’s crazy, it’s covering it, it’s a secret, it’s a secret amongst them, they’re wiping out the people, even their own people, but black people as well, that’s their plan’ (FBAC, 05)

> ‘I know, yeah, it’s a bad thing to say but they’re wiping out people but they don’t tell you, it’s a secret project honest to God, and they’ve got this excuse to tell you, you know smoking, this that…. but they only put into your heads what they want you to know only to give in your head, I know you know that cancer research help making cancer better, yeah, finding a way of improving, yeah, yeah, improving people, yeah, but they’ve been doing this for years, they’ve been doing it for years and there’s no change, there’s no change, and I was saying, as I just said to you they know what they are doing, cancer is a secret project’ (SBAC, 01).

The findings of this study suggested that while BAC participants perceived cancer to be a deliberate and hidden population reduction project; African participants did not share this view. However, to identify the burden of cancer in their community, participants from both communities associated cancer with late diagnosis.

5.2.4 Late diagnosis

Almost all participants talked about, or knew about, late diagnosis and described it in their own words, including ‘*it was late for him*’ or ‘*by the time he went to the doctor it was too late*’, indicating that cancer was associated with late diagnosis in black men. There appeared to be a clearly established understanding of late diagnosis of cancer as a routine phenomenon among black men. This association of cancer with late diagnosis was also strongly linked with low cancer survival rates in the community. Of the 17 participants who reported that they knew a black person who suffered from cancer, all but one had witnessed that person die from cancer:

> ‘I’ve seen a West-Indian gentleman come in and unbeknown to him he had got bowel cancer, you know if you’re bleeding from the back passage it’s not good and fortunately for him he was

> coaxed to going in to have some investigation. When he had the investigation, he'd got a large tumour in his bowel, he was extremely shocked, extremely shocked because this is not what he expected at all, but then he went through, had the operation and he successfully had that cancer removed and he's alive today' (FBACF, 16)

Apart from the participant in the above quotation, the remaining participants who knew someone with cancer stated that it was too late for the individual to survive cancer. One second-generation BAC described his friend's situation as:

> 'But by the time he realised and got the chemotherapy and all these different therapies it's a bit too late at that time cos he couldn't do nothing then' (SBAC, 04)

Another participant explained the sad reality that people, even with obvious signs and symptoms of suspected cancer, do not want to go to hospital. The possible reasons for this avoidance are presented in Section 5.5 under the sub-category 'Avoiding Babylon'. The female healthcare professional participant reported from her experience that black men were reluctant to get tested, even when they had obvious symptoms.

> 'I know people that are bleeding from the back passage now, and are totally ignoring it and now that is a symptom, but you're trying to explain to them to get tested and even though the symptom is there they're still not going' (FBACF, 16)

Participants thus tended to perceive that deaths from cancer were a result of late diagnosis. Black men in this study strongly associated cancer with late diagnosis and subsequent death.

> 'There are lot of people from our community, especially woman died of cancer in this country especially in London… so in our community cancer means death, yeah, you see it's not common practise to go for checking so in most cases we are aware of having cancer late, in its very late stage on and so end up in death' (FBA, 14)

> what I found out now that a lot of people who, who don't get checked, like one of, one of my friends who was too late and he died like about, about five weeks ago, you see what I'm saying' (SBAC, 18)

Apart from participants not seeing cancer as a black male disease, late diagnosis was also linked with lack of awareness about cancer in the black community.

5.2.5 Lack of awareness in the community

All participants explicitly mentioned that there was a lack of awareness about cancer in their community. This observation applied to both African and BAC participants, regardless of their generation. Some identified this lack of awareness as being the root cause of why black men did not consider cancer as an illness that could affect them. Although all participants, regardless of generation differences, echoed the same message that there was lack of awareness in their community, the following examples are drawn from each group (FBA, SBA, FBAC and SBAC) to show their individual perspectives.

> 'You see the NHS they've still got a really long way to go, yeah, they've still got a really long way to go' (SBAC, 011)

> 'It's just I'm sitting here and I just know its awareness, awareness, awareness take it to them' (FBAC, 22)

> 'Black people need to be aware that the situation can happen to them and this is how we need to look after ourselves rather than just left to those who go to the GP then and then discover that they've got a cancer, but I think we need to be sort of made, people need to be made aware that black people also can have these cancers' (FBA, 06)

> 'I don't think people are aware of it, aware of prostate cancer and lung cancer; again I don't think people are generally aware of cancer, yeah, all those type of cancers, yeah, I don't think, so awareness is important' (SBA, 15)

The participants' views on the importance of raising awareness about cancer both in the BA and BAC communities corresponded with individuals' responses when asked about their awareness of cancer risk factors, signs and symptoms of cancer, and availability of early detection programmes for cancer. Regardless of generation, there were a few participants who believed that prostate cancer was associated with female genitalia.

> ‘Prostate isn’t that for women or can you get it, is it men thing? I just know it’s a cancer, I think it’s for women anyway, I thought, I think it’s for women, yeah I think prostate cancer’s like for women I do, I thought it was like for women it’s like you know, private parts [laughs] yeah I thought it was for women’s like private parts’ (SBAC, 08)

Participants were generally unaware of cancer risk factors, signs, and symptoms of cancer, black men’s susceptibility to prostate cancer and the NHS prostate cancer management recommendations. Only one second-generation BAC participant, born in the UK, reported that he knew the procedure for requesting a prostate cancer test, as a result of his father having been diagnosed with prostate cancer:

> ‘For a screening, yeah, you have to go yourself and said I want to be screened because my dad had, my dad had prostate cancer’ (SBAC, 11)

This particular participant explained that despite his father dying from prostate cancer and his advice to his three brothers to undertake a prostate cancer test, his brothers ignored his advice and did not present for testing. This was further explored in further questioning in a subsequent interview using theoretical sampling. In his response, the participant reported that his siblings avoided the test mainly because of cultural views towards prostate cancer testing, which will be presented next under cultural views in section 5.3.1.

5.3 Cultural views

One of the primary findings of this study is that culture is a highly influential factor in black men’s views towards cancer. This sub-category outlines how black people’s culture determines the way they perceive the issue of cancer. It is important to highlight that this sub-category overlaps with the next sub-category, ‘*Religious beliefs’*. However, a decision was made to keep the categories separate, as merging them would compromise the ability to explain the essential components of each category at the

micro level. For example, there was a cultural tendency not to go to the doctor among both African and BAC communities. However, the respective justifications for not going to the doctor or to hospital varied. Thus, if the two sub-categories were merged, important details could be concealed, missing this important micro knowledge. More importantly, as the main aim of this research was to explore the influence of culture on the views held by BA and BAC men living in the UK towards cancer, it was of paramount importance to explore cultural views in more detail in order to achieve one of the primary research objectives: to explore health-related cultural similarity and difference between BA and BAC men in relation to their views towards cancer.

It was evident that black men's cultural views shaped a distinct way of looking at cancer and related issues, including early detection, preventative measures to minimise the risks, and understanding that smoking was a risk factor. The sub-headings below show significant cultural views that were contributed properties to this sub-category.

5.3.1 Digital rectal examination (DRE) is culturally disgraceful

Although it is recognised from existing literature that men from other ethnicities may find a DRE an unpleasant experience and culturally sensitive, the degree of sensitivity articulated by participants in this study showed that a DRE for black men was effectively a '*no-go*' (FBA, 24) area. Culturally, it was considered disgraceful for a man to be subjected to a rectal examination, as this may conflict with the significant meaning of being a 'proper' man. If a man were to be subjected to a DRE, he could be perceived as homosexual, illegal in many African countries, and other community members, especially other men, would no longer consider him a 'proper' man.

> 'Pride, well, when I said macho, you know, black man he maybe be ashamed to be seen, maybe be seen as a weakness that's what I mean, it could be seen as a weakness to his male ego, you know, a male ego, he might not have a good standing if his friends then find out, oh you went to the doctor for your

> prostate, you know you might put him down so he ain't gonna wanna do that' (FBAC, 05)

> 'In our tradition men cannot open their anus for other one to go in and so that's culturally is not accepted for a man, it's only women to do this kind of thing, for men to open their anus for examination, so culturally it's not acceptable they, this uh, a very disgraceful thing because you will not consider like a man after that you know that' (FBA, 13)

Participants reported that if a black man were subjected to a DRE, he would be unlikely to share information about the experience with his close friends, as it would be considered a taboo topic, to the extent that black men would be shocked even to hear that a fellow black man had a DRE. This was the experience of one 53-year-old African participant, who was shocked to hear that his friend had a DRE:

> 'He was talking about this kind of examination, I think the examination was anal examination and he was frank and even not ashamed to talk about that subject and he has done that. We were shocked even to hear that he did that and the other friend said I will never and ever do that' (FBA, 13)

The findings of this study suggest that at present black men would not willingly present themselves for a DRE unless they became increasingly ill and ran out of alternative options. This appeared to be the case for both African and BAC participants.

> 'That is highly shocking in community so for you to say that you are going to invade someone or examine someone's back passage they would already have a mental block, nobody not go push them finger up me baaty [back passage] [laughs] I think that is the main cultural issue actually' (SBAC, 20)

> 'Putting their finger in my back passage I don't want that, I don't want to be, you know, invaded by the doctors and stuff like that, it does give that nightmare of being probed' (FBA, 06)

> 'To be honest, I will never even considered it, you know what it is, this pushing finger thing … I don't think black mem like even the thought of it' (SBA, 26)

Many participants mentioned this high level of cultural sensitivity to DRE and they perceived it was linked with late diagnosis by being a '*mental block*' for not attending early detection services. Seven participants also acknowledged that combating this

aversion to DRE was a challenge and needed to be discussed more within the black community. As one African first-generation participant suggested, even though there was a significant social cost attached to it, one way of addressing resistance to DRE would be to share testimony from an individual who had gone through a DRE and benefited from the examination. The importance of describing this type of examination as 'life-saving' and contributing to early diagnosis was also emphasised. The promotion of health benefits was seen as a way that black men could be encouraged to present for examination.

> 'That man which I told you about that he was telling us, yeah, that was an exceptional I can say that, he wrote a poem about that, and the title is I lost my virginity [laughs] and I was wondering why he wrote that poem, he's a poet, a good poet, but it was a poem how the procedure went, … he was saying that, he shouldn't have done it as a man, but by doing it he didn't regret, losing his virginity is okay for the sake of his health,… I think it is good to break this cultural barriers, yeah, silence, yeah, to break this silence somehow, yeah, I know it's people may see you as gay, I think it is good way, the message is good' (FBA, 13)

> 'That's another stumbling block, but I think the more it's out there the more people that go forward and have this examination, that men if you for example, if you've got fifty men to have this examination those fifty men could go on to tell, yeah, they could go on to tell other men, you gonna take the test man and no nothing go to and take it, so it's like they'd have to coax other (SBACF, 17)

5.3.2 Smoking herbs as a healthy and happy lifestyle

In the black community there was a specific cultural meaning attached to smoking. Smoking 'herbs' such as cannabis or marijuana, even though mixed with tobacco, was not considered the same as smoking a purely tobacco cigarette; it did not have the same purpose or meaning for participants. Rather, smoking herbs was considered meditative, and Rastafarians would mainly use it as a ritual. If someone smoked herbs but not cigarettes, then that person would be classified as a non-smoker. The following

dialogue, taken from an interview with a 19-year-old second-generation BAC man is an example:

> I Do you smoke
>
> R I'd say I don't smoke [laughs] I don't, I don't smoke, keep healthy, and keep fit
>
> I Okay, that's interesting, how about herb?
>
> R Yeah, but that is not cigarette it's natural, you know, you can't really say that if you like, you know, you can't really say that smoking herbs is going to cause that, you know what I mean, like you can't really say that, cos it could just happen to anybody (SBAC, 08)

Smoking herbs was considered to be healthy if performed properly and with the right mind-set. This embedded philosophy and the cultural meaning attached to it indicated that BAC men considered herbs to be harmless, even if mixed with tobacco. A 54-year-old first-generation BAC man who disclosed smoking herbs described this as follows:

> 'I could tell you a reason why I smoke herbs, and to me in my mind it doesn't harm me, so I haven't got a conscious about it, it's like some people say herbs are bad for you don't smoke it, but if you haven't got a conscious it doesn't matter to you, it only matters to me if it's, ooh I shouldn't be smoking that it might give me cancer, it's my conscious telling me, but some people haven't got the conscious, it doesn't do nothing' (FBA, 05)

Smoking herbs was also a sign of a peaceful and happier lifestyle, promoted through music in association with iconic figures such as Bob Marley, Peter Tosh, Burning Spears, and others. As mentioned by one participant, there was no perceived link between smoking herbs and cancer:

> Bob Marley for example, he's said to have smoked a lot of herbs, anytime I get pictures of Bob Marley when we see him, he's always, they show him with lots of herbs, maybe it's not true but that's what they show, that's, they just show him smoking a lot, and he was singing all the time and he was peaceful, happy and so on, even though he's also supposed to have died of cancer as well, in fact he was, Bob Marley himself was a man of you know he was strictly vegetarian and that sort

> of lifestyle, so he then he gets cancer, now how does that work, I'm not sure you know, you don't know for sure of the links, there's no links; you don't see the links you know (SBAC, 04)

None of the African participants disclosed smoking herbs. When asked, most African participants were less passionate than their BAC counterparts about smoking herbs; they preferred smoking tobacco cigarettes. For Africans, smoking was a sign of belonging to the higher social classes. Many African participants grew up in a society where smokers were categorised as the elite. Hence, they believed that smoking was a status symbol that indicated joining the elite class.

> 'Most of the people think that smoking is for the rich people so they join the sector of smoking because they want to be on the member of high class people smoking, yeah' (FBA, 06)

The findings of this study suggested that although there were differences in the meaning and symbolisation attached to smoking in the African and BAC context, recognition that smoking was a health hazard that increased the risk of getting cancer was minimal in both communities.

5.3.3 Big is beautiful

The findings of this study indicate that there was belief that being heavy and putting on extra weight makes a person appear prosperous and affluent. This perception that 'big is beautiful' was mainly mentioned by African participants, stating that an African male with a high bodyweight was highly respected and regarded as wealthy. Being big was also considered a visible indicator in the community regarding a man's ability to look after his wife and support his family. Among BAC men, being big was also of significance, but with a slightly different explanation relating more to the negative connotations of having a low body weight; being slim was a sign of poverty and deprivation. Regardless of the different perspectives on body image, both communities

considered big was beautiful and sought after. For BAs, it appeared to be particularly significant:

> 'I mean sometime when I go back home my mum asked me, oh you still look the same, are you sure you're eating properly, you haven't put any weight on and what's wrong with you? You know what I mean, and if you're married and your wife is not putting any weight on or whatever, they consider, well they do think you are not looking after the woman properly you don't look after your wife that's why she is getting thin, well it obviously if you see what I mean big is good in African culture… if you eating healthily you're not gonna, you're never go, well you hardly gonna put any weight on, so you're thinking, oh yeah I need to put some weight on so that people think I'm successful or whatever, so you start eating junk food' (FBA, 12)

For participants, bodyweight had a symbolic meaning attached to it and African men were expected to gradually put on weight during their lifetime. African participants stated that when they travelled back to their home countries, one of the common things that they had to address was their families, and especially their mothers, concern about their weight. Putting weight on was seen as reassuring to the family, indicating that the person was leading a comfortable life abroad. These cultural views explain how some black men choose their lifestyle, wherein leading a healthy lifestyle to reduce the risk of cancer becomes less important.

> 'Even now if I have to go back home my mom will be asking me, why are you not a little bigger, are you eating well and all those things, because they expect you to be a little bit big, massive, muscular' (FBA, 06)

Second generation BA men had different views about weight. The most desirable female body shape was reported as petite but with large buttocks. For men, fitness was perceived as more important than weight.

> 'For some of older generation for them being big is good no change, yeah, but for younger like me so there is change of mentality in terms of what it's all about being healthy, it's not being big, yeah, it's about fitness, you need to be fit yeah' (SBA, 21)

Although views about being big differed between first and second generations, the perception of having physical superiority carried the same symbolism in both generations. Physical superiority also emerged as a property of cultural views and is presented next.

5.3.4 Strong physical superiority

Black men believed that they were physically stronger than others; they also believed that one of the benefits of having a superior physical presence was that they had a better immune system for dealing with illness. The evolution of this belief about physical superiority built up over generations and encouraged black men to believe that they were greater than an illness like cancer. As a result there was a strong belief that cancer did not affect them.

> 'A lot of the young Afro-Caribbean men particularly aged between eighteen to fifty don't believe they can get those types of illnesses you know… in all honesty it's like they think they're super human, this cancer and whatever can't affect them' (FBACF, 16)

> 'I don't know how, I can't explain it, but we are blessed as an African, because there are a lot of things which we can handle, our immunity can handle which this people's immunity can't handle it, because I think we are stronger than them, that is the difference' (FBA, 10)

> 'Actually get back in my memories I know black people saying come on we are stronger, the African skin is stronger and we do have strong body, you know, believing that African immune their immune system is strong, you know, things like that' (SBA, 15)

5.3.5 Hierarchy's power to command

The findings of this study showed that, in both African and African-Caribbean culture, social hierarchy was important in various aspects, including communication and conveying information. As participants explained, in these cultures, obeying the word or order of respected and older members of the community was widely practiced.

Participants highlighted the importance of health professionals, such as doctors, communicating assertively, powerfully and authoritatively with patients, rather than engaging in any form of shared decision making. This active and assertive approach would demonstrate to black men that health professionals cared about their health, and could subsequently promote increased uptake of services by black men and compliance with treatment regimes. Participants reported that health professionals should demonstrate that they are in command but should also show that they care, providing reassurance that they will not cause black men harm. Participants explained that this approach would engender more trust in health professionals. A 54-year-old BAC man illustrated this in his response:

> R ‘He’s a Rasta [participant referred to his friend], he’s got a different perception, he’s got all these people who are English people around him, this is what I’m saying, if he was a Jamaican like a strong Jamaican I said, look brother you have to go through the procedure man this serious, if you talk to him in his tone of voice then he would have to take him serious’
>
> I Do you think that would have made him go
>
> R ‘I think that is crucial, I think if he was a black doctor, “what you talking about, you have to come back, I’m booking your appointment and you’re coming back here do you understand, it’s serious [loud tone of voice]”, that kind of talk will make him realise and say yes doctor, all right doctor, yeah man, I will come; you must show him you care for him: “listen, I’ll phone you the day before to make sure that you’re ready for this operation.” This is what is lacking in health services, yeah, they should employ more black doctors, African doctors, who’s familiar with, with the Caribbean and stuff like this’(SBAC, 11)

Social status was perceived as important to both BA and BAC participants. However, for African participants, status and authority were associated with occupation and also with age; if a person was older than you they commanded respect regardless of their

profession. For BAC participants it was the style of communication that primarily commanded respect; preferably loud and authoritative.

> 'I've spoken from African point of view right now, we are expected to listen anyone who is older than you, you know, you have to respect that person even he is one year older than you… because actually he is more experienced than you, I do believe we actually brought up in the world actually to be obey authority you know to respect for hierarchy, so should any order actually come from the authoritarian person like older than you, a religious leader and people expect to obey that law and order' (SBA, 15)

5.3.6 We do not go to hospital

Participants had strong and fixed cultural views about what it meant to go to hospital. For both communities there was a culture of using traditional healers or taking traditional herbs to deal with illness rather than going to hospital. Many BAC and African participants believed that Mother Nature had always provided treatments and cures for any illness.

> 'For most people from the Caribbean or Africa, mother nature has always provided the best natural remedy, you know natural herbs for the treatment and cure of any illness or disease, that was how our forefathers dealt with illness, yeah, you know, they're closer to mother nature' (SBAC, 20)

Among Africans, although this view represented a long-standing cultural tradition towards curing illness, participants recognised that more recently, modern medicine had become more visible in their home countries. Although acknowledging the developments in modern medicine, the majority of Africans participants preferred to go to traditional healers or to seek religious remedies such as holy water and exorcism. Going to hospital was the very last option, only to be considered when people became very ill. This view applied both before and after participants had moved to the UK.

> 'Normally we don't go to doctor unless we are forced illness unless you are forced by illness to your bed you don't go to the doctor, most of the time we got traditional and religious things

> for it like holy water and there are a lot of people who claim that they can take out bad and evil spirits from human beings,….that gentleman (exorcist) taking out the evil spirits from a lot of people so this includes cancer, back pain, yeah, even I've heard a priest claiming that he can cure the HIV' (FBA, 14)

A similar view was held by BAC men; unless a person became very ill he would not go to hospital; hospital was a last port of call. However, there were cultural differences in the justifications for not going to hospital. African participants mentioned that African men (particularly first generation), living in western countries like the UK, expected to do well in life and be financially secure for themselves and their families back home. Participants referred to this as 'the dream' of African immigrants. For first-generation Africans, going to hospital was a sign of weakness. If fellow community members saw an African man visiting his GP frequently or going to hospital, he would be considered weak. Seeking medical attention was seen as a sign of weakness since illness could mean a man's dream to succeed was about to be crushed. Participants explained their reluctance and preference not to go to hospital unless it was unavoidable.

> 'They all think, oh what's wrong with this one, why he's always going to the doctors, going to hospital to the doctors, so yeah people, people don't want to show that side of themselves, no, I don't want to show that side of weakness, you know you're here to do something good for you and your family, to achieve something, you know what I mean, not to be, not to go hospital to doctor, yeah, people think you are weak, you are a loser, losing your dream' (FBA, 12)

> 'Like, myself, I don't visit the GP that regularly, because it's like been a weak, like, sort of like, you can't achieve your dream, you know what I mean, you can't afford to be seen as a weak, you have no option except to make it so you have to be strong, yeah, you get me' (FBA, 06)

For BAC men it was about belonging, and a recurring expression articulated by this group was that 'Western medicine is not our thing' described as '*Babylon*'. These participants explained that they had their own 'medicine' (herbs) - which were prescribed by natural healers both in the Caribbean islands and in the UK.

> ‘Right, this is a pride of belonging, which is we have our own traditional medicine, herbs, modern medicine is not ours. We have our own, that’s it, don't want to go Babylon, it is not our thing our culture and thing, we have our own, that’s it’ (SBAC, 16)

Moreover, BAC men inherited this mantra of ‘going to hospital is not our thing’ from their parents. This was echoed by a number of BAC participants, who recalled being advised by their parents not to go to hospital, as they considered hospital to be a road that leads of death.

> ‘Even my parents they never go, well my father never go to hospital he doesn’t even, if somebody was in the hospital, even had a friend he was in the hospital and his friend sent him some things to help him you know some, some gifts, I was young, but he said you know we don’t go to the hospital [begins to whisper], not even to visit’ (FBAC, 09)

> ‘We don’t go to hospital, most black men don’t go, because, it’s like the waiting room of a, of a, of a undertakers parlour, when people go to the hospital they’re, they feel that, you know next thing happened you’re going to be dead, you know, now some of that, you know, partly is to do with the medicine and part of it’s just a dislike of the hospital, but many people do not even visit because it, it just carries this thing that they make you sicker’ (SBAC, 11)

It is evident from the data that the reasons that BAC men avoided going to hospital overlapped across two sub-categories: ‘*Avoiding Babylon*’ and ‘*Suspicious mind*’. This mirrored participants’ explanation for themes like mistrust and past historical events, namely slavery. However, these specific elements will be presented in detail further in this chapter, in Section 5.7, under the sub-category ‘*Suspicious mind’*. As mentioned in the outset of this category (cultural views), the category also overlaps with the next category, religious beliefs, which will be presented next.

5.4 Religious beliefs

Religious beliefs formed another significant sub-category influencing the views of black men towards cancer. Most participants talked about their religious beliefs. Participants

also highlighted that a majority of black people were religious and took religion very seriously. This should be considered alongside the findings of the research, which suggest that religious beliefs influenced how black men established their views about cancer. This will be further elaborated by presenting findings in the following sub-headings.

5.4.1 Eternal life

The concept of eternal life was very important in terms of how participants viewed cancer. For BAC participants, especially those who followed the Rastafarian religion, one of the core elements of the religion was that once someone reached a high level of spirituality, he would receive eternal life and become immortal. As this gift of immortality was earned throughout life, it was important for the believer not to jeopardise receiving such a gift by questioning it once it had been received. Participants mentioned that for someone who reached this level of spirituality, illnesses like cancer were not a concern, as the person would be bigger and much stronger than the illness, because his spiritual strength was much more powerful.

> 'It's very difficult because, all right, for example, these things go right into the roots of our belief system… one of the belief is a Rasta Man would say I cannot die you understand, they would think, no I just cannot die because I'm deemed with eternal life and you know I cannot die, so a lot of them evade the death issue, you know, so when you buck up [meet up] on death now or cancer, that can't bother me man, it is like cancer doesn't touch them, they'll say something like that cannot affect me because I am over that' (SBA, 04)

For Africans, eternal life meant being a spiritual human rather than just flesh and blood. African participants believed that eternal life, if granted, would be retained despite getting cancer, as God would remove the cancer from the body as a result of the richness received in eternal life.

> ‘God gives people eternal life, you know, if you believe and act as a human being reach to the highest stage in your soul and spirit, you know, even if you have cancer if you believe and prays to God you can live long; eternal life cannot die’ (FBA, 10)

Although participants from both communities indicated the significance of eternal life, there were differences between the communities’ beliefs in terms of the effect of eternal life. BAC men believed that once a person received eternal life, cancer would not affect them, while African men believed that as a result of receiving eternal life, a person would be cured from cancer.

> ‘In simple way it means living forever without dying, well God created man to live forever isn’t it, but it’s just through sin that is why we are die, you can live forever but we all sin, if we stop sin our life will be prolonged that’s simplifying it, if, if you’re blessed with eternal life any ailments, cancer ehhh prostate cancer, whatever, can’t affect you, you know you are bigger than cancer, that’s a simple way to say it, you know it’s more thought process than just that…’ (SBAC, 20)

The concept of eternal life (immortality) described by participants was associated with individuals’ high level of spiritual rituals. However, even for less spiritual but religious people, cancer had some positive aspects, by offering different perspectives of life, as described by participants in the section below.

5.4.2 Life will be more meaningful

Some participants explained this component of religious thinking. If a religious person was affected by cancer, it would change his life for the good, because as death approached, it was time to take life seriously in preparation to meet God. Thus, life would become more meaningful to a cancer patient and this belief would help individuals to do meaningful things that were acceptable in the eyes of God. It was suggested that an experience of such illness offers individuals some certainty as to the direction in which their soul was heading, and that therefore they must do things that

would help this journey. The following segment of an interview with a 52-year-old second-generation BAC man is a good illustration of finding the good in bad news.

> I If you get cancer what would be your reaction?
>
> R My reaction would be I have to go to the doctor [laughs, not convinced about treatment], … I would be, I'd say my prayers, I would see my priest, I would, I'd just have to take life a lot more serious, I'd have to cos I know that my day is coming to an end and I'm coming to, I'd be looking forward to meeting my creator actually, so that's what I would do personally
>
> I So are you saying it's not all bad news?
>
> R No, no not all bad news, do you see what I mean, because you have your bible you can read and the way it's gonna, the words are going to have meaning to you more, maybe before it didn't, but now when you read it it's going to give you a lot more meaningful when Christ said things or St Paul or Peter or any of the apostles, and you can, I can identify, I can identify with it now more, yeah, it's not really bad news really (SBA, 04)

5.4.3 The Power of God

There was a widespread religious belief among Christian participants from both the African and African-Caribbean participants that cancer was a punishment from God for people's reckless behaviour. Hence, having cancer could be seen, particularly among the Christian members of the community, as a curse from God for being sinful.

> 'That's why God set the order, he said man go with your woman and stay with your woman, but man don't do, they've got eyes for every woman, and everyone will let him, he jump on her [multiple partners], but you pay the price in the end' (FBAC, 05)

Some participants indicated that a majority of the people in their community who held the view that cancer was a rebuke from God were less educated or knew very little about what cancer really was.

> ‘It’s just grows, just grows something in your body cos your evil action, God always sees us, you know what I mean, you get punished for what you’ve done before, that’s right, that’s right, I don’t think they necessarily understand what cause, what are the causes of cancer’ (FBA, 12)

Relating to the religious belief that suggests cancer was a punishment from God, there was the belief that only God had the ability to cure cancer. One participant stated that religious people in his community who strongly believed that cancer was from God, also believed that any cancer treatment (whether Western medicine or traditional herbs) would not bring cure, but was simply a tool of ‘God’s will’. There was unseen spiritual guidance and protection that enabled treatment to be effective; treatment became effective only if God’s mercy came through to heal the person:

> ‘Some people they just don’t believe this is a kind of problem of health issue we can get it, get rid by scientific way, … because they have a strict belief once you get cancer you can get rid of it by help of God rather than by scientific medicine. That is it, it is very, you know, some people believe with that yes that’s true … well everything, herbs or, you know, any tablet, I mean medicine, even the doctor himself is a bridge … without the power of God will, no one can save you…’ (FBA, 03)

In contrast to the religious beliefs of Christian participants regarding cancer, the Islamic way of thinking about the issue was that chronic illnesses, including cancer, was a way of gaining forgiveness from Allah. It was perceived that people were suffering on earth in their temporary mortal life in order to wash out their sins and to ensure that their permanent life after death would be in heaven. One religious Islamic cleric who was recruited using theoretical sampling also confirmed this religious belief. Another Islamic participant who mentioned this religious belief stated that

> ‘Anything regarding, regarding to science is in the Koran, but I can only really recite, what I know is in Islam if he is a good person and have cancer things like that it is a sign of washed-out, forgiveness from Allah because he don’t take the sin, he will be pure when he go to Jannah [Paradise]’ (FBA, 10)

5.5 Avoiding 'Babylon'

Participants used the term '*Babylon*' to magnify their disassociation with something that they needed to avoid. The term 'Babylon' used by participants had negative connotations in the light of Rastafarian philosophy; where Babylon' symbolised economic and political oppression. BAC participants in particular used this term often in referring to the modern healthcare system. Examining the data closely in the final stages of the data analysis process revealed that participants mentioned '*Babylon*' 147 times in 12 interviews. Although this sub-category overlapped with the sub-category '*Suspicious mind',* merging these two into a single category would minimise the opportunity to carry research participants' voices throughout the research process leading into writing up, which Charmaz (2006) suggests is one aspects of undertaking the Constructivism Grounded Theory method. With this in mind, the core properties of this sub-category are presented below.

5.5.1 Me not going to Babylon (modern medicine as 'Babylon')

Participants viewed Western medicine as Babylon, which was toxic and impure and considered to be the road to death. In particular, pharmaceutical medicine was viewed as toxic and damaging to internal organs. Some participants also considered healthcare professionals to be a part of Babylon.

> 'Nothing can touch IanI [<u>you and me/I and I</u>], me not going to Babylon doctor to fix me, I will go and get some herb, get some malunggay, some mariandina, some whatever and use that herb to cure me that's natural that's right not Babylon' (SBAC, 20)

> 'They wouldn't like to put their hands in the hands of the medical system here because they're not doing a very good job of looking after their own sometimes, much less us, so you feel that kind of genocide, as a black man you'd probably say, why me now go to doctors and let them kill me' (SBACF, 17)

5.5.2 A person like me - black doctors

Another reason that black men avoided the UK healthcare system was the perceived lack of black healthcare professionals; doctors and nurses who could understand their way of life, culture, and methods of communication. The findings also suggested that for black people, treatment was not only about taking medication or undergoing interventions in a given medical procedure, but also about being understood and feeling cared for. The presence of black healthcare professionals would enhance such feelings. This was also an important component of attempting to establish trust and confidence in the healthcare system.

> 'From a kid I've always watched them, whether it be Black, Asian or White doctor, the Black man will prefer his own… you go in for an Indian like, Indian surgery, yeah, and you see how long the Indian man step inside and with the doctor, you go in there and you're in and you're out straight away he said bye right you're supposed to sit down so he can prescribe you your ailments, but they don't… I would be happy to see black doctor' (SBAC, 01)

> 'I know that might not be a case always with everyone but with me I prefer seen by a black doctor or a black nurse, yeah, the background of health professional matters, it matters actually, I think treatment always started from communication, communication is very basic and big thing, so if there is any barrier whether it's the colour, the language, the culture or anything there can be a barrier or there can be an element which enhance the communication to each other so you can see why it's important to see black doctor or nurse' (FBA, 14)

> 'I think partly the problem is, right, we don't have enough black doctors, we need more black bringing in, we need more black surgeons and we need more black people in, in those areas' (SBAC, 11)

A small number of participants reported that they had been involved in community work and perceived that black men were more willing to go to their community centre for an intervention, including cancer screening, than attend a GP practice. If they were invited by their GP they would be more reluctant to attend.

> ‘I know that our elderly members if we invite them for screening here in our community centre they will come, if their GP ask them they might be reluctant or they might think that I’m okay I don’t need to go or it’s not important and they will reject the invitation, yeah’ (FBA, 13)

5.5.3 Traditional (natural) herbs versus Western medicine

A majority of participants were keen to talk about the comparison between their traditional (herbal) medicine and modern Western medicine, using the expressions ‘our black people’s own medication’ and ‘Western medicine’. Most participants reported that black men were afraid to take medication, believing it made them worse and weaker. Many participants were also convinced that in Western medicine settings, their body tissue, like melanin, could be extracted without their consent (this will be presented in detail in section 5.7.3). The overall view was that Western medicine was toxic, impure, and contaminated, causing more harm than good: Babylon. Whereas herbs were pure, natural, and given to humans by God since the start of time, making them a more effective remedy.

> ‘The medicine western medicine have gone through trials, they mix with chemicals, they’ve gone through processes, a lot of them have side effects, a lot of side effects, you can take the tablet and you’re going to get something else, a lot of our people don’t believe in those things…we have our own, don't want to go Babylon’ (FBACF, 16)

> ‘God give us the earth and he gave us the herbs to eat and that is our medicine, that’s our proper food, but we stray from that and start eat different things, taking western medicine and that causes reaction in your body, and can trigger different kinds of cancer’ (SBAC, 08)

One participant, who was a natural healer (traditional herbal medicine practitioner), drew on his own experience to compare and contrast Western medicine with herbal medicine; he stated, for example, that chemotherapy offers very little benefit and that its harm overrides its benefit.

> ‘Well personally I haven’t seen much benefits in the chemotherapy myself, like I wouldn’t, I don’t tell people to don’t do it, because they have to make their own decision, but and I work with people whether they do it or they don’t do it, but when we look at the chemo if you look at the real world wide benefit, it’s just a tiny per cent of the people, you know who I think benefit with it, they did a survey where how many benefit and it was just a tiny percentage, and then personally I think that the chemo actually weakens your response to cancer, because it knocks down your immune system, and knocks down your appetite, it knocks down your ability to fight back you know’ (FBAC, 09)

This particular participant also asserted that, from his experience as an herbal medicine practitioner, most black cancer patients used natural herb remedies as backup, even if they primarily used modern medicine. He further claimed that more people who have recovered from cancer have done so through using herbs rather than through chemotherapy.

> ‘A lot of times when people go get cancer, even if they’re taking, no matter what treatment they take they will also take some herbs, like for example the Guinea hen, hen herb is particularly very good for prostate, people also use another herb called Soursop, which is considered also a powerful cancer herb, so people I mean that’s a popular knowledge there about these anti-cancer herbs and like I say most people when they do get sick, even if they’re taking like chemotherapy or different other treatments, they also tend to take these herb, herbs are more effective than chemo’ (FBAC, 09)

This claim that herbal medicine was more effective for cancer treatment than western medicine was echoed by many BAC and by a few African participants. It is important to note that the female healthcare professional participant also commented on the use of herbal remedies to treat cancer, indicating that black people were keen to take herbal remedies in preference to western medicine.

> ‘When you look at some of the alternative medicines that have been developed recently and have claimed to heal cancer, like mariandina for example, the merengue and other herbal remedies that have been put together, you know we tend to look at those natural remedies rather than looking into Western medication’ (FBACF, 16)

This established belief by the black community had convinced participants that modern medicine was harmful, and that their 'God given' '*our own*' natural-herb medication was more effective in treating cancer. Holding this view emerged as one of the major reasons which would allow black people to avoid 'Babylon'. A desire to avoid Babylon could discourage black men from utilising western medical services. Participants expressed that even if black men accessed western cancer services as a last point of call, they would likely withdraw from, or refuse, cancer treatment. To provide support for this belief about non-compliance participants relayed stories about people they knew who had refused or terminated their cancer treatment. In the following quotation, the participant talks about his friend who terminated his treatment because he remained unconvinced that going to hospital (Babylon) had been the right course of action; he died the following morning after discharging himself from hospital.

> 'This brother's wife she told me he was in hospital like for three weeks and he didn't want to stay there, then he came home as normal, he's acting as normal then he went to bed, and then in the morning he just died' (SBAC, 04)

The following quotation is from a participant who discussed a close friend who terminated his cancer treatment because of the adverse side effects. This participant was using his friend's condition to explain how western medicine ('Babylon') was harmful.

> 'He's going through, he's taken radiotherapy, yeah, then he, he, he done the first two and then he had a, he had, he had a nasty reaction, and then he's not gonna bother with, with the last process' (FBAC, 08)

It is also important to point out that many participants mentioned that black men refuse treatment so as not to suffer from the potential side effects of modern medicine in comparison with herbal remedies. However a few participants also mentioned some black men who refused prostate cancer treatment, preferring to give priority to their sex life.

> ‘One person had prostate cancer he’s from Africa, western African he has been referred to hospital and the hospital doctor asked him to take it out [the prostate], to remove it, he said, no I love sex’ (FBA, 13)

5.6 Alienation

Alienation was an axis around which participants’ suspicion, mistrust and apprehensive views rotated. Participants felt unwanted and alienated by the social system, which breaks down population by age, ethnicity, and class. Participants spoke about their feelings of disfranchisement, referring to various institutions, including the healthcare system in the UK.

> ‘About the blacks, they don’t give a shit about the blacks, they don’t give, they don’t care about the blacks’ (FBA, 11)

> ‘I’m fifty-eight now, when I reach sixty-five and I take ill, they’re not going to bother with me, they’ll leave me to die, because what am I going to do for them, it’s better for me to go out of the way so that someone else can have this place, yeah, so they won’t, I’m being honest’ (SBAC, 01)

Participants perceived that black people were considered less important than others in UK society and within the social system, including the healthcare system, than their white counterparts. Most participants mentioned alienation as a reason not to trust the NHS, as detailed in section 4.7.2 under the sub-category ‘*suspicious mind*’. Participants also reported discrimination and racism, mainly by establishments, alongside other ill feelings. These ill feelings emerged as a contributory factor with two layers: feelings of being pushed and controlled by the system.

5.6.1 Controlled by the system

Participants expressed their conviction that black people were controlled by the system, naming the education system, prisons and the criminal justice system, and also the healthcare system as the main tools and mechanisms for control. Participants from all

backgrounds shared this view. However, BAC participants, both first and second generation, were more sensitive to this issue than African participants because of past historical events, primarily slavery. This finding was strongly linked to the next sub-category, '*Suspicious mind*'. Section 4.7.2 provides further interlinked information.

> 'The system is against black, if you look at everywhere healthcare, prison system, education, yeah, all of them, you know what they are doing, they will tell you that you are crazy then put you in hospital or jail that is where black men end up man' (FBAC, 05)

> 'I was born here, the mind-set isn't right, they've been messed up, they've been through the system man, some people call it brain wash, but you've just been messed up, they messed us up, but a lot of us aren't conscious of it…. you've been inculcated into your head to hate each other and to hate yourself, not just our generation, it go back to slavery and it hasn't stopped.' (SBAC, 04)

Two female participants who were recruited as part of the theoretical sampling approach echoed this feeling of being controlled. The female healthcare professional participant described why the healthcare system was perceived as a mechanism to control black men:

> 'The other thing that you need to look into is the high representation of black people within the mental healthcare system that's where everybody is and the prison association, where the medication there is deemed to be a method of control, a lot of our brothers have been controlled, they are taking medication, … and that medication has honed them down to a level where they are being controlled by the system, turned into zombies' (FBACF, 16)

5.6.2 Doesn't want to be black

Some black men reported that they did not want to be black because of issues associated with being black, including slavery, being disrespected, and other perceived societal outlooks and injustices. It was also evident from the data that a black person was considered more likely to be able to promote public awareness about cancer among the black community than a white person, especially well-known individuals such as black

male celebrities. However, these participants indicated that most black people did not view the majority of black male celebrities as a 'proper black men'. UK-based black male celebrities were frequently described in interviews as not being black anymore, because they were seen to have become more westernised in their cultural, social, and behavioural aspects.

> 'Black doesn't want to be a black man, because he'd bring you back to slavery, nobody wants to go back there, but subconsciously we think we can go back there, cos they can do it to us again, so every black man doesn't want to be a black man, so he'd dye his skin, he'd put blonde wig, he tried to be not a African who he really is because he's so terrified and frightened, and then he just give up in it, did you know only one, only one footballer who has black wife out of how many of these black footballers? Only one…. who's confident or brave enough to stand up and make, and just be a black man, all the black people who are in the public eye got to behave like the white man, they're not really being a black man' (FBAC, 05)

> 'Well [laughs], well, I mean when black people get, you know, actually, let me put it this way, when black achieved they changed, music change style, everything, you understand, they become modern Westernised,…. Yeah, it's true, they, they don't, mm, yeah, they don't want to be black… I am being honest, that is how they act, for me anyway and they don't want to be black' (FBA, 11)

Although participants strongly believed that black male celebrities could use their influence to promote public awareness about cancer, they were also perceived by black men to be more acculturated. Hence, their influence in changing black men's attitudes towards cancer were probably limited.

5.6.3 Money and class

Although participants acknowledged that the NHS was free at the point of access, they also perceived that levels of affluence had a powerful impact in determining who received the best healthcare services. They reported that the less affluent, or poor, did not get a 'good deal' out of the system. When seeking clarification on who was poor, the response was that black people were the poor.

> ‘Yeah, it’s [NHS] supposed to be free but, I don’t think, I think they pick and choose who they want, let me explain to you, … this is the God’s truth, you put your, one of your family in the hospital and she’s not well she’s soon to die they’ll do it for you, honest, with cancer my sister died of it, that’s what I was trying to say to you, without money you’re nothing’ (FBAC, 01)

> ‘Without money you don’t survive in this white-dominate system, yeah, but go to the hospital and say, look I’ve got cancer I need a cure, as long as you’ve got the money you’re alright, me and you if we haven’t got the money and you’ve got an illness, you haven’t got a chance’ (SBAC, 20)

As illustrated in the above quotation, most African and BAC participants emphasised the importance of affluence; ‘*without money we are nothing*’. They also reported their belief that the system does not encourage black children to prosper in terms of financial reward and career opportunities.

> ‘Well I think most people have cynicism, probably it’s a little bit stronger among blacks, because there’s so much stuff that hasn’t worked out for us, you know what I mean, and then also we add that to the financial thing that to get the better treatments you need more money, but the system is not working for blacks, we are the poorest of the poor’ (FBAC, 09)

5.6.4 Identity clash - where to belong

BAC participants perceived that they lived in a culture inside a culture; living in two cultures. From these participants’ responses it appeared that they had been deprived of their ancestry’s culture. They also felt disconnected from the ‘British’ culture because they perceived they did not belong. Six BAC participants stated that this confusion as to where they belonged made them suspicious of authority. This identity clash escalates participant’s suspicion.

> ‘Remember, you haven't been disabled, you’ve got your culture, Ethiopian culture, over thousands of years passed down, ours has been broken and we’re blind and deaf to everything, so we don’t know nothing… they know how to trick and fool us all the time, you know (SBAC, 04)

> ‘Because of my experience and my parents come from Jamaica and I was born here, but my parents, I still don’t even know

> their history properly because of slavery, my mother doesn't know her grandparents and they were slaves and that's just a little gap, just a little gap, you know, but because of the way everything was, it's disconnected, I've lost track of' (FBAC 05)

> 'They force their culture on us and it doesn't fit, it's like a suit that don't fit and it's uncomfortable, you want to take it off but you can't, well that's them squeeze the culture on us like that, and even that can cause cancer, in fact, just worrying can cause you cancer' (FBAC, 01)

5.7 Suspicious mind

Participants were uneasy about society's structure as a whole. Their suspicion of the healthcare system, the NHS as an organisation, and the healthcare professionals working within it was very apparent. The majority of BAC participants mentioned that the residue of past historical events like slavery made them apprehensive of doctors and their practices.

> 'As we have issues already as coming from slavery, the first thing we're thinking of, well they're gonna experiment on us but if you were white you'd probably think it's a doctors, and you wouldn't think they're experimenting…well if you've been slavery and you're talking of even today we touched on some form of genocide' (SBACF, 17)

Participants were not only suspicious of NHS practices, but also of cancer as an illness and the treatment for it. This seemed to give rise to several conspiracy theories. It appeared that the BAC participants' suspiciousness was strong and deep, as presented in the following three main properties.

5.7.1 Mistrust of the healthcare system (NHS)

African participants were grateful and appreciative of the NHS. This was mainly because they came from countries where free healthcare was not widely available or accessible.

> 'In the UK, you know, the NHS would provide the service people would welcome people from Africa' (FBA, 02)

> ‘Up to so far I think from my background, my South African background, I think the NHS is the best place to be is like a high class health services, if you compared it to what we have back home, because back home we have got two system for the private and the government, and the government is not good, the private is good but you need to have money, so the NHS I think is the best’ (FBA, 06)

However, although African participants expressed appreciation, overall, participants from both the African and BAC communities mistrusted the healthcare system. Africans’ mistrust appeared to stem mainly from bad experiences of having accessed the system and then feeling disfranchised.

> ‘There’s no trust, trust issues, there’s a huge trust issue, a lot of men will not got to the hospital because they won’t take the tablets, me no one want nobody come to kill me off’ (FBA, 10)

Although BAC participants shared the same feelings, the causes of their mistrust went back further, to the period of slavery

> ‘When you’re looking at the Caribbean islands as well you must remember what they’ve suffered and gone through, that’s slavery as well, and how can you in this time, even though it happened so long ago, if you are ill, if you are then putting your hands in the hand of the oppressor yourself, back into the hands of the oppressor, if he put you into slavery and you are ill you are giving him the opportunity to do as he will with you, so rather than put your hands back into the hands of the oppressor, you’re gonna say, I’m gonna cure myself and we don’t need you, there’s no trust’ (SBAC, 17)

In addition to views expressed by participants such as cancer is not our illness and lack of awareness about cancer in the community; this deep mistrust of the healthcare system appeared one of the reasons for late diagnoses. One participant asserted that, as he does not trust the healthcare system he would not go for cancer screening if he invited.

> I Will you go for cancer test if you invited
>
> R Doesn’t trust NHS man, me not go there, don’t trust them, I don’t trust Babylon man (SBAC, 20)

African men did not raise slavery as a reason for their mistrust of the healthcare system. The main reasons given by African participants as to why they did not trust the NHS were bad experiences and a shortage of black health professionals in the NHS.

5.7.2 Conspiracy

There was a widespread assumption among participants that a conspiracy existed, wherein a cure for cancer existed in Western medicine, but this cure was not given to black people because they were black.

> ‘You know, cos surely there is a, I know there’s a cure for cancer, they’ve got a cure for cancer, they don't give it to black people’ (FBA, 01)

In addition, some participants reported that black people had a cure for cancer in their own traditional medicine, but this cure was not accepted by Western medicine. A conflict of interest was proposed; the falling revenue from cancer drugs that would result from the emergence of a ‘traditional’ cure would lead to individuals and organisations being put out of business. Participants pointed out that by rejecting the black people’s cure for cancer, and undermining black medicine, and particularly herbs, Western medicine continued to promote itself and its interests.

> ‘Yeah there’s a cure, we’ve got it already but if you open your mouth you’ll get killed, they will kill you, if you open your mouth and say, look, I’ve got the cure for cancer, well what would happen, their systems would be destroyed because it’s money, all the money that goes to cancer research and everything wouldn’t be there anymore cos you’ve got the cure’ (FBAC, 05)

> ‘We have the cure for it but the problem for the cancer industry they can’t market it, they can’t market because they can’t, you can’t get it exclusive on natural things, that’s why they went slow on … on bringing this to the fore, like they found different things over the years that they know would work, but yet the market because that is how this whole thing go, the companies put money into the research, not to cure cancer but to make money off the cancer medication, but if you use a herb you can’t, you can’t get exclusive rights on that because it’s a herb, right, it grows on earth, so this is why they’ve been very

> hesitant, you know so this is, and people sense that because then if you see, if you know of people taking herbs and got rid of it, but yet we see that the cancer … the people who are supposed to be studying cancer never say that the herbs, in fact they say this don't really work, so this is the values' (FBAC, 09)

Another widespread conspiracy theory among participants was that when black people give blood samples, their melanin is taken without their knowledge to be used in the cosmetic industry. This was another reason mentioned by participants, reinforced by advice from their parents, as to why black men preferred to avoid giving blood samples in medical settings.

> 'My mom used to tell me when I was young, when you go to the doctor don't let him take your blood, let me explain, if you have our skin melanin, you heard the word melanin, the white man you've seen it all the actors, all the actors, film stars they're always brown aren't they, they're always, skins always, a lot of them their skins are brown you think it's tanned, no it isn't they take our blood and then they pass it on and use it, because our melanin, you see' (FBAC, 01)

> 'All the things they've been doing with black people and the foetuses, how have they been getting the melanin, where are they extracting the melanin from to now be selling melanin injections, now they're telling you, you don't have to go on the sunbed they can sell you melanin injections, so we know that melanin comes from black people, so where is the… where, how are they getting that resource' (SBAC, 17)

5.7.3 Suspicion

There was a strong sense of suspicion among black people towards the healthcare system, as illustrated below. Some African and many BAC participants believed that black people were subject to clinical research and scientific experiments without their consent. African participants in particular asserted that they were unfamiliar with the system. They also highlighted that there was no influential BA person in the NHS, in participants' own words, a '*big person*', to advocate on their behalf. Given these reasons, African participants showed their suspicion of the healthcare system by asserting that no one protects African people from being '*guinea pigs*' in the healthcare

system. For BAC participants, lack of understanding of the healthcare system was not a concern, but they did not trust the system at all. African Caribbean participants' suspicion appeared to be deeper than that of the African participants, because of links to slavery as shown in section 5.7.2. The result is that they did not have first-hand experience and understanding of how research was carried out, what kinds of participant-safety and protection measures were in place, and the degree of ethical scrutiny in place to ensure that research did not compromise patients' wellbeing. Most participants would not believe that safeguards were in place and they seemed convinced that doctors experimented on them without consent.

> 'To tell you exactly, yeah, and another thing is we're all [black people] guinea pigs, I know that, we're all guinea... we're guinea pigs, we're guinea pigs, honest, I found that out when I was eighteen, I realised' (SBAC, 01)

> 'Mistrust, they're not gonna give blood because of this, they're not gonna go and take the tablets because of that, because of this, I'm not having the operation so they can use my descender [Semen/reproductive tissue], it's comes in many forms this mistrust and suspicion' (FBACF, 16)

The combination of the research process being invisible to black people and their history, mainly slavery, along with reported experiences of medical negligence or bad personal experiences within health services did not seem to provide these participants with any reason to reduce their suspicions towards the healthcare system.

> 'Experimenting on our kids… there's a lot of, and experimentation is another thing that people say, we don't want them experiment on me, a lot of mistrust, a lot… It's happening, it's, black people are very, very suspect of the system more so' (FBAC, 09)

> 'Don't forget the experiments probably going on, but their own people probably not taking no notice, but as we have issues already as coming from slavery, the first thing we're thinking of, well they're gonna experiment on us but if you were white you'd probably think it's a doctors, and you wouldn't think they're experimenting, but they still are experimenting' (SBACF, 17)

5.8 Advertisement and information influence very little

All participants agreed that cancer-related advertisements and information outlets did raise awareness about cancer. However, they strongly believed that in their current format, cancer-related advertisements available within mainstream mass media, and cancer-related information in mainstream publication outlets such as Cancer Research UK or Prostate Cancer UK had very little impact on raising awareness among black communities. There were several reasons for this, the most dominant and significant of which are presented as follows.

5.8.1 Linked to money-making

Participants felt that cancer advertisements were very much linked to financial gain, with inconsistent money-driven health messages being relayed. Examples they provided were that; one day it would be all over the media that consuming particular foods and alcoholic products would minimise the risk of cancer or increase the chance to be healthy, and the next day the same products would be presented as having the opposite effect, the same product now considered a hazard to health. The following quotes from participants are examples of the inconsistent messages participants felt they had been subjected to:

> 'I think companies and producers employ scientists to study for this, and that's why it, I mean that's what people think sometimes because when, yesterday for instance or last year someone says don't eat red meat or don't drink red wine, red wine's not good and again they come back next time and tell you, oh red wine is good for your blood and for your heart, healthy heart they, they say that or, so this kind of thing it's a bit confused the consumers or individuals who watched that advert' (FBA, 13)

> 'Most of these cancer groups they don't get into diet, they can't get into diet, because some of their biggest sponsors are some of the things that have contributed to this, like fast food industries and things like that you know that they can't come out and say, can they say if you've got somebody like McDonalds or Ben &

> Jerry's sponsoring breast cancer, they're not going to say don't take dairy, that, you know, they're not going to say don't take greasy fried food, you know, but they will say, oh watch the labels' (FBAC, 09)

In a related way, it was perceived that the people presenting the advertisements were neither cancer patients, nor were they involved out of their goodwill; they were involved in such advertisements in order to make money for themselves.

> 'But with them they've got makeup and everything they're perfect you know, it's just like, is it PPI [Payment protection insurance] You see them walking and they're advertising, you see them walking down in their suits and that, they're making big money by doing that, even the person that you just mentioned going on there and advertising for cancer, they get paid for it, they're not going on there on their own' (FBAC, 01)

Another deep but extreme and perhaps controversial view held by some participants on this issue was that adverts and advertisers did not report the whole truth; they only reported what they thought the public needed to know. One example of these views is presented below:

> 'Well there's advertisement straight away tells you money, and when it comes to money it's just corruption isn't it, so there's always something at the back of it, you mix the truth with a half-truth, and mix a half-truth with a lie and then it seems like the truth, ain't it, so they can tell you about the cigarette, stop smoking, but behind it there's something else really it's deeper than that, it's not just a cancer' (FBAC, 05)

5.8.2 Not specific or appealing enough to blacks

Participants expressed the view that general targeting of information and advertising was not effective for the black community, and that a more targeted, customised (directed towards black men) message may be a good way of sending out the right message. Some participants pointed out that the current information was useful and informative, but still, it was not considered to be appealing enough to black men. The most common reasons proposed by participants were that information and advertisements were too general and did not target the black community, the individuals

(people) presented in the advertisements were not seen as suitable to attract black men's attention, and the information was not considered culturally sensitive. The participants in this study believed that information was not designed purposely to attract black people, and, most importantly, black people were not involved in the information development process to ensure that culturally sensitive information was being published. Participants from both communities raised these views and examples are provided below.

> 'I would say it's more, well, it's geared towards the, the general population, so it's it, it's not specifically for any, any community really, and yeah, I, I would say it, it's no I, I think it would be more helpful, would be quite helpful if some of the information is specifically targeted to, like, the African, the African community' (FBA, 12)

> 'Most advertisements are not cultural tailored ones, they're too general and they are not sensitive to others' cultural and others needs and characters to community, each community groups because of that it doesn't work for black community it doesn't that much' (FBA, 14)

> 'Well first and foremost I don't think there's enough advertisement on, on National TV to, to educate the Afro-Caribbean community, the, the adverts that I've seen so far, they're short, they're non-specific in the way they approach cancer for the Afro-Caribbean people, they're not, they make people aware of, of cancer, but I think the people who create the, the advert need to do more' (SBAC, 11)

> 'I tell you there's no information, to me there is no information for the black community, if we want anything we have to go and do what they want to do' (FBAC, 05)

Participants indicated that the current information-giving approach and the information available about cancer itself were very general, and not considerate of black community groups' culture, mindful of the way they think or, attitude towards cancer. When participants were asked consecutive questions to refine and develop this category, participants suggested preferred methods of presenting cancer-related health information to the black community, which will be presented next as one sub-heading.

5.8.3 Preferences and modes of presentation

Both communities emphasised the importance of using the right methods to relay information in order to raise awareness in the black community. These included workshops, leaflets, verbal, and online formats. Participants noted that how information was presented was vital for attracting black men's attention. It was problematic to assume that information would reach its target audience of black men simply by virtue of being presented by a black man. Black people were perceived as very sensitive and had a tendency to look for what was behind the message before accepting it at face value.

> 'For you to get the information to black people, well, you'd have to get into their culture, get into their culture like I say, get into their head, and the information to them that's attractive to them, because most black man if it's not attracted to him it just bounces off, in one ear out the other they say, in one ear out the other, it doesn't stop in between, so if you want it to stop there now look at their culture' (FBAC, 05)

Another related issue which was pointed out by few participants in order to highlight the degree of black people's sensitivity towards public-health campaigns came from the fear of been blamed for issues that were a burden for the wider society, like HIV, drugs, and crime. As further elaborated by one 26-year-old second-generation African participant, publications that put black men as a centre of attention made black people anxious in the first instant as they perceived the publication to have a hidden agenda of blaming and finger pointing.

> 'If you put a black man image, it could be offensive and they treat it negatively and thinking you're stigmatising them, believing this kind of thing is only actually going to the black people, you know, so they will ask why, what are you trying to say? Don't forget black people get blamed now and in the past for all sort of things like HIV, drug, crime for wrong reasons by the system, so if you put only black man they say here we go again look the system here, what you trying to say, you're saying only black going to have this kind of disease, so in that case they see the blame and finger pointing than the actual message so as a high priority they must get the balance right in

> that information they put and even with actually in passing the message across… If white people and black being shown side by side on the poster only then they can see both side of the story' (SBA, 15)

There were differences and similarities in the ways that the BAC and the African communities preferred to receive public-health information, including about cancer. For BACs, music and fashion events were more appealing.

> 'Music, the kids these days they love their music, if you could get them, the message across to them with music that would be one way of doing it, or through fashion cos they love fashion, nobody spend money on clothes or makeup like the black man, he's so that's if you could think of a way to use that to get the information across that would work as well, you'd get them totally' (SBAC, 11)

> 'I've done about three Sickle Cell events where they ask you to come and sing for free in the community, but it was a day we just went along and then just gave us a talks, music and awareness about Sickle Cell, so they kept pushing it out there, pushing it out there, pushing it out there, that is what need to be done about cancer' (SBACF, 17)

> 'With fashion now, I don't know how you'd do it, but you can work it in our way, if I sit down I could think of something, I can always think of something, I'll give you just example like where there's a fashion show so you can put the cancer poster there, you know not even that's the clothes you wear, if you made these desirable and everybody wears them, but there's a meaning with it, you know, so this represents your kidney and you can only wear it if you have good kidneys, you know, something silly like that, I've got one of them kidney coats, I look after my kidneys cause I've got this, well, I could just tell you if you have, oh well, look at the basketball player, he wears certain trainers and all the black youths are wearing them, well it's the same thing if you want to teach the black men about cancer, use fashion' (FBAC, 05)

Based on the African participant's responses, Africans preferred word-of-mouth and face-to-face methods, which were seen as more useful ways of relaying information in the African community.

> 'For our community what we need is word of mouth is actually important, so, you know, word of mouth is spread like it can actually goes around quickly, you know, you'd be surprised how

> much you can actually pass on in a short time and its effective' (SBA, 15)
>
> 'In Africa, I think a one-to-one communication, you know what I mean, face-to-face communication is important to reach African communities because that is how we used to pass and gain information and some of, some of us we are not interested reading or going to the internet, we don't bother, the elderly even when they want to know the news, talking about my community, they want to know the news, but they ask people what is on the news instead of going online or watching it themselves, they just prefer to ask because this face-to-face talk is important' (FBA, 13)

Participants from both communities mentioned that primarily testimony, community gatherings, and venues that black people visit frequently were their preferred methods of information dissemination.

> 'You need testimonials, you need workshops where people are willing to come up and discuss, you know, people that have had prostate, bowel cancers that have actually had it, that's what you need to do, bring those people in and explain, get them to explain the signs and symptoms that they ignored, and you know they actually went through and had the test' (FBACF, 16)
>
> 'I think it's, it's better to reach them through their community groups and these days there are also African business centres like restaurants and shops, there are also a lot of churches of Orthodox and Protestant, so if community leaders approach all these channels that would be effective' (FBA, 13)
>
> 'Well food shops, yeah, a lot of people go there, yeah, restaurants as well, yeah, Caribbean restaurants specifically because that's where black people visit, and even other restaurants as well, we'll start with the Caribbean ones and then move round a circle' (SBAC, 08)

Regarding the 'right person' to present the information or advertisements, the findings suggest that rather than coming from health professionals, black men would be more receptive to education and health promotion if it came from their own community members, particularly from respected community member such as community and religious leaders:

> 'I think that generally we tend to stick together, we always tend, tend trust community leaders which they are respected and look

> up to by their community, conveying the information through the community leaders, I think that would be more helpful,… people take it seriously, more seriously, if it comes from them because of people have got that, this trust and respect to that person that's important, you know what I mean, that's right' (FBA, 12)

This issue of involving the black community in cancer health promotion again raises the following and final sub-category in a different context, as one way of bridging the gap between black men and the healthcare system.

5.9 Gap in service provision (bridging the gap)

The findings of this study suggest that there is a wide gap within the health service in engaging with black men and providing cancer-related information that is relevant to black men in the UK. Many participants noticed this gap and suggested there was a need to bridge it.

> 'NHS could do more, if you see it, NHS and black people are two disconnected things, clearly there is a valid need for the gap between the NHS and the black communities to be bridged' (SBAC, 11)

The lack of knowledge about black men's views towards cancer within the NHS, and the resulting gap in service provision, were reported by healthcare professional participants (see section 5.1.1 and Appendix 10 for participant's occupations). One of the healthcare professionals asserted his view as follows:

> 'There is lack of knowledge in NHS about black men culture and attitudes towards cancer, so that alone is demonstrating that there's a gap in understanding how and where to provide information, we need to be bridging that gap' (FBA, 06)

Another first-generation man who was also a healthcare professional showed a more balanced view by recognising there was a gap, but that the NHS was trying its best to narrow it. However, two more participants who were healthcare professionals, one first-generation African male and one first-generation BAC female participants echoed the

view that the NHS needed to do more to bridge the gap between the NHS and black communities.

> 'Black people are very, very suspect of the system more so, NHS needs to do more to bridge the gap, and we need to be bridging that gap' (FBACF, 16)

In this context, participants felt that the NHS needed to work in collaboration with the black community in order to engage with black men and meet their needs.

5.9.1 Negotiating the needs

One of the elements indicating the existence of a service gap was that participants recognised that black people needed to negotiate their needs with healthcare professionals and with the NHS. Some participants felt that the voice of black people was unheard in the healthcare system, and took responsibility for this by highlighting a lack of unity in the community with which to negotiate their needs. Despite cancer-related information being available and provided by various governmental and non-governmental organisations, few participants seemed convinced they needed to be proactive collectively as a group to utilise the information. The following quotation demonstrates that some black men have already lost interest, even before trying to access the available information. It also illustrated black men's perceived need to negotiate with the healthcare system as a group in order to access and utilise information.

> 'If I come forward and I want the information I want bits and pieces to help me, you know, in my sickness and all, my people behind me then they might listen to me, but if it was me one and I want the same information because it's me one and you think, just that I thinking it's just me thinking that if we are together as a black community they might listen to us and pay attention more okay, yeah, I just think to myself if it's me one they won't hear, but unless a group of us and the fullness is behind me then it will work' (SBAC, 04)

Another major focal point that participants considered as a big need within the black community was guidance and training for black community organisations, in order to raise cancer awareness among community members.

> 'What we need from NHS or Department of Health professional support and information resource, we can translate information, we can organise different events to promote awareness among the community members' (FBA, 14)

> 'It would be helpful if the community leaders themselves understand about cancer, the causes of cancer, the symptoms of it, a bit about the treatment, so that they can go in and ready to teach and explain to people and make them understand what are those factors are, I think it's, it's very important, it is, it is, it is very important' (FBA, 12)

Both African and BAC participants strongly emphasised the need for support from the NHS in giving guidance and training to black community and religious leaders. In connection to this, the only two female participants suggested creating a black-led clinic as an effective way to bridge the gap between black men and the healthcare system. This finding is presented in the following section (5.9.2); the reason this section is identified as an independent property in this sub-category is its unique nature and the fact that it was primarily suggested by the only female participants.

5.9.2 Black-led clinic

Negotiating with the healthcare system to create black-led clinics was suggested by two female participants, one of whom was a healthcare professional, and justified by the following reasons. Firstly, it was perceived that many black men did not want to go to NHS hospitals, mainly because of cultural issues, mistrust, or avoiding potential harms (Babylon). As a consequence, they did not access factual information about cancer; they were not willing to uptake available cancer tests (DRE), and they presented at a late stage if they were affected by cancer. Secondly, similar facilities currently existed for other ethnic-minority groups and hard-to-reach communities to accommodate specific

needs regarding cancer and other chronic diseases like diabetes. The two female participants argued that black people were the only group left out in this context, without an alternative option. Significant quotes extracted from the interview illustrate this:

> 'Because they [black men] don't understand the signs and symptoms, they present late and then end up having emergency surgery…why black man Afro-Caribbean men don't readily go to the doctors, they don't because they don't trust the healthcare system, understand, … I did a lecture and two West Indian men came up after the lecture, didn't want anyone to see them, and one of them said in a corner away out of sight hiding that he's bleeding from the back passage, what should he do, that was just from a talk, now if there was a clinic there'd be a referral' (FBACF, 16)

> 'We need to put a service in place for our community that can act between the hospital and our community, the Trust, a point of call, education referral and also alternative medicines' (SBACF, 17)

> 'I think what we need to have in place and that's not in this community at the moment, is a black-led health related organisation. There's no black-led healthcare organisation within this system at all, do you understand,… we can educate the NHS too, we can provide the medication, it's two way' (FBACF, 16)

> 'It's already happening for other communities, if you've got a Pakistani group, a Bengali group that can't speak English, what do they do? They use a Bengali service … well, at least they've got somewhere to go, right now there's nowhere to go for brothers, at least there will be a service for them' (FBACF, 16)

Following this interview, follow-up interviews were conducted with male participants to explore black men's views from each group (FBA, SBA, FBAC and SBAC). The suggestion of a black-led clinic was favourably received. One second-generation African participant was open-minded in his reply:

> 'If the screening or pitching can be carried out by black nurses and doctors that would be preferable but the important thing is being value and understood by doctors and nurses, if the doctor is Asian or white I don't think there is a problem, but the important thing is his or her approach' (SBA, 15)

The final property of this subcategory is linked with black-led clinics, but involves more practical suggestions from participants in order to bridge the gap between black men and the healthcare system by promoting grass-roots level health promotion.

5.9.3 Grass-roots level community involvement

As indicated in section 5.2.5, all participants acknowledged a lack of awareness about cancer in their community; the majority of participants suggested a bottom-up health-promotion strategy in collaboration with black community organisations to effectively raise awareness about cancer and also to encourage the uptake of early cancer detection among black men, including the DRE. Participants perceived health promotion campaigns carried out by governmental organisations such as the Department of Health and NHS to be a top-down strategy, which also linked to their suspicious views of the healthcare system as a whole. Further, participants highlighted the importance of community and religious leaders' involvement in bottom-up health promotion campaigns as this brought a number of advantages. The most common advantages noted by participants were: the leaders' ability to influence their community members due to the levels of trust, acceptance and respect accorded to them as leaders. As a result people will give their cancer related health message more serious consideration.

> 'Specifically in a community level wise, things like the community heads, they can still use that kind of advantage to explain, to teach to show people the benefit and the importance of that, it's good to know about cancer risks, so that they will also encourage people to take a screening … people will listen to them so you can use their influence, yeah' (FBA, 03)

> 'There is a difference between the community leaders and another providers, yeah, people may not be very open to talk about it for outsiders but people will be very much open to listen to those community leaders than others, yeah, trust and their influence … they are closer, they are like one of us, you know what I mean, rather than those doctors or nurses, you don't know them before and I don't trust them anyway, yeah' (FBA, 22)

Many African and BAC participants asserted another significant benefit regarding the importance of engaging in grass-roots level health promotion. In addition to restoring trust (see section 5.7), the health promotion message would be transmitted quickly among community members, as individuals who attend an event would pass the information to their fellow community members through word-of-mouth.

> 'Cancer organisations need to work within the various different black communities, cos people trust their community and the information will pass through the community fast cos people always talk each other what is going on in their community' (SBAC,11)

African participants specifically mentioned that there were a number of healthcare professionals whose skills could be harnessed to raise cancer awareness in their community. The use of bottom-up health promotion could reduce NHS costs as these health professionals' involvement would be voluntary. One first-generation African participant who was involved in voluntary work for his community illustrated this well:

> 'Don't forget in each community groups there are health professionals some who are working within the NHS and there are lots of them who might have not been working here, but with a lot of experience and knowledge back at home in health sector, lot of nurses, doctors, they're one of the respected community members, if we ask them they will be happy to help as volunteer to promote awareness in the community, so we can use them and save a lot of money for the government, I mean we can save resource if we, we use these people'(FBA, 14)

Participants in both communities, regardless of whether they were first or second generation, believed that cancer health campaigns should work closely with black community groups and communities themselves should be more involved with guidance from the NHS. The findings of this study very strongly suggested that black community groups and the Department of Health should work together to increase awareness about cancer within the black community, and particularly among black men.

5.10 Summary

BA and BAC men living in the UK had varying perspectives on how they viewed cancer as an illness and the issues surrounding cancer. These views were very much associated with their culture, religion, and their perceived meaning of social systems, including the healthcare system. There were similarities and differences in BA and BAC men's views towards cancer, which reflected these cultural, religious and social beliefs. However, none of the participants, either BA or BAC, perceived cancer as a black man's illness. Some of the reasons both groups gave for the existence of cancer included consuming processed foods, the political desire of a deliberate plan to reduce the human population, and going as far as believing that airplanes spray carcinogen toxins on the population. However, the main reason noted for cancer not being a black disease was simply a lack of awareness, and consequently, late stage discovery of the disease in patients.

Cultural views affected awareness levels, and accordingly the unwillingness of members of the two communities to take up available early-detection programmes. For example, the black men were culturally uncomfortable with DREs, a main tool for identifying cancer at an early stage, and smoked herbs like cannabis, which they perceived to be a preventative measure of cancer. The black men generally viewed being physically big as beautiful and healthy and did not have positive views about going to the hospital or seeking medical care.

Religious beliefs also heavily influenced participants' views of cancer. For example, some believed cancer to be a punishment from God and that individuals who suffered from cancer were more likely to live a meaningful life since they had a limited time to live and were on their way to meet God.

The findings revealed that BA and BAC men did not have a healthy relationship with the healthcare system, for several reasons. Most participants used the term "Babylon" to describe modern medicine and did not believe that modern medicine could heal a person with cancer, but rather weakened the patient's immune system. They also did not trust doctors who do not look like them, and as such, participants tended to resort to herbal/traditional medicine.

This research showed that black men felt alienated and controlled by the system in many ways. Reference was made to the judicial and healthcare system (notably mental health services), indicating that black men were disproportionally controlled and/or treated unfairly by these institutions. It was also mentioned that when a black person suffered from cancer, unless the person had the financial means, he/she would die in the hospital system.

The overall picture of the findings revealed that there was a pattern of mistrust and suspicion of the healthcare system held by a majority of research participants. Participants expressed concern that clinical experiments undertaken in the days of slavery could still be happening to black people in the healthcare system, without their knowledge or consent.

The research also showed that participants perceived current advertisement and health promotion methods do not appeal to or reach the black community. In order to close this gap, participants suggested black-led clinics and more health professionals who were aware of the black community's culture; this would ensure black men were more comfortable, removing much of the mistrust and suspicion. They also felt grass-roots level community involvement was important in reaching the black community, for encouraging early detection, and reducing avoidable morbidity and mortality.

Chapter 6 **: Discussion**

6.1 Introduction

The aim of this study was to explore the influence of culture on views of cancer held by BA and BAC men living in the UK. The findings of this study were presented in the previous chapter (Chapter 5). The purpose of this chapter is to discuss the emerging theory of cancer through black eyes. As in the findings chapter (Chapter 5), the terms '*black'*, '*black men'*, '*black people*' and '*black community/communities*' have also been used in this chapter to refer to both BA and BACs, collectively. The discussion seeks to interpret the significance of the study's findings in light of what was already known about BA and BAC men's views towards cancer, and any new evidence that has emerged since data collection for this study commenced. It also presents new understandings regarding the views of black men in the UK towards cancer and shows how knowledge in this area has been advanced by this study. The discussion was structured to answer crucial questions raised in the introduction chapter: What is the meaning of cancer to black men? Why are black men less aware of cancer risk factors and early-detection services? Why are they less likely to attend early-detection services? Why do black men present late with symptoms of cancer? The emerging theory of cancer through black eyes presents potential explanations for these behavioural patterns by looking at, and seeking to understand, cancer in the context of the participants' perspective.

The discussion begins with an overview, providing background information to show the process of how the theory of cancer through black eyes was constructed from the data, with a clear explanation for why the theory followed the interpretive rather than positivist approach. After highlighting significant points about the development of the theory in the overview section, the main body of the discussion (section 6.2) will

commence, where the findings will be compared and contrasted with the existing literature. Subsequently, the application and compatibility of the emerging theory (cancer through black eyes) to existing public-health promotion models will be discussed. The strengths and limitations of the proposed theory as well as the research process as a whole and the implications of this study will be presented at the end of the chapter.

6.1.1 Overview

In the grounded theory method, two types of grounded theories can be developed: formal and substantive theories (Charmaz, 2014; Glaser, 2007; Glaser & Strauss, 1967). The level of 'conceptual abstraction' and the level of 'generality' are the main characteristics to distinguish the difference between the substantive and the formal theory (Charmaz, 2014; Glaser, 2007; Polit & Beck, 2008). Formal theory is associated with a high level of conceptual abstraction and generality, secured mainly as a product of analyzing and synthesizing a number of different substantive theories from related areas (Charmaz, 2014; Glaser, 2007). In the context of the present study, to develop the 'theory of cancer through black eyes' at the formal level of the theory, the researcher would have to constantly compare, analyse, and synthesis the theory of cancer through black eyes with other substantive theories in relevant substantive areas. Other substantive areas could include, for example, cancer viewed through the eyes of other ethnic minority groups, through women's eyes, through Caucasian eyes, through bisexual or homosexual eyes, etc. As a result of this analysis of cancer through different social and ethnic groups (different substantive theories), a formal grounded theory with a high level of abstraction and generality can be developed. In contrast to the formal theory, a substantive theory has a low level of conceptual abstraction and generality, as it focuses on a specific substantive area (Charmaz, 2004; Glaser, 2007; Polit & Beck, 2008). In light of the explanation and characteristics provided above, the theory of

cancer through black eyes proposed in this study focused on a substantive area categorized as a theory with low-level abstraction and generality (often termed 'vicarious transferability') rather than on a formal theory that is believed to have greater generality across multiple groups. Thus, it is proposed that the current study is a substantive grounded theory applicable only to the group being studied, although it may have resonance to wider populations via vicarious transferability.

The theory of cancer through black eyes developed as a core category alongside seven sub-categories that emerged from analysis of participant interviews. All categories were refined and developed using theoretical coding to reach a conceptual level that led to the development of an analytical story in a theoretical direction (Charmaz, 2006, 2014). The core category was linked to the seven sub-categories; the initial framework was constructed by creating an abstract understanding of the sub-categories' relationships with each other as well as with the core category. Figure 6.1 shows an extension to the diagram of the core and sub-categories presented in Chapter 5 (Findings Chapter), with Figure 6.1 highlighting the potential consequences of participants' views and illustrating the theory of cancer through black eyes. The interrelationships between each sub-category, the link between sub-categories and the core category, as well as the macro- and micro-level similarities and differences presented in the Findings Chapter are illustrated in a diagram (Appendix 14). The process of making raw data theory-sensitive (data theorisation) enabled the final stage of constructing the theory to be achieved. The theory of cancer through black eyes explained the views of black men towards cancer and the potential consequences of these views.

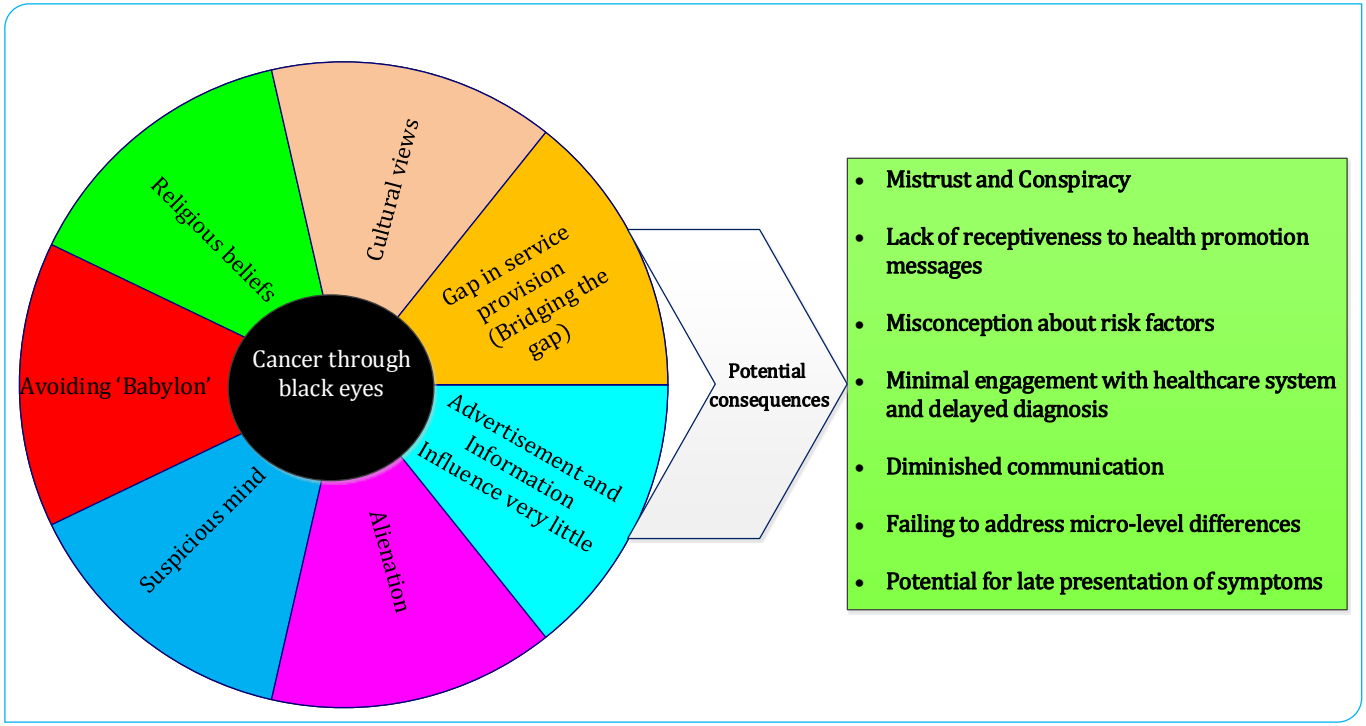

Figure 6.1: Core and Sub-categories Illustrating Cancer Through Black Eyes, With Potential Consequences

A constructivist grounded theory approach (Charmaz, 2006) was used to undertake this study, with the theory of cancer through black eyes following the interpretive theory approach. Accordingly, the objective of this theorising was directed more at generating an understanding of how black people viewed cancer as an illness and cancer-related issues, by looking at relationships between categories, rather than making predictions by treating categories as variables (discovering theory, positivist approach). This theory of cancer through black eyes provided a comprehensive understanding of the phenomena in this study, namely, the views of black men towards cancer: cancer through black eyes.

6.2 Cancer through black eyes

The theory of cancer through black eyes is grounded through the data collected; the data were interpreted by juxtaposing the interpretation of the findings (referring to core and sub-categories) with existing literature. The substantive theory of cancer through black eyes was developed to generate knowledge of how black men perceived cancer; their understandings were constructed based on their interactions with, and meanings of, the social world. Accordingly, black men had their own distinct views, beliefs, and meanings, including what cancer means, why it is a problem for white Caucasian populations and not themselves, where to go for help, where not to go for help, who is to be trusted, and which cancer-related issues are perceived as a problem. By examining these perceptions and beliefs, the proposed theory provides an explanation of why black men preferred to avoid or to engage minimally with a Western healthcare system in the UK, and the potential consequences of their choices.

Within this study, black men constructed their views based on their understandings and the meanings they ascribed to social systems and establishments, such as healthcare systems like the UK NHS. Cancer was not viewed as a purely medical condition

through black eyes. Black men's views towards cancer and cancer-related issues were closely linked to socially constructed perspectives of themselves and what being black means, what the advantages and disadvantages of being black in society were, and historical phenomena like slavery, which strongly influenced their perceptions and relationship with Western medicine. Cancer through black eyes was constructed by their interpretations of their meanings of the world and was influenced by their cultural and religious beliefs.

Cancer was not recognised through black men's eyes as a black man's illness. Consuming mass-produced non-organic food was identified as one of the major reasons for the growing number of white people falling victim to cancer. Most participants, (18 first-generation black men) had grown up consuming organic home-cooked food in Caribbean and African countries. Hence, participants did not see any reason that they should be at risk of getting cancer, or how cancer could be linked to black men who adopted a healthy diet.

Gaining a detailed understanding of the meaning of cancer and cancer-related issues from black men's perspectives helps us to understand why black men are less aware of cancer risk factors and early-detection services, as noted in previous studies (Waller et al. 2009). This understanding may also explain why, despite there being no evidence to suggest that black men have better or worse access to diagnostic services in the UK (Metcalfe et al., 2008), black men are less likely to attend early-detection services and often present late (Austin et al., 2009; DH, 2011). Accordingly, the following section (6.2.1) focuses on the understanding of cancer risk factors through black eyes.

6.2.1 Misconception about risk factors

Most participants in this study showed little awareness of clinically well-known risk factors, signs, and symptoms of cancer, including prostate cancer. Exceptions included

one natural healer and three qualified nurses who were able to identify the risk factors, signs, and symptoms of major cancer types. As these four participants were first-generation blacks (two BA and two BAC), it could be suggested that first-generation participants showed better understanding of cancer risk factors, signs, and symptoms. However, given that these four participants' occupations were healthcare related, it may be that the knowledge of risk factors stemmed from occupation rather than any real differences between first-and second-generation Africans and BACs. Although only the natural healer and one female nurse were aware of black men's increased susceptibility to prostate cancer, none of the remaining participants shared this awareness, including the two male qualified nurses. Moreover, among both African and BAC participants, regardless of generation, there were participants who believed prostate cancer to be associated with female physiology. Hence, the participants' understanding of cancer risk factors, signs and symptoms from a modern-medicine perspective was generally minimal. This lack of awareness was perceived by the interviewees as extending more generally to the black community. Since the lack of cancer awareness in the wider black community was recognised by participants themselves, the participants' own minimal level of awareness was not a contradictory finding.

Two quantitative studies carried out in the UK have produced similar findings, with black men demonstrating low levels of awareness about cancer (Rajbabu et al., 2007; Waller et al., 2009). Rajbabu et al. (2007) recruited both black men and white men, while Waller et al. (2009) included both male and female BAs and BACs, alongside participants from four other ethnic minority communities: Indian, Pakistani, Bangladeshi, and Chinese. Although the evidence is only based on two studies, there are two important elements that can be extracted from the findings of these quantitative studies. Firstly, UK-based black men were shown to have markedly similar patterns of low-level awareness about cancer to African-American men in the USA (Allen et al.,

2007; Gwede et al., 2010). Secondly, in comparison with other ethnic groups in the UK, black participants' awareness of cancer was minimal. Further, and similarly to the findings of the present study, in Rajbabu's et al. (2007) survey, the results indicated that black men were unaware of their increased risk of developing prostate cancer. However, these two quantitative studies did not provide an explanation as to the reasons for this lack of awareness. The in-depth qualitative approach adopted in the study reported here suggests that black men had low awareness about cancer because health-promotion endeavours do not show awareness of cancer through black eyes and do not provide effective health-promotion materials sensitive to black men.

When approaching the issue of black men's minimal levels of awareness about cancer, it is important to mention specifically why black men may be less aware of cancer risk factors. Common unhealthy behaviours that are known to be major clinical cancer risks, such as smoking and unhealthy eating, have socially constructed meanings in the black community. These often bear important positive symbolisation through black eyes, which is influenced primarily by culture and religion. Public-health campaigns constantly remind the public that smoking is dangerous and linked to cancer, particularly lung cancer, which has one of the lowest survival rates of all cancers and is the most common cause of cancer death in the UK (Cancer Research UK, 2012; 2013b). However, the findings indicated that BA men considered smoking to be a sign of status, associated with the elite and influential sections of society. In spite of BA men's reluctance to acknowledge the risks of smoking in relation to cancer, the social benefits and significance of smoking are likely to outweigh the current public-health warning.

Similarly, for BAC men, smoking had a deeper meaning, particularly in terms of the consumption of herbs such as cannabis and marijuana. In the BAC community, for example, smoking cannabis was not only socially acceptable, but often socially desirable. Moreover, cannabis and other herbs were believed within the community to

be conducive to good health, with an ability to prevent diseases, including cancer, and were often regarded as an effective natural remedy for cancer. A systematic review conducted by Martín-Sánchez, Furukawa, Taylor, and Martin (2009) to evaluate the effectiveness of cannabis as a clinical medicine, suggested that although clinical use of cannabis had moderate effectiveness for treating chronic pain, it could cause potentially serious harm. The findings of Martín-Sánchez et al.'s (2009) systematic review contradict with the views held by this study participants'; which perceived cannabis as effective remedy. Smoking herbs also played a significant role in religious rituals among followers of Rastafarianism. Far from being a cancer risk factor, smoking was perceived as a remedy and was positively encouraged. Thus, the effect of smoking through black eyes was contrary to the clinical significance and health promotion campaigns.

Obesity is a major public-health problem in developed countries which accounts for two-six per cent of total healthcare costs in several developed countries (WHO, 2003). Systematic reviews of clinical evidence indicated that obesity and being overweight predispose a person to different health problems, including cancer (Martinson, Teitler, & Reichman, 2011; Misganaw, Haile, Ali, & Araya, 2014; Polednak, 2008; Whitlock et al., 2009). Most studies focused on the area of black people's perception of overweight and body image appeared to be USA based studies. Further, these studies were focused particularly on African-American women; few included black men. The results of one USA-based survey conducted in 1999 reported that an average body size was preferred by both African-American men and white men. However, African-American women preferred to have a larger body compared with white women (Becker, Yanek, Koffman, & Bronner, 1999). Another current USA-based research study reported that both African-American and Latino teenagers of both genders perceived that being overweight was acceptable and tolerated in their respective cultures (Barroso, Peters,

Johnson, Kelder, & Jefferson, 2010). African-American male participants in the two studies noted above showed different views about body image preferences. While African-American men in Becker et al.'s (1999) study reported a preference for an average body size, African-American teenagers who participated in Barroso et al.'s (2010) focus-group study described being big as culturally acceptable. Further, these African-American teenagers who participated in the Barroso et al. (2010) study reported that being big was preferable for the following reasons: being able to fill out their clothes better, a physical attraction to the opposite gender, and increased chance of succeeding in sports. Although, much like the findings of this study, the findings of Barroso et al. (2010) showed that being big was culturally acceptable, the reasons given by the African-American teenage boys in Barroso et al. (2010) differed from those given by the BA and BAC participants in the current study, where being big and overweight was perceived as a sign of prosperity. It was also perceived as an indication of a man's strength and ability to take care of himself and his family. Culturally, among BAs, a man was expected to steadily gain weight over time, while in the Caribbean community, being slim was extremely undesirable. Black men's cultural expectations, and what being overweight symbolised, undermined the notion of it being a cancer risk factor.

Hence, it would be too simplistic to state that black men are entirely unaware of risk factors, resulting in vital misunderstandings from a public-health perspective. The important point that must be fully understood by health promoters is that black men may appear less aware of cancer risk factors because they have their own interpretations of the risk factors, tied in with culture and religion, and not necessarily because they have limited knowledge of the subject area. Hence, there is a mismatch between the clinical significance and black men's interpretation of risk factors which affects black

men's lack of receptiveness to health promotion messages. However, it is not the only reason for black men to lack receptiveness to cancer related health promotion messages.

6.2.2 Lack of receptiveness to health promotion messages

Cancer-related public-health campaign information and advertisements did not appear to be reaching, or be taken seriously, by black men. Black men in this study were suspicious of authority and institutions, including the NHS, which they perceived to be tools to control black men. Hence, black men who came across cancer-related information provided by governmental organisations or advertisements broadcast in the mainstream media assumed that the information was a 'half-truth'. Thus, a top-down health promotion and information-giving strategic approach would lack credibility and be unappealing in black men's eyes.

Participants in this study had their own understanding of cancer, which was not perceived as a major concern for black men. Culturally, black men considered themselves to be physically superior with stronger immune systems than white men. This perception of the black man as being stronger and '*generally immune of the ailments*' relates back to slavery in the USA when slave owners would value those black men with physical endurance for economical and political reasons (Savitt, 1981). This historical view has passed through generations to the present day, leading black men to consider themselves stronger than others in their ability to cope with illnesses like cancer. As was evident from the findings of this study, even when participants knew someone who suffered from cancer, they did not expect cancer to afflict them. This, arguably, shows a lack of knowledge about cancer among black men. Until public-health campaigns aimed at black men are sensitive enough to understand cancer through black eyes, the effort made to increase public awareness of cancer and to reduce health inequality in this regard may continue to be ineffective.

Healthcare providers aiming to relay cancer-related information should recognise what information is required, how it should be presented, and who is the most appropriate person (or body) to disseminate the information for it to have any impact on black men. For example, in 2013, one charitable organisation (Prostate Cancer UK) produced a prostate cancer awareness pamphlet replete with images of black men, in an attempt to raise awareness among black men about prostate cancer (the researcher of this study also contributed to developing this pamphlet). However, the findings from the study reported here indicate that black men's mistrust of the system and the authorities leads them to perceive this campaign as being yet another attack on the black community. As participants explained, black people were often accused of burdening society with issues such as HIV, crime, and drugs. Thus, having only images of black men in the pamphlet may have sent the wrong message to black men. Participants felt that they were being accused of placing the burden of prostate cancer on the NHS and were therefore to be held responsible. The lack of culturally specific information coupled with black men's suspicion when well-intended images of black men are portrayed on information leaflets presents a conundrum. It makes it unclear how to promote public-health issues, such as cancer, among black men, ensuring that the information is perceived as trustworthy. A possible solution suggested by study participants was to produce cancer-related information containing images of both black and white men side-by-side, so as not to point the finger of accusation, and to then emphasise the message about black men's particular vulnerability to prostate cancer in the written text. Cancer-related public-health campaigns, therefore, need to work closely with black communities, as was the case with the successful Sickle Cell disease health-promotion campaigns.

Sickle Cell disease health-promotion campaigns in the black communities have been effective (Bates & Robinson, 2011). In contrast to this study's findings on cancer, black men have responded to campaigns on Sickle Cell disease and have acknowledged that

the disease does directly concern them, resulting in increased acceptance that Sickle Cell disease is a black person's disease, increased knowledge about the condition and, positive attitudes towards Sickle Cell disease treatment. It has been reported that the main reason that Sickle Cell disease health-promotion campaigns have been successful was that the NHS worked closely with the black communities; individuals from the black communities became involved in planning, gathering community members, and arranging events that successfully delivered the message that Sickle Cell disease was a concern for black people (Bates & Robinson, 2011). Engagement with local black communities as a health-promotion approach was advocated by black men in the study reported here. Lessons may be learned from Sickle Cell disease health-promotion activities, with a similar approach adopted to develop an effective cancer-related public-health campaign for black men in the UK.

The black men in this study emphasised the importance of involving community organisations, religious leaders, and 'ordinary' black men for effective dissemination of information. Allen et al. (2007) conducted a qualitative study in the USA using focus groups to explore African-American men's perceptions about prostate cancer. They observed that their participants preferred to access information from churches and barbershops. The similarity between Allen et al.'s (2007) findings and those of this study were that black men in the USA and in the UK preferred to access information from sources that were independent of the healthcare system. Black men's preference to access health information outside the healthcare system was a result of lacking trust in the system.

6.2.3 Mistrust and Conspiracy

Although black men did not recognise cancer as their health concern, their views were polarised, with some believing cancer was a political de-population project. Participants

put forward a number of reasons to justify this view. For example, given the burden of cancer in humanity, they perceived that there was no progress in Western medicine to cure or to minimise the risk of getting cancer. The Black men in this study were critical of research aimed at finding a cure for cancer. At the same time, they believed that the risk of cancer could be minimised by black people's use of traditional herbs, i.e. that black people have a cure for cancer. Black men had their own distinct understanding and meaning of cancer and cancer-related issues, linked to culture, religion, political and social issues.

As mentioned in section 6.2.2 disseminating factual cancer-related information to black men is clearly complex, as the information should not be perceived as coming from the top down from the non-black establishment. The high level of suspicion held by black men against the establishments reinforced their conspiracy theory that cancer is part of a secret de-population programme.

Section 5.3.6 and 5.5 of the findings chapter illustrated that black men preferred to avoid going to hospital. This unwillingness to go to hospital by black men was linked with their lack of trust in the healthcare system and of healthcare professionals. Evidence from the USA indicates that lack of trust in the healthcare system and in healthcare professionals is a major concern to black men in the USA (Brandon et al., 2013; Forrester-Anderson, 2005, Pedersen et al., 2012). A major source of this mistrust was the perception that black men were treated as medical specimens by clinical researchers (Savitt, 1981), particularly in light of the betrayal involved in the Tuskegee syphilis study conducted by the USA Public Health Service between 1932 and 1972, where treatment was deliberately withheld from black men while they thought they were receiving free healthcare (Allen et al., 2007; Brandon et al., 2013; Forrester-Anderson, 2005).

Although the findings of the present study were similar with regard to the existence of mistrust, participants in the present study did not specifically mention the Tuskegee study as a reason not to trust the healthcare system and healthcare professionals in the UK. Participants' mistrust came mainly from their past experience, perceiving the NHS to be a tool to control them. Mental health services were particularly mentioned in this context by many research participants. Black men's lack of trust towards the healthcare system and healthcare professionals had several layers, including black men's feeling that the system was there to control them (Babylon) rather than working for them. This led to feelings of disfranchisement and alienation, and subsequently to suspicion towards, and conspiracy theories about, the healthcare system (suspicious mind), whose roots were embedded in cultural and religious belief. This mistrust and suspicion led to avoidance of the NHS (avoiding Babylon). This link is illustrated in Figure 6.1 and in more detail in Appendix 14. It can be seen that addressing black men's mistrust is necessary in order to improve their relationship with the Healthcare system and organisations such as the NHS. One way of addressing black men's mistrust is to have organisations such as the DH, the NHS, and Public Health England proactively create a counter-narrative to black men's sources of mistrust towards the Healthcare system. To avoid the top-down approach that makes black men even more suspicious, involving respected and influential black men from their communities should be seriously considered during the preparation and dissemination of such a counter-narrative throughout the black communities.

6.2.4 Potential for late presentation of symptoms

How cancer is viewed through black eyes has significance in the presentation of symptoms and being pro-active in seeking cancer screening. To date, there has been no standardised national prostate cancer screening programme in the UK. According to the prostate cancer management policy, individuals who are concerned that they might be at

a risk of developing prostate cancer can request screening (Public Health England, 2014). This means the early-detection services for prostate cancer are not organised at a national level, and that prostate cancer tests can only be obtained if an individual is pro-active and requests screening.

The main screening methods are prostate-specific antigen (PSA), performed by taking a blood sample, and digital rectal examination (DRE), involving feeling the prostate gland through the rectum. For the black men participating in this study, both taking blood and undergoing rectal penetration were major barriers to being pro-active in presenting for screening.

The Black men in this study perceived that, during times of sickness, black people in western medical settings may be unethically and unknowingly used as experimental subjects. Accordingly, black people believed that blood taken from them in healthcare settings was used to covertly extract melanin for the cosmetic industry without their consent, making them suspicious and reluctant to submit to blood testing. This suspicion of a conspiracy also related to black men's perception of the healthcare system as 'Babylon,' leading them to try to avoid it altogether. The Caribbean participants in particular mentioned that they were advised by family members not to give blood samples in Western healthcare settings.

As for the DRE, black men equated the procedure with homosexuality. In Caribbean countries including Barbados, Jamaica and, Trinidad & Tobago, homosexuality is a criminal activity (Itaborahy & Zhu, 2014). In 38 African countries homosexuality is also a crime, punishable by death in countries like Sudan and Nigeria, or life imprisonment in Sierra Leone, Tanzania, and Uganda; in most other African countries, an average of ten-year prison sentences can be expected for homosexuality (Itaborahy & Zhu, 2014). Attitudes towards homosexuality within black communities still carries a

stigma and have not changed with the times in the same way that they have within most Western communities (Itaborahy & Zhu, 2014). Consequently, undergoing a rectal examination was seen as an activity that a 'proper man' should not engage in, as it would compromise his masculinity and be viewed as reprehensible. This cultural barrier to early presentation was a further factor potentially contributing to late diagnosis.

This negative attitude towards DRE was also identified as a key barrier for African-American men in the research findings of Blocker et al. (2006) and Friedman et al. (2012) in the USA. A UK-based survey carried out by Rajbabu et al. (2007) also showed that, compared with their white counterparts, black men held more negative attitudes about prostate cancer screening. This present study's findings indicated that both BA and BAC participants perceived the DRE as culturally unacceptable. This could be seen as evidence that men from different black sub-groups (African-American, black-African and, black-Caribbean) held similar attitudes towards the DRE. Pedersen et al. (2012) conducted an influential systematic review to appraise black men's knowledge and perceptions of prostate cancer. The review reported that black men's willingness to be tested for prostate cancer was influenced by cultural and social factors. Although the review included 33 studies, only two were carried out in the UK (Pedersen et al., 2012). The two UK studies were Rajbabu et al.'s (2007) survey and Metcalfe et al. s' (2008) retrospective study, investigating whether prostate cancer diagnostic services were equally accessible to black and white men. Accordingly, the conclusions drawn from Pedersen et al.'s (2012) systematic review contained little evidence relevant to UK-based black men that could inform policy makers, cancer-related service providers, and public-health campaigns targeting black men. In particular, little evidence was available to explain UK-based black men's social and cultural reasons for not accessing the available screening services and presenting late with symptoms.

In the study reported here, the reasons for not attending for screening were complex and multifaceted. Black men simply did not believe that cancer was a black person's disease; they identified more with the risks of Sickle Cell disease and HIV than with those of cancer, despite empirical evidence showing that black men are more likely to suffer from prostate cancer than their white counterparts (Metcalfe et al., 2008). Black men also believed that they were physically stronger than men of other ethnicities and that they were therefore not susceptible to such illnesses; if they were diagnosed with cancer, they could beat it with their strength. Black men's belief in the concept of an eternal life meant that their spiritual life made them praiseworthy in the eyes of God, making them either immune to cancer or capable of being cured by God's will, thereby negating the need to undergo screening. It was a common view that the regular use of herbs such as marijuana and other 'traditional' herbs served not only to prevent cancer, but also to treat it; believing these natural remedies were superior to those offered by the '*toxic*' and perceived '*impure*' Western medicine. These cultural, religious, social, and sometimes political perceptions held by black men led to minimal engagement with the healthcare system and a lack of receptiveness to cancer related health promotion. As a consequence, black men's opportunity and ability to make an informed choice to undergo screening appears to be limited, leading to an inevitable pattern of late diagnosis. To break the cycle of late diagnosis, early detection strategies need to be conceptualised outside the current strategy, which requires individuals to be proactive in requesting screening for prostate cancer. For example, instead of waiting for black men to request screening, a better approach would be GPs invite black men with a family history of cancer to undergo prostate cancer screening. Although black men prefer to avoid going to hospital, having a DRE, and giving blood samples, it is conceivable that witnessing a loved one suffer from cancer could motivate them to accept a GP's invitation to undergo a prostate cancer screening. Then after a given time evaluate this

approach whether it encourages black men to uptake screening and to engaged with the healthcare services.

6.2.5 Minimal engagement with healthcare system and delayed diagnosis

Seeing cancer through black eyes also helps to understand why black men often present late with symptoms of cancer. Both African and African-Caribbean participants in this study indicated that they were reluctant to go to hospital and this is influenced by important cultural beliefs that need to be recognised by service providers. Waller et al. (2009) conducted a survey to examine help-seeking behaviour and potential barriers namely 'emotional barriers', 'practical barriers' and, 'service barriers' for delaying cancer diagnosis among six ethnic-minority groups in England. The results indicated that African and Caribbean men had the lowest endorsement of almost all barriers, while Chinese endorsement scores were highest (Waller et al., 2009). Although Waller et al.'s (2009) survey showed that the barriers described were not hindrances to black men attending hospital, the limitation of the survey method to explore participants' view in detail failed to provide an indication of what black men considered as a major barrier for not going to hospital. Given that there is evidence to suggest that black men often present late with symptoms of cancer (Austin et al., 2009; DH, 2011), the reason and/or a barrier for black men not going to hospital at an early stage was not provided. This highlights the importance of conducting qualitative work to uncover possible reasons for late presentation.

The findings of this qualitative study indicated that not going to hospital was primarily due to cultural barriers associated with fixed cultural attitudes. Black men from both communities viewed going to hospital as a last resort, only to be taken when someone became very ill. The reasons they preferred to avoid hospitals, however, differed between the two communities. For first-generation Africans, visiting a GP or a hospital

was a sign of weakness for two main reasons. Firstly, being ill meant being physically weak among strong fellow men. Secondly, it was perceived that ill people were unable to pursue their dreams of being successful in life. Second-generation African participants, however, did not seem to experience the same social pressure concerning seeking medical attention.

For BAC participants, one of the reasons for avoiding hospitals was a sense of pride in the black man's traditional herb remedies. BAC participants explained that since they had their own natural remedies, Western medicine was not considered something that black men needed. The findings further indicated that BAC participants also inherited the concept 'we don't go to hospital,' with first- and second-generation BAC participants holding similar views about going to hospital. More importantly, the impact of slavery on the views of BAC men towards cancer and their health-related behaviours was substantial. This historical event has had serious ramifications on present-day BAC men's views, how they construct meanings, and how they interact with the authority, including the NHS. The quotes from participants presented in the Findings chapter highlighted the reflection of this essence in their subjective views. No UK based study could be identified that examines how slavery influences black men view towards cancer or other health-related issues. However, publications in the USA highlight how the legacy of slavery shaped African-American's relationship with the modern healthcare system and healthcare professionals (Brandon et al., 2013; Forester-Anderson, 2005; Savitt, 1981; Sutherland, Moodley, & Chevannes, 2014).

Despite these micro-level differences in the explanations by African and African-Caribbean participants, most participants, except for second-generation African participants, noted that they were unwilling to visit a GP or a hospital. Subsequently, this unwillingness by black men to go to hospital could be seen as a potential contributing factor for late diagnosis.

In addition, another macro-level similarity among black men across all black sub-groups appeared to be their acceptance of late diagnosis as part of cancer. As was evident in this study, in both African and Caribbean cultures, across both the first and the second generations, the understanding of cancer was that it leads to death, which could be seen as another potential contributing factor for not going to hospital early. In the USA, black people reportedly believed that cancer was a death sentence and this attitude towards cancer was identified as a reason black people were unconcerned about cancer (Bloom et al., 1989). Although Bloom et al.'s study was conducted 25 years ago, it has been cited in recently published study by (Copeland, 2006). In the UK, Ehiwe, McGee, Filby, & Thompson. (2012) conducted a focus group study among Ghanan and Nigerian immigrants residing in Luton. Ehiwe et al. (2012) recruited both men and women participants and reported the association of cancer with certain death as a barrier which would prevent black men and women from going to hospital (Ehiwe et al., 2012). This similarity of the association of cancer with certain death, as observed in studies in both the USA and the UK, could be minimised by providing factual information and having healthcare professionals working together with black communities to raise awareness, as reported by participants in this study. Suggestions for how, on a practical level, healthcare professionals could work together with black communities are presented in Section 6.3.2.

6.2.6 Diminished communication

As communication skills are key tools in delivering effective healthcare (Lurie et al., 2013), healthcare professionals also need to be aware of how to deliver information effectively in the context of black men's culture of communication. USA-based studies suggested that most non-black doctors had a limited understanding of how to communicate with black people (Clarke-Tasker & Wade, 2002; Johnson, Roter, Powe, & Cooper, 2013; Jones et al., 2009). Black men in the present study felt that doctors

from other races did not understand them. Additionally, participants also noted that the subtle, indirect language used with the white community was usually ineffective with the black community, which prefers a more direct, authoritarian approach to medical advice.

The findings of this study showed that hierarchy had a significant place in communication in the African and African-Caribbean communities. In African-Caribbean culture, a respected person was expected to speak loudly to convey the importance of the message, ensuring that the listeners would obey the message, whereas in African culture, the speaker's age had a significant value in the social hierarchy, ensuring the effective passing of information. It may be challenging to address these cultural differences and expectations about the way black men prefer to receive information and accordingly to deliver information in clinical practice. However, understanding the cultural differences and similarities would be helpful for public-health campaigners and healthcare professionals when they encounter black men in their practice.

6.2.7 Failing to address micro-level differences

The present study highlighted micro-level differences between African and African-Caribbean men's views, which were important for understanding the reasons behind their views towards cancer. However, at the macro level, both groups shared similar views towards cancer and cancer-related issues. A survey carried out in the USA showed that there were macro-level similarities and micro-level differences among USA-born, African-born and, Caribbean-born black men in engaging in prostate cancer risk-reduction activities and in early-detection services (Odedina et al., 2011a; Odedina et al., 2011b). Further, Odedina et al. (2011b) recommended that developing effective health-promotion programmes and policies to address the needs of USA-born and

foreign-born black men be based on the understanding of the varying characteristics of each group.

This study also found health-related cultural differences at the micro level between African and African-Caribbean men in their views towards cancer and cancer-related issues. Although the findings of this study were similar to those of Odedina et al.'s (2011a; 2011b) survey, this qualitative study explores these cultural similarities and differences providing an explanation of the wider issues relating to cancer through black eyes. Services being developed to reach out to black men, in particular in terms of cancer awareness, must be refined to address each particular (African and African-Caribbean) group's views at the micro level. Given the growing African population in the UK (see Table 1.2), the need for targeted health promotion for both African and African-Caribbean men is needed for better health outcomes. However, before attempting to address black men's needs at the micro level, addressing the needs of black men as a whole based on their health-related cultural similarities at the macro level seems practical. It is important to understand the issue of cancer through black eyes and then gradually develop a micro-level approach towards addressing the needs of black men in both communities by designing appropriate health-promotion programmes and public health policies.

6.3 Revisiting the Public Health Models

Chapter 2 of this thesis presented a review of potentially suitable public health models that could be used to guide the study. The most commonly used public-health promotion theories and models were reviewed for their potential effectiveness for cancer-related public-health campaigns among black men in the UK. Following this review of models, the Community Organization Model was chosen as the most relevant and appropriate to provide a theoretical foundation for the study. The models can now

be revisited in light of the findings to assess if the decisions made about a suitable model were well founded and appropriate.

6.3.1 Relevance of the findings to public health models

Three categories of public health models had been considered potentially relevant to the study; interpersonal, individual and community level models. The interpersonal and individual level models had been considered inappropriate as there was little evidence of the effectiveness of these models when applied to public-health campaigns aimed specifically at black men. However, it is now useful to revisit the discarded models to assess if they could have been a useful model to underpin the study.

The interpersonal models included social learning/social cognitive theory, the theory of reasoned action, and the theory of planned behaviour. Social learning/social cognitive theory assumes that people acquire knowledge from one another by observation and imitation and use this acquired knowledge to change behaviour (Bandura, 1977). The concept of learning by observation or imitation from others to promote cancer-related health campaigns among black men could be problematic given the study findings. Participants expressed views that contained misconceptions and conspiracy theories, including perceiving cancer as a deliberate social engineering programme to reduce the population. Hence, the imitation of these views would arguably not assist in changing behaviour or lifestyle to raise awareness of cancer risk or to utilise cancer-related information from mainstream providers. Social learning theory remains useful for explaining health-behaviour changes by concentrating on individual characteristics (Nutbeam et al., 2010) but remains limited in promoting cancer-related health campaigns among black men.

The theory of reasoned action emphasises that humans are rational and make reasoned decisions, with their reasoning based on their attitudes and their subjective

environmental and social norms (Fishbein & Ajzen, 1975). The usefulness of this model in relation to health promotion programmes aimed at reducing smoking and sexually transmitted infections had been questioned, although the model was considered effective for identifying specific factors that influenced or encouraged negative health-related behaviours (Nutbeam et al., 2010). In the current study, cultural and religious factors combined with participant's perceptions of themselves as black men in society appeared to be major influential factors in terms of their current views about cancer and cancer-related issues. As the theory of reasoned action was considered useful for identifying influential factors (Nutbeam et al., 2010), the use of this particular theory to promote cancer-related health campaigns among black men may have some resonance with the study findings given that the present study identified influential factors that gave rise to negative attitudes.

To improve the effectiveness of the theory of reasoned action, a more refined version was introduced. The theory of planned behaviour proposed that 'perceived behavioural control' was an additional domain that determined human decision making (Ajzen, 1991). The key concept of the theory of planned behaviour emphasised that, in order for public-health promotion to be effective in changing people's behaviour and attitudes, people needed to perceive that they had power and control over opportunities and resources (US Department of Health and Human Services, 2002). The findings from the present study indicated that black men perceived that they were disfranchised and controlled by the social system. Participants in the present study expressed a lack of trust towards the healthcare system and healthcare professionals. Hence, the theory of planned behaviour continues to appear inappropriate in relation to cancer-related health promotion campaigns among black men.

The individual level models included stages of change/transtheoretical model, the health belief model (HBM) and nudge theory. The stages of change/transtheoretical model

advocates that providing factual information alone does not help people to change their health behaviour; behaviour change is a process undertaken through different stages of change (Prochaska, 1984; Prochaska & DiClemente, 1982). The model has been shown to be effective in clinical settings for dealing with addiction, to help recovery from addictive behaviour (Bridle et al., 2005). The findings from the present study indicate that health promotion needs to address the multi-layered nature of the views of black men as constructed from their cultural, religious, social, and economic outlook. This is not a good fit with a model that looks at a staged change approach to behaviour.

Two core elements of the HBM include 'perceived susceptibility to illness' and how 'the severity of illness is perceived' are believed to motivate individuals to take action and develop positive health behaviours (Sheeran & Abraham, 2005). Findings from the present study indicated that black men did not necessarily perceive cancer as a threat to health. Participants perceived that black men were not susceptible to cancer in general, including prostate cancer. Through black men's eyes, the issue of cancer was viewed from a wider perspective, taking into account social, political, religious, and cultural aspects. Since black men did not appear to perceive cancer as a threat to health, the HBM continues to be considered unsuitable to promote a cancer-related health campaigns to black men.

Nudge theory is often used to promote positive health behaviour at a personal (individual) level by influencing people through subtle guidance to make a choice in a certain (default) direction (US Department of Health and Human Services, 2002). As illustrated in the theory of cancer through black eyes, black men had a collective meaning and collective views as a community towards the risk of cancer and early detection, including views on smoking, body weight, DRE, and giving blood samples. These black men's collective meaning and views towards cancer risks and early detection were intertwined with social and cultural norms. Accordingly, this individual

level model (nudge theory) remained unsuitable as a theory for promoting cancer-related health campaigns to black men.

The findings of the present study suggested that neither interpersonal nor individual-level health-promotion models sufficiently capture the multi-layered nature of black men's views towards cancer and cancer-related issues. Therefore both interpersonal and individual level health-promotion models remain arguably ineffective for devising cancer-related public-health promotion campaigns for black men. The study findings support community-level health-promotion models as they do have the potential to address the multi-layered nature of black men's views towards cancer and cancer-related issues. Four community level models had been considered: organisational change, diffusion of innovations, ecological approaches and community organisation.

Organisational change theory advocates the involvement of institutions to increase the effectiveness of public-health promotion. However, black men in the present study were not responsive to cancer-related advertisements and health-promotion information that was delivered by institutions (e.g. NHS), perceived by black men as a tool for controlling them. Thus, this particular model may not be appropriate for health promotion activities that take a top down approach or for a community who demonstrate a lack of trust in the healthcare system.

The diffusion of innovations theory revolves around the effectiveness of communication and innovations in spreading new ideas, or a product gaining momentum and being accepted over time. The momentum with which the new idea or product is received in the community will dictate whether, and the extent to which, a community will change its behaviour (Rogers, 2003). The implementation aspects of this model involve different stages, making the model complex and time consuming (Brian & Glanz, 2008). Although engagement with the public at a grass-roots level using interpersonal

communication, peer-to-peer conversations or peer networks is considered key for spreading the adoption of an innovation (uptake of the new innovation by the target audience), the diffusion of innovation model tends to be a top-down approach. This top-down approach is apparent when the three pathways by which health behaviour programmes or innovations can be disseminated are considered. Firstly, the distribution of materials and tools, which is known as a 'direct to practice' approach; secondly, enactment and implementation of policies, legislation, or regulations; and finally, a systematic, sustained, and long-term approach that uses multiple strategies and methods, including ongoing evaluation (Owen, Glanz, Sallis, & Kelder, 2006). The findings of the present study indicated that black men were not receptive to top-down approaches to public health promotion. Moreover, the diffusion of innovation model does not give a clear and sufficient platform to create an environment for health professionals and members of communities to work in partnerships, an approach that could be seen as a useful opportunity to minimise the mistrust held by black men. The diffusion of innovation model has some relevance for the study findings and, if there were no preferable options available, an adapted version of the diffusion of innovation could have provided some degree of fit with the data. However, since the community organisation model appeared to be a better option for effective health-promotion among black men, it remains the better fit based on the findings of this study.

The ecological model has a focus on both individual and social environmental factors for successful health promotion interventions (McLeroy et al., 1988). This model was considered favourably at the outset of the study, given its focus on multiple levels and not being restricted to solely top-down or bottom-up approaches. The model assumes that changes in the social environment will produce changes in individuals and the support of individuals is essential for implementing changes (McLeroy et al., 1988). The model is complex, given the multiple levels of focus including individual,

organisational and policy levels. However, the main focus of an environmental model is to look for environmental causes of behaviour and to identify environmental interventions. In the present study, it was not necessarily environmental factors that predominantly shaped participants views. The model may be well suited to population based challenges that require organisational and policy changes, such as smoking cessation programmes, but it is not clear if the model has resonance with the current study findings that focus on minority views. Addressing all levels of the model would be complex and challenging and arguably not practical at this early stage of intervention. The findings from this study call for close working between healthcare professionals and local communities at the outset to build trust, engaging fully with service users, and giving black men ownership of health promotion interventions that are directly relevant to their needs.

Based on the findings of this study, the community organisation model remains the most suitable and applicable approach for undertaking cancer-related public-health campaigns among black men in the UK. Participants expressed feelings of being alienated and disfranchised, with a lack of trust towards the healthcare system and healthcare professionals, and a lack of receptiveness to top down health-promotion programmes. The community organisation model places the target community's values, concerns, preferred ways of receiving information, and local knowledge at the centre of health-promotion programmes (Braithwaite et al., 1989; WHO, 2009). Hence, disfranchised communities are able to gain greater ownership and control over health-promotion programmes. The community organisation model also provides an opportunity to design a bottom-up health-promotion programme by working at a grassroots level, and to build trust between the black community and healthcare services. This aspect of the model is a good fit with the views expressed by participants on a lack of trust in institutions such as the NHS.

6.3.2 Application of the theory to the Community Organization Model

The theory of cancer through black eyes demonstrates that black men's views towards cancer and cancer-related issues are influenced by numerous factors which emerged as subcategories: '*Cultural views'; 'Religious beliefs'; 'Avoiding Babylon'; 'Alienation'; 'Suspicious mind'; 'Advertisements and information influence very little', and 'Gap in service provision (Bridging the gap)*'. As illustrated in section 6.2, there are essential issues in each subcategory which are not understood within current cancer-related health-promotion campaigns. For example, black men's cultural and religious views and meanings towards clinical cancer risk factors (smoking and obesity) are not recognised by cancer-related health-promotion campaigns. Again, black men's suspicions and feeling of disfranchisement, which make them less receptive to health promotion campaigns information provided by institutions, are not considered when trying to devise better ways of approaching black men.

In the *Community Organization Model*, disfranchised populations are able to gain greater ownership and control in the health promotion programme (Braithwaite et al., 1989). Participants in this present study expressed that they felt alienated and expressed feelings of disfranchisement, therefore the *Community Organization Model* can be a helpful tool to diminish gradually this disfranchised feeling reported by black men. The model gives black men responsibility, control and, more importantly, preferable ways of receiving information. During the process, black men can build trust and close relationships with health service providers. This would enables black men to consider the information as credible and take it more seriously. As is evident in the study findings, black men suggested that the involvement of '*ordinary*' black men and respected members of the community, such as religious and community leaders in health promotion, is vital to its effectiveness. Similarly, the preferred modes of passing on information, such as testimony, community gatherings, music and fashion events,

were identified as attractive arenas in which to undertake health promotion. The means of communication with black men was identified in this study as being a crucial element in the effective transmission of the message. All of these issues are inherent in the *Community Organization Model* of health promotion, as the model's key concept is prompting positive health behaviour by putting the community's values, preferences, concerns and local knowledge at the centre of health promotion programmes (Braithwaite et al., 1989; WHO, 2009). It also worth here to recall the effectiveness of Sickle Cell disease health promotion campaigns which more closely involved black communities as discussed in Section 6.2.2, last paragraph on page 218.

In spite of a greater interest by healthcare professionals and public-health policy makers in working on community-level health promotion, more convincing justification is required to attract the required resources from limited healthcare funding in community settings (Nutbeam et al., 2010). Acceding to the WHO (2009), however, the *Community Organization Model* is more cost-effective compared with other health-promotion models. The findings of this study indicate that members of the target community (black men) could also contribute valuable resources including venue and black health professionals volunteering their time (some participants showed their interest during the data collection period). Moreover, as the model promotes empowering communities by sharing responsibility and authority in health promotion campaigns, a positive outcome is more likely to be gained. From the perspective of public health promotion programme campaigners; expenditures of other costs, such as professional time, publication and advertising could be minimised by using the *Community Organization Model*. Thus, the *Community Organization Model* could be cost-effective as suggested by the WHO (2009). The *Community Organization Model* can provide a number of benefits which directly or indirectly link to the findings of this present study. Hence, of the four most commonly used health promotion models at community level ('Organizational *Change*

Theory', 'Diffusion of Innovations Theory', 'Ecological Approaches' and 'Community *Organization Mode*l'); the *Community Organization Model* appears the most suitable for promoting cancer related public health campaigns among black men in the UK, with potentially less costs and higher effectiveness.

Having a better understanding of the target community's views is the initial and critical step of *Community Organization Model campaigns*. This must be effective before entering to the targeted community's boundaries and engaging with them (Braithwaite et al., 1989). The theory of cancer through black eyes provides a sound foundation for cancer related public health campaigns to employ the *Community Organization Model* targeting BA and BAC men. Accordingly, the conceptual framework has been developed to promote cancer-related public-health campaigns. Figure 6.2 illustrates this research's conceptual framework for how the *Community Organization Model* could be applied to promote cancer-related public-health campaigns among black men. The shaded part of Figure 6.2 indicates that black men's views are influenced by different factors, including their cultural views, religious beliefs, suspicion towards the establishment, feelings of alienation and disfranchisement, and their meanings of clinical risk factors of cancer. Furthermore, black men's views also determine their receptiveness to cancer-related public-health information, as well as their willingness and ability to utilise available services such as DRE.

Direct or indirect cancer-related services and service providers, including health-promotion information and early detection services, are influenced by different factors as shown in the unshaded part of the Figure 6.2. One of the main aims of service providers is to improve outcomes by enhancing cancer services and reducing inequality (DH, 2011). Hence, in order to provide sound, appropriate, and culturally sensitive cancer-related services, service providers should have evidence-based information about the current views of black men to enable them to understand the issue of cancer through

black eyes. Consequently the combination of black men's awareness about service providers and service providers' evidence-based knowledge about black men views will be a common ground that could lead both parties to work in partnership. Thus, the outcome of this engagement could help to establish black men's trust and bridge the gap between black men and the healthcare system leading black men as a community to start taking responsibility to improve their cancer-related knowledge. Hence, based on mutual understanding and commonly contracted objectives, planning and implementation of a cancer-related public-health promotion programme could commence. In return, the outcome of the implemented programme will influence how black men view the issue of cancer. In due course, the effectiveness of the programme could be evaluated. It has to be noted that working in partnership with black men is not only important for promoting effective health promotion; such a working relationship will also boost black men's confidence and trust towards healthcare professionals and the healthcare system, with a secondary effect of willingness to report symptoms, as the findings of this study show that black men, even with signs such as bleeding, avoid going to hospital not only because they do not know the signs and symptoms of cancer, but also to 'avoid Babylon'. Working in partnership with black men at the community level will help to gradually minimise their lack of trust towards the healthcare system and, as a secondary effect, could encourage timely seeking of help if they are affected by symptoms indicative of cancer. During the participant recruitment process and the data collection process, a number of community organisations and some participants indicated an interest in becoming involved in promoting cancer awareness within their community. Black community organisations acknowledged that they had sufficient infrastructure, including venues for community gathering and skilled individuals, but needed NHS input for legitimacy, formality, initiation, and continuity of a health-promotion programme. Employing the *Community Organization Model* could

accordingly ensure effective cancer-related health-promotion campaigns within the black community at low-cost.

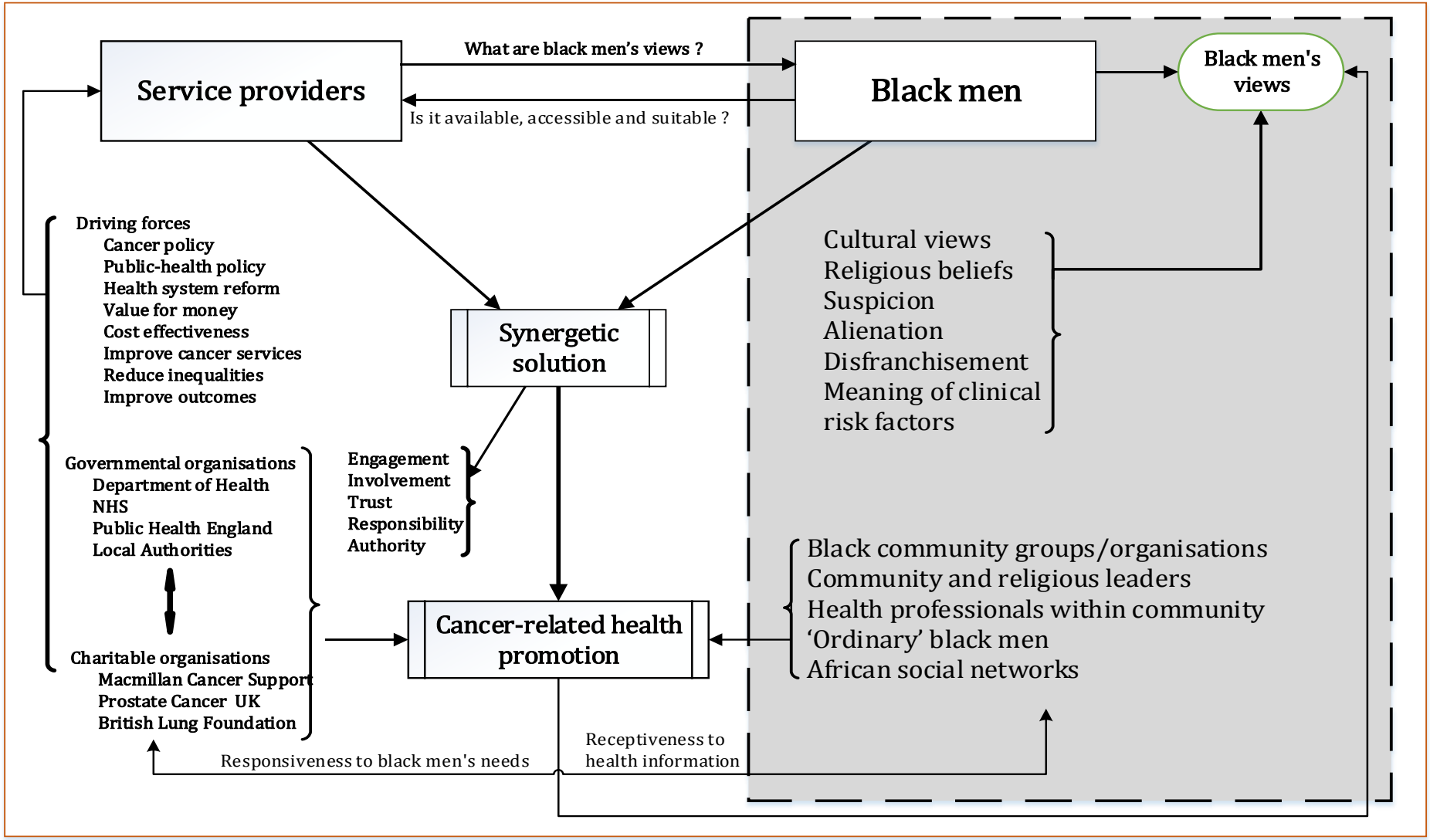

Figure 6.2: Conceptual Framework of the Community Organization Model for Health Promotion among Black Men

6.4 Evaluating the theory

Evaluating the emerging grounded theory within the grounded theory method follows a clear procedure, namely, evaluating the emerging theory against the criteria of what should be recognised as a sound theory. In the classical grounded theory method, sound theory fits, works, has relevance, and should be modifiable (Glaser, 1978; 1998). In the constructivist grounded theory method, the aim is to create a theory that has credibility, originality, resonance, and usefulness (Charmaz, 2006; 2009; 2014). As this study was conducted using the constructivist grounded theory method, the theory of cancer through black eyes was evaluated for its credibility, originality, resonance, and usefulness, based on Charmaz's (2006) constructivist theory criteria.

Charmaz provided a list of suggested questions that researchers should ask themselves when evaluating their emerging theory against each of the four criteria comprising the method (see Table 6.1). In total, Charmaz suggested 19 questions; six for evaluating credibility; four for originality; another four for resonance, and five for evaluating the usefulness of the theory (Charmaz, 2006, 2014). During the evaluation process, however, the theory of cancer through black eyes was evaluated by capturing the core concept, essence, and spirit of each of the four criteria. The 19 questions were carefully considered and those that were pertinent and relevant were addressed.

Charmaz (2006; 2014) recognised that grounded theory varied for a number of reasons, including disciplines and studied phenomena; the 19 questions would therefore not be relevant for all studies. For example, one of Charmaz's five suggested questions for evaluating the usefulness of the theory included having researchers asking themselves '*how does your work contribute to making a better world?*' (Charmaz, 2006, p.183). Although it was possible to make assumptions regarding the '*possible contribution*' of this present study towards making a better world, it was considered overly ambitious to

make claims in relation to a 'better world' based on current study findings. It was possible to evaluate and to make rational assumptions as to the contribution of this study to current knowledge in the field. Hence, the theory of cancer through black eyes was evaluated by capturing the core concept, essence, and spirit of each of the four criteria (credibility, originality, resonance, and usefulness) based on Charmaz's suggested questions.

Table 6.1: Charmaz's Criteria to Evaluate Grounded Theory Study

Credibility

- Has your research achieved initiate familiarity with setting or topic?
- Are the data sufficient to merit your clam? Consider the range, number, and depth of observations contained in the data
- Have you made systematic comparisons between observations and between categories?
- Do the categories cover a wide range of empirical observations?
- Are there strong logical links between the gathered data and your argument and analysis?
- Has your research provided enough evidence for your claim to allow the reader to form an independent assessment –and agree with your claim?

Originality

- Are your categories fresh? Do they offer new insights?
- Does your analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significant of this work?
- How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?
- Have you revealed both liminal and unstable taken-for-granted meaning?
- Have you drawn links between large collectivities or institutions and individual lives, when the data so indicate?
- Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

Usefulness

- Does your analysis offer interpretations that people can use in their everyday worlds?
- Do your analytic categories suggest any generic processes?
- If so, have you examined these generic process for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world?

(Charmaz, 2006, p182-183).

6.4.1 Strengths of the theory

Credibility

The core elements of Charmaz's (2006, 2014) concept of credibility can be summarised as follows. Theory is credible if it is grounded in sufficient data, has logical links with vigorous data analysis, and provides convincing evidence to establish the theory. The theory of cancer through black eyes is based on sufficient data gathered by conducting 34 interviews, in which participants openly expressed their views. During the interviews, using theoretical sampling, participants who were recruited as a theoretical sample confirmed the views of previous interviewees, or showed similar views at times with deeper explanation. Given the participants' openness to providing their genuine views, the data was more reliable. Every attempt was made to gather high-quality data, by creating a relaxing environment for participants, using a more informal, conversational style rather than a straightforward, formal question-and-answer style, and consulting the supervisory team throughout the data-collection process to take advantage of their experience, comments, and advice for improving interview technique. Given the researcher's effort to gather quality, in-depth data, participants' openness and the input of the supervisory team, the researcher can confidently claim that sufficient, convincing, and in-depth data were collected. Thus it can be seen that the foundation of the theory of cancer through black eyes was credible.

Data analysis commenced by performing initial line-by-line coding. As was highly recommended by proponent of grounded theorists initial and theoretical coding were performed with an open mind to explore any theoretical possibilities detected from the raw data (Charmaz, 2006, 2009; Corbin & Strauss, 2008; Glaser, 1992; 2001 Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). In order to achieve a systematic comparison between emerging categories and the raw data (interviews), memos were written for each interview after reading its transcription and reviewing the related field

notes (audio-recorded notes). These memos were kept separately. At a later stage of the data analysis, during theoretical coding and the refining of emerging categories, a comparison was made between individual interview's memo and the emerging categories. This technique was very helpful to make sure emerging categories matched or captured the highlighted points in each interviews memo. Also making sure all unique, significant, or different views raised by single or by a few participants were included in the findings, made the link between data gathering, data analysis, and the theory of cancer through black eyes credible. As the result, the researcher believes that he has provided sufficient evidence in the Findings chapter to establish the theory and for his argument. This will allow readers to form an independent assessment about the credibility of this grounded theory.

Originality

A number of factors can be used to evaluate the originality of the study. Charmaz's (2006) criteria for evaluating the originality of grounded theory studies focused on whether they bring new insight to the knowledge and/or extend existing ideas, concepts, and practices (Charmaz, 2006; 2014). The theory of cancer through back eyes was based on emerging categories that offered fresh and new insights about the views of black men towards cancer, and provided new ways of looking at black men's needs and their preferred ways of receiving health-promotion information, recognising black men's understanding of cancer risk factors in light of their social and cultural values.

The theory helps to understand and give insight into the world of black men in relation to the studied phenomena; its original contribution offers evidence that could be useful for devising public-health strategies focused on black men that extend beyond cancer, including diseases such as diabetics and stroke. This claim is not made to sensationalise the study, but rather, as presented in the Finding chapter, to associate black men's views

towards the healthcare system, smoking and body weight, with the above-mentioned public-health issues. The findings of this study could potentially be used as additional evidence for profoundly changing practices associated with the provision of information and communication with black men. In addition, these findings could be used as evidence for individuals or community organisations interested in promoting awareness within their community. Study participants reported that the black community was disadvantaged by a lack of culturally oriented clinics (black-led clinics), since lack of evidence made it impossible to secure the government funding received by other ethnic minority groups. Accordingly, the findings of this study could have a significant impact on the target population.

During the study the researcher attended three health-promotion events within the black community. Taking advantage of these opportunities allowed for observation of the types of communications that were effective and further understanding of, the cultural and religious values that would need to be incorporated in health promotion programmes within the black community. These experiences helped the researcher to understand in depth the reasons and meanings of participants' responses during the data-analysis period. Accordingly, effort has been made during the interpretation of data to capture the essence of the community's culture in order to understand 'taken-for-granted' terms and avoid distortion of the original meaning. The originality of the theory of cancer through black eyes in terms of bringing new insights to the knowledge base and to practice is therefore solid.

Resonance

A strong combination of originality and credibility ''increases the resonance, usefulness, and the subsequent value of the contribution'' (Charmaz, 2006, p.182, 2014, p.338). As highlighted above, the credibility and originality of this study was

established, and relying on Charmaz's definition, the resonance and usefulness of the theory of cancer through black eyes were founded on a strong base. Additionally, constructivist grounded theory pays close attention to language and explores in detail the taken-for-granted properties of words to construct theoretical categories, by interpreting participants' meaning without distorting participants' social meaning of the taken-for-granted words. The quality of this practice linked directly with the resonance of the developed grounded theory. In this study, participants' meanings of a number of taken-for-granted words were explored. For example, what did the word cancer mean to black men? What did the NHS mean to them? What was the meaning of being a black man in the society in which they lived? The present study has revealed the meaning of these taken-for-granted words from individual participants' perspectives, but also the links to black men's collective views towards cancer and cancer-related issues. One way of evaluating resonance is to ask if the grounded theory makes sense to the research participants, or people who share participants' circumstances, (Charmaz, 2006; 2014). Four black men (two African and two Caribbean), none of whom participated in this study, were asked to read the findings of this study and give feedback to what extent they agreed or disagreed with the findings. The feedback gathered from these four black men confirmed that the findings made sense to them: '*it is true*'.

Usefulness

The final criterion for evaluating the strength of the grounded theory was its usefulness. The study's credibility and originality increased the usefulness and the consequent value of the contribution of the grounded theory (Charmaz, 2006, 2014). The usefulness of the study was considered in terms of the contribution of the study to knowledge. The theory of cancer through black eyes contributes to advancing knowledge in the studied phenomena. This study is unique in that it is a qualitative study focused on black men and involving two generations of BA and BAC men. It is useful for understanding

health-related cultural similarities and differences among these groups. This understanding will help health professionals such as nurses and public health professionals improve their cultural competences. The study is a useful source of evidence for other researchers planning to undertake research in this field. Moreover, the theory of cancer through black eyes has the potential to significantly contribute to the understanding of cancer and cancer-related issues from black men's perspectives and accordingly to designing effective health promotion programmes targeted at black men.

6.4.2 Weaknesses of the theory

The weaknesses of the theory of cancer through black eyes are highly dependent on the weakness of the research process as a whole. Therefore, almost all identified weaknesses are presented in section 6.5.2, which discussed the weaknesses of the research process as a whole.

6.5 Evaluating the research process

The strengths and weaknesses of the research process as a whole are evaluated and reflected in this section. The research process was evaluated from a methodological, personal, and practical perspective, to identify issues that might have affected the quality of this study.

6.5.1 Strengths of the research process

Good and well-considered research should have a compatible theoretical and philosophical foundation (Crotty, 1998; Denzin & Lincoln, 2005). In this study, the researcher ensured that the ontology ['no single external reality'], epistemology [constructivism], theoretical perspective [interpretivist], methodology [qualitative; constructivist grounded theory], and method [one-to-one semi-structured interviews] were consistent and appropriate to the study aims and objectives. Furthermore these

theoretical and philosophical foundations were compatible with the researcher's own stance, which revolved around '*seeking to understand specific contexts through participants' perceived knowledge and beliefs*'. Accordingly, the study was carried out with passion and interest, adding value to the quality of the study.

Employing qualitative methodology was a strong point of this study. As mentioned in the Introduction and Literature Review chapters, most existing studies in this area were quantitative. While these quantitative studies have uncovered knowledge about general patterns, such as black men being less aware of cancer risk factors and presenting late, they were unable to explore the underlying reasons for these patterns. By employing a qualitative methodology, the researcher of this study was able to collect rich data to understand black men's views towards cancer and cancer-related issues. Consequently, participants were able to articulate their views in their own words, using expressions that could not be captured through quantitative methods. As a result, this study produced original understanding about the underlying reasons behind black men's views towards cancer. Although all qualitative approaches are generally well regarded for their advantage in gathering rich data, for the reasons provided in Chapter 4 (Section 4.6.4), the selection of constructivist grounded theory can be seen as one of the strengths of this study. Firstly, this specific grounded theory approach gives priority to understanding the phenomena being studied rather than explaining and predicting (the main source of positive grounded theory criticism as epistemological fallacy); in relation to the present study, constructivist grounded theory provided a tool for understanding the views of black men towards cancer, generating comprehensive knowledge from the interpretation of participants' responses.

Secondly, the constructivist grounded theory approach gives the opportunity to carry participants' voices throughout the research process, as one of the characteristics for evaluating good research is its potential benefit to the studied population. Carrying

participants' voices throughout the research process and through to the interpretations of findings gives participants a chance to have their voices heard.

The method used, one to one interviews, was a strength of this study; the researcher benefitted from collecting very rich data. The interview method allowed for follow-up interviews to clarify, check, and confirm concepts that emerged from previous interviews with participants. The interview method allowed ample opportunity to build rapport with, gain the trust of, and gain access to the world of participants. The researcher's personal background as a cultural insider played an important role; research participants had their own assumptions about whether the researcher was a cultural insider or not, and these assumptions could also influence the research (Crang, 2003).

The researcher was born and raised in Ethiopia, Africa. As the researcher was possibly considered a cultural insider by the participants, there were a number of advantages in regard to the research; understanding the culture, and forming close relationships with community leader and research participants. Being a cultural insider made it easier to access black community organisations and to advance the participant-recruitment process as it was relatively easer to access the '*gate keepers*' and gain their trust. During data collection, the researcher had the privilege to be trusted by most respondents to the extent that they were willing to share very sensitive information. This included personal experiences related to cancer, narratives about the consumption of herbs, and with some participants, the disclosure that they had been in prison. More importantly, participants shared their views and beliefs without any restriction, regardless of how controversial and/or conspiracy-oriented those views might have been. As a cultural insider, the researcher had prior assumptions regarding some of the issues that might emerge from the interviews such as minimal level of awareness of cancer symptoms, but he also remained very open-minded. For example, the researcher had not expected that cancer and cancer-related issues would be perceived by participants in such a complicated

manner, linked with different social, historical and political ties and going far beyond a pure medical condition; he certainly had not anticipated the level of suspicion, conspiracy theories, and the extent of existing gap between the healthcare system and black men.

The researcher was very humbled and appreciative of participants' openness and their ability to express their feelings, trusting that the researcher was there to understand their views and not to judge them. This allowed the researcher to gain in-depth and rich detailed data, adding to the quality and originality of the findings. Mohammad (2001) stated that her ethnic and cultural background gave her easy access to conducting research among British Muslims. Similarly, Liu (2010) highlighted that her personal position as a Chinese cultural insider allowed her to gather high-quality data from Chinese elders in the UK for her grounded theory PhD research. On the other hand, the researcher also had to be aware that being a cultural insider could have its own disadvantages (Crang, 2003). Some of these disadvantages in relation to this study are presented in the next section.

6.5.2 Weaknesses of the research process

For researchers, while being a cultural insider had its advantages, it also had disadvantages. For instance, if a member of the community did not feel assured of confidentiality, he/she would not participate in the study to protect their privacy and to preserve their social status within their community. Secondly, some participants may not have disclosed information simply because the researcher was a cultural insider and the participants could be worried about being judged. In relation to this study, the researcher did not encounter the above-mentioned problems. However, there was a potential risk that participants might assume that as a cultural insider, the researcher would already be aware of many cultural nuances, making it unnecessary to disclose or

to explain them. To minimise this, when the researcher noticed that participants' tended towards this assumption, he endeavoured to use the participants' own words to probe for further details. However, the researcher was cautious about disrupting the flow of the interview by interrupting the participants too often.

One of the notable limitations of this qualitative study was that the findings of this study cannot be generalised to all black men, for several reasons. In this study, 34 interviews were conducted, with 27 participants. The sample size was not a representative sample of the UK-based African and African-Caribbean population, as the study was not designed to make generalisations of the population under study or to test a hypothesis. In addition, BA and BAC men were the target groups of this study. Given that black people have immigrated to the UK from over 60 countries (from both geographical regions), the findings of this study need to be considered in context. Therefore, no attempt was made to generalise the findings of this qualitative study to generate a generalisable statement about the target population. Although the extent of methodological detail provided should allow some vicarious transferability which is in-keeping with qualitative study's characteristics.

There were 27 participants (17 BA and 10 BAC) involved in this study. Out of the total 27 participants, 16 participants had obtained a university first degree qualification. Two of these were both second generation BAC (one female and one male) and the remaining 14 participants were BA men (12 first generation BA, two second generation BA). It can be notice here that out of the 17 BA participants 14 of them were obtained a university degree. This seems to suggest that there was a sampling bias. However, African graduates are more likely to leave their country of origin; for example in 2004 an estimated 60% of Gambian, 25% of Sierra-Leonian, and 10% of Kenyan university graduates were resident in the USA (Schifferes, 2004). Many African graduates, most of whom were previously employed in well-paid and highly skilled occupations, are more

likely to immigrate to rich western countries such as UK and USA (Schifferes, 2004; The Foreign Policy Centre, 2006). Given this flow of migration, the pattern of first generation BA participants holding degrees was therefore not unexpected. More importantly, this variation of academic qualification between BA and BAC was not seen as a significant influential factor in participants' view towards cancer. For example, despite a highly educated BA sample there were no significantly disagreement with their BAC counterparts in the view that cancer was not a black person's disease.

The recruitment process included the use of print (posters) and radio advertising for reaching black men. There was a significantly higher response rate from potential participants who had heard the radio adverts than those who had seen the print adverts. Since the radio station transmitted locally in the West Midlands, in order to balance the number of participants based on geographical location in the UK (Yorkshire, the North West, the Midlands, and London), the researcher was unable to invite all potential participants who showed interest through the radio advertisement. This decision compromised the chance to recruit a greater number of participants, and the researcher recognises the possible influence of this limitation on the findings. Hence, the theory developed from these findings was conditional on time, place, and situation.

Participants who were recruited through the radio advertisement could be assumed to be black men with set cultural and religious beliefs, since the advertisement was broadcast on the Afro-Caribbean Millennium Centre & Radio station, whose target audience is black communities. The audience can be considered as black people who would like to maintain a close relationship with their black identity, culture, and traditional values. These participants' high sense of belonging to a black identity could be reflected in their responses, including expressions of immense suspicion of the healthcare system linked to slavery and a perception that there is a cancer treatment that can cure cancer; and it is withheld from black people. Consequently, some findings could be seen as directly

related to this specific population. Upon reflection, this effect could be neutralized by recruiting participants using social media, including Facebook, Twitter, and YouTube. If social media had been used as a recruitment method, it could have also provided a mechanism to collect data on a broad spectrum of participants' views towards cancer. However, 70 per cent of participants were recruited by disseminating printed recruitment posters and participant's information sheets in over 16 black community organisations across four major UK cities, namely Leeds, Manchester, Birmingham, and London. Hence, the finding of this study must be viewed in the context of the recruitment process.

The researcher's skill and experience in undertaking research inevitably affected every stage of the research process; choosing the right methodology, recruiting participants, interviewing, analysing data, constructing grounded theory, and presenting the findings. By recognising his own limitations, the researcher accepted that during data gathering, his interviewing skill required development and may not have been of a high standard at the outset. However, an effort was made to minimise this by seeking feedback in three stages: Firstly, the supervisory team listened to the recordings of the first two interviews and again during the half way point of data collection to provide feedback on the researchers interview style; secondly, final interview transcriptions were provided to each participant to confirm that what was transcribed was their account and that they still agreed with the views they expressed during the interview; and thirdly, after completing the first draft of the Findings chapter, the researcher asked four black men (two African and two Caribbean), none of whom participated in this study, to what extent they agreed or disagreed with the findings. These individuals noted no disagreement.

Further, as this research was the first pure grounded-theory study conducted by the researcher, the ability to develop a theory was challenging. This lack of experience

could have affected the study. However, to minimise the impact of this limitation, three highly experienced research supervisors provided constant and on-going advice and guidance, which the researcher benefitted from to improve the quality of this study.

6.6 Implications

The findings of this study have important implications for current cancer and public-health policies, for cancer-related public-health promotions targeted at black men and other ethnic minority groups, and for healthcare professionals, including nursing trainers and educators. Evidence suggests that social and health inequalities span across cultures and, that social and cultural factors are strongly linked to health and illness (Armenakis & Kiefer, 2007). This present study's findings showed a strong link between participants' cultural beliefs and their views towards cancer-related issues. Some of the views of black African/African-Caribbean men living in the UK towards cancer might also be representative of other minority groups' with similar cultural beliefs. For example, Thomas, Saleem, & Abraham (2005) conducted focus groups with 135 participants (85 women and 50 men) from African-Caribbean, African, Arabic, Greek, Gujarati, and Pakistani communities. Their findings showed that strong cultural and religious beliefs and low levels of literacy, were among the main barriers to accessing cancer screening services particularly among Muslim female participants. Similarly, Liu, Beaver, & Speed's (2014) qualitative study findings suggested that Chinese elders in the UK held strong traditional beliefs regarding health, and preferred traditional Chinese medicine to modern medicine. These findings suggest that the healthcare needs of ethnic minority groups will require more than minor modification of a healthcare system which, as suggested by Lee and Owens (2002) has been designed around the needs of a white middle class culture. In this section, study implications will be presented for policy, public-health promotion, and training and education.

Recommendation for further research are also presented at the end of this section (section 6.6).

6.6.1 Implications for public-health policies

Consecutive cancer policy documents '*Cancer Reform Strategy*' (2007) and '*Improving outcomes: A strategy for cancer*' (2011) acknowledged the existence of cancer-related inequalities among minority groups and identified the lack of evidence about the different causes of cancer-related health inequalities. There is a lack of evidence regarding the most appropriate and effective interventions to reduce these existing inequalities among minority groups (DH, 2007, 2011). Although the establishment of the National Cancer Equality Initiative (NCEI) and the National Awareness and Early Diagnosis Initiative (NAEDI) aimed to address inequalities by providing evidence-based information to policy makers (DH, 2011), the absence of one organisational body responsible for overseeing and improving minority groups' cancer outcomes compromises the current working cancer policy target of matching cancer outcomes in the UK with comparable European countries by 2014. Given the fragmentation of current public health services provision across different bodies such as the NHS, Public Health England, Local Authorities, and charitable organisations; the presence of one specific body to overseas minority groups' health becomes even more important for providing synchronized services to black men. Thus, allocation of one responsible body to minority groups' health needs should be considered, as this body will benefit black men by providing specifically targeted cancer-related services in cooperation with NCEI, NAEDI, the NHS, Public Health England, local authorities, and black community organisations.

Based on this study's findings, social, religious, and cultural symbolisation of smoking, consuming an unhealthy diet, putting on weight, and masculinity encourages black men

to engage in unhealthy behaviours. More effective ways must be found to help black men improve their health behaviour. This requires a more holistic approach to policy and practice, addressing lifestyles that encompass multiple rather than individual unhealthy behaviour. In addition, behaviour change should be linked more closely to inequalities policy and be focused more directly on improving the health behaviour of black men in relation to smoking, consuming an unhealthy diet and putting on weight in the context of their religious, cultural, and social factors. More research and better use of the data already available in NCEI and NAEDI is key to crafting better policy that can address black men's needs. In particular, it would be helpful to know whether it is easier or harder to change the behaviour of those with multiple risks (e.g., for prostate cancer: being black men with a family history of cancer; having another health condition; and engaging in unhealthy lifestyles), whether it is more effective to tackle the risks in sequence or in tandem, what the most cost-effective approaches are, and what we can learn from other areas of public-health promotion like diabetes, HIV, stroke, cardiovascular, and Sickle Cell disease health promotions among black men.

Another issue that cancer and public health policies need to consider in order to improve black men's health is black men's suspicion and conspiracy theories. As evident in this study, there are considerable suspicions and conspiracy theories around the issue of cancer as perceived by black men. Cancer and public-health policies should have a specific strategy for eradicating such suspicions and conspiracy theories. As long as black men remain suspicious, cancer-related public health improvement efforts will have only minimal positive change among black men in terms of their views towards cancer and cancer-related issues.

6.6.2 Implications for public-health promotions

Despite the availability of a wide range of information about cancer provided by a number of governmental and non-governmental organisations, participants did not perceive cancer as a major concern for them. The findings indicated that cancer-related information provided by organisations such as Cancer Research UK, Prostate cancer UK, and the NHS, or advertisements broadcast in the mainstream media were very general and not specific to black men. Participants described the current format of the information as too unappealing to black men to be taken seriously. In addition, the study found that participants associated smoking with social, cultural, and religious beliefs. Culturally, being 'big' or 'oversized' was considered a sign of wealth or power, and of worthiness of respect from fellow community members. Furthermore, Participants' personal experience of knowing someone with Sickle Cell disease was a positive influence on their awareness of the disease. However, in the case of cancer, it appeared that such experience had little positive impact. Cancer-related health campaigns therefore should consider the theory of cancer though black eyes as one additional resource in the preparation of future health campaigns for black men. Looking at cancer through black eyes will help to understand the important issues to be considered in designing effective health promotion for black men. Cancer-related health campaigns also need to be carried out in collaboration with black community organisations. Based on this study's findings, a community-level health-promotion model, particularly a 'Community Organisation Model' appeared more effective, as it captured and was able to address black men's information needs as expressed by participants in this study. The findings of the study are likely to be of relevance to the planning, development, and evaluation of health-promotion initiatives for other diseases, including diabetes, which is considered a public-health issue for black communities in the UK.

6.6.3 Implications for training and education

This study revealed a mismatch between the clinical meaning of cancer and black men's meaning of cancer and its risk factors. This mismatch showed that the healthcare system and the professionals within it are not in step with the service users and needs to understand cancer through black men's eyes, and accordingly the need for dissemination of information to black men. The findings of this study suggest that the healthcare system needs to consider the necessary adjustments to meet black men's needs. One solution is to provide ongoing cultural competency training and to distribute research findings such as this study to healthcare professionals, which could help healthcare professionals to assess their approach towards black men and to make necessary adjustments to their current practice. Although it is important to raise black men's awareness about cancer, it is equally important to raise healthcare professionals' awareness of black men's views towards the subject (cancer) and also towards the healthcare system's shortcoming (service providers) as a whole, to maintain a balance of understanding between service providers and service users.

Nurses on wards and in community settings should be better informed about black men's perception of the healthcare system and of the healthcare professionals within it, in order to convey health information more effectively and to encourage black men to consider cancer as a health threat. Nurses and other healthcare professionals who are involved in producing and disseminating cancer-related public-health programmes need especial trained about cultural and religious influences which effect the receptiveness of black men towards health promotions. It should not be ignored the importance of cultural communication hierarchies in effectively conveying information. This would involve healthcare professionals using a strong, somewhat authoritarian manner of communication with patients, while still showing black men that healthcare

professionals indeed care about black men' health, which would improve black men's adherence to treatment and reduce withdrawal from or refusal of treatment.

It can be argued that this cultural communication hierarchy may not be compatible with the modern Western healthcare system's ethics frameworks, in which health professionals explain to patients the benefits and side effect of a given treatment, and then leave it up to the patient to decide whether to accept or refuse the treatment being offered (NHS, 2013; Nursing and Midwifery Council (NMC), 2008). However, the findings of this study provide evidence that there is no harm in being aware of black men's cultural communication hierarchy method and using it as appropriate in the best interest of the patient. For example, it would be much better to assert the importance of complying with cancer treatment to a African-Caribbean male using a *loud tone of voice* rather than allowing him to discharge himself from the hospital knowing he may die as a result. This could be ethically controversial, but there would be plenty of time for the patient to decide on self-withdrawal after receiving professional advice that uses a cultural hierarchy communication method. The lack of culturally relevant communication in the healthcare system was reported by participants in this study as one additional contributing factor for black men to be reluctant to comply with cancer treatment. Cancer specialist nurses have a vital role to play in this regard, so they need to be competent enough to use this cultural way of conveying information effectively.

The absence of black healthcare professionals in the NHS discourages black men from engaging with the healthcare system. Encouraging young people from the black community to enter into medicine and nursing courses could be seen as a positive long-term plan to increase the number of black healthcare professionals. Pre-registration nursing training programmes which include cultural competency modules focused on how illness and cure are understood by different cultures could be beneficial. This would be particularly applicable to public-health related nursing registration

programmes, where the importance of familiarity with the culturally understanding of black men is important in providing effective health-promotion information, and to encourage early detection and early diagnosis.

Although this study has focused specifically on black men and their views on cancer, the findings may have broader applicability for healthcare professionals who come into contact with minority groups more generally. Understanding the health beliefs of different minority groups is important for designing effective cancer-related services. Healthcare professionals need to be equipped with cultural competency skills. Understanding how illness and treatment are perceived by different minority groups is essential if service delivery is to effectively target different communities and cultures within our highly multi-cultural healthcare environment.

Evidence from this study suggested that black healthcare professionals already working in healthcare services, such as the NHS, tended to favour natural remedies in preference to the Western medicine offered within their own work environments. This created a dichotomy in their views. Such a dissonance could have implications for health education in the future. This needs more detailed exploration to be fully understood and redressed.

6.6.4 Recommendation for further research

This study provides a deep understanding of the views of black men towards cancer. However, this qualitative study was conducted by recruiting a small sample, making generalisations of the findings difficult. Further quantitative or mixed-methods research is needed to understand to what extent the views of black men towards cancer as identified in the findings are held throughout the studied population. The first and second generations of BA and BAC men were the focus of this study; by including the two main black sub-groups (BA and BAC) in the UK, cultural similarities and

differences between these two groups were revealed. Further qualitative or mixed-method research focusing particularly on each group is needed to advance evidence-based knowledge and understanding with epical regard between these two groups and their views towards cancer. This could be obtained by more focused and undiluted data from each black sub-group and would also help to improve the lack of existing UK-based literature in this area.

Black men appeared to be very suspicious about clinical research. For example, participants in this study perceived that black people's blood is taken without their knowledge and consent within healthcare settings. This perception by black men further exacerbated their mistrust of the healthcare system and of healthcare professionals. Researchers and research networks need to encourage black people in their local area to become involved in their research teams as lay people. There is ample opportunity to include black men in local and regional ethics committees as lay members. These opportunities would give black men first-hand experience of how research should be scrutinised by both professional and lay members of ethics committees, in preparation to research project prior to commence. Such a practice could help to restore black men's trust about research, the healthcare system, and healthcare professionals. In addition this study further recommend exploratory study about black men's involvement in healthcare research process.

6.7 Conclusion

The purpose of this study was to explore the influence of culture on the views of cancer held by black African and black African Caribbean men living in the UK using a grounded theory approach.

This study showed that black men held distinct views about cancer, cancer risk factors and cancer-related issues such as the NHS, healthcare professionals and the healthcare system itself. These views minimised the effectiveness of cancer related health promotions, early diagnoses and treatment. The way in which cancer was perceived was affected by various context ranging from socio-political economic issue to cultural and religious beliefs. The views which black men constructed from these various areas resulting in feelings of suspicion, development of conspiracy theories and mistrust of the healthcare system's positive intentions to provide health provision using modern Western medicine. All the issues mentioned above seriously undermined the current health-promotion methods and advertisements making them less influential in changing black men's view towards cancer, it's early detection and treatment in a positive direction. These findings showed health related cultural similarity and difference between black African and black African Caribbean men which need to be taken into account as an overview which would affect all areas of the study. The findings of this study emphasise its importance as a resource for policy makers. Black community organisations throughout the UK can also be referred this study as a resource in initiating cancer-related public-health campaigns within their communities, and particularly among black men.

6.8 Dissemination plan

The findings of the study will be disseminated through the following channels.

- Providing a summary of the findings to study participants who show interest during the interview period or at any stage of the study.
- Providing an executive summary of the study to African and Caribbean community organisations and also to charitable organisations, such as Prostate

Cancer UK. This will help to reach individuals who are interested and/or work in providing cancer-related services to the black community.

- Disseminating to local media resources; this includes the Afro-Caribbean Millennium Centre radio station, which collaborated in the recruitment process.
- Publishing the study in an academic peer reviewed journal and presenting at conferences and seminars. It is hoped that the findings from this study will inform healthcare professionals, policy makers, and other organisations working in cancer care, to enable them to provide services that are relevant and acceptable to BA and BAC men in the UK in relation to increasing awareness, lifestyle change, and recognition of early symptoms and signs of cancer.

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Appendices

Appendix 1: Ovid Medline Search Results

As shown in **Error! Reference source not found.**, the final search result from the Ovid Medline database yielded a total of 308 references. However, the number of identified papers from this database is reported as 296 in Figure 3.2. This is because out of the 308 references, 12 references were internal duplicates in the Ovid Medline database. The articles hit number on the search result (after sorting the search result list in ascending alphabetical order) and the reference of the article is provided in table below.

Hit numbers	Reference
9 and 50	Hoyo et al., (2003). Barriers and strategies for sustained participation of African-American men in cohort studies. *Ethnicity & Disease*. 13, 4,470-6.
89 and 90	Thompson et al., (2010). Comparing the use of evidence and culture in targeted colorectal cancer communication for African Americans. *Patient Education and Counseling, 81*, 22-33.
92 and 93	Jones et al., (2007). Complementary and alternative medicine modality use and beliefs among African American prostate cancer survivors. *Oncology Nursing Forum, 34*, 2, 359-64.
122 and 123	Philip, E. J., DuHamel, K., & Jandorf, L. (2010). Evaluating the impact of an educational intervention to increase CRC screening rates in the African American community: a preliminary study. *Cancer Causes & Control, 21,* 10, 1685-1691.
166 and 167	Ajape, A. A., Babata, A., & Abiola, O. O. (January 01, 2010). Knowledge of prostate cancer screening among native African urban population in Nigeria. *Nigerian Quarterly Journal of Hospital Medicine, 20,* 2.)
193 and 194	Weeks et al., (2012). Patients' expectations about effects of chemotherapy for advanced cancer. *The New England Journal of Medicine, 367,* 17, 1616-25.
208 and 209	Goldman, R. E., Diaz, J. A., & Kim, I. (2009). Perspectives of colorectal cancer risk and screening among Dominicans and Puerto Ricans: stigma and misperceptions. *Qualitative Health Research, 19,* 11, 1559-68.
210 and 211	Burris, J. L., & Andrykowski, M. A. (2011). Physical and mental health status and health behaviors of survivors of multiple cancers: a national, population-based study. *Annals of Behavioral Medicine, 42,* 3, 304-12.
259 and 260	Cogbill, S. A., Thompson, V. L., & Deshpande, A. D. (2011). Selected sociocultural correlates of physical activity among African-American adults. *Ethnicity & Health, 16*, 6, 625-41.
288 and 289	Deshpande et al., (2009). The use of sociocultural constructs in cancer screening research among African Americans. *Cancer Center, 16,* 3, 256-65.
301 and 302	DuHamel et al., (2011). Validity of the process of change for colorectal cancer screening among African Americans. *Annals of Behavioral Medicine, 41,* 3, 271-83.
303 and 304	Klein et al., (2011). Vitamin E and the risk of prostate cancer: the Selenium and Vitamin E Cancer Prevention Trial (SELECT). *JAMA: The Journal of the American Medical Association, 306*, 14, 1549-56.

Appendix 2: Literature Included in the Review

Author and Title	Aim	Methodology	Method	Sampling	Sample (n)	Study area	Findings	Quality
Agho and Lewis (2001) Correlates of Actual and Perceived Knowledge of Prostate Cancer among African Americans	To investigate the effects of education, income, age, and health insurance coverage on actual and perceived knowledge of prostate cancer	Quantitative	Survey	Convenience	African American men (n=108)	USA	Participants demonstrated poor knowledge about prostate cancer and less than 40% of participants reported having had prostate cancer screening. Actual knowledge of prostate cancer was negatively correlated with education, age, and income. Both actual knowledge and perceived knowledge of prostate cancer were correlated with having health insurance coverage.	High
Allen et al (2007) African-American men's perceptions about prostate cancer: Implications for designing educational interventions	To explores African-American men's perceptions about prostate cancer and screening for it	Qualitative	Focus groups (n=4) and In-depth interviews (n=14)	Purposive stratified	African-American men aged 35-70, and key community informants (11 men and three women, n==14) Total (n=65)	Boston (USA)	Amongst healthy men, knowledge about prostate anatomy and function of the prostate was minimal; only a few healthy male participants were able to identify the prostate anatomy or to explain its purpose. Several healthy men were surprised that the prostate is a male reproductive gland. Some assumed that developing prostate cancer was related to having a number of sexual partners. Few knew that African-American men are at increased risk of getting prostate cancer.	High
Austin et al. (2009) Perceived barriers to flexible sigmoidoscopy screening for colorectal cancer among UK ethnic minority groups: a qualitative study	To explore barriers to the uptake of flexible sigmoidoscopy (FS) screening among UK ethnic minority groups	Qualitative	Focus groups (n=9)	Convenience	Women and men of African-Caribbean, Gujarati Indian, Pakistani, and white British backgrounds (n=53)	London (UK)	African-Caribbean people thought bowel cancer to be less common among their community. African-Caribbean participants described the bowel preparation (enema) as 'self-harm' and difficult to do. African-Caribbean men considered FS as a threat to masculinity. African-Caribbean men were less likely to attend a screening.	High

Bass et al. (2011) Perceptions of Colorectal Cancer Screening in Urban African American Clinic patients: differences by Gender and Screening Status	To explore African-Americans' own perceptions of barriers to colorectal cancer screening and clarify gender differences in screening status	Qualitative	Focus groups (n=8)	Convenience	African American men and women aged 50-70, who were patients in a general internal medicine clinic (not cancer patients) (n=23)	USA	Men who had never been screened had less trust of their doctors and the healthcare system compared to those who had been screened. Embarrassment and the connotation with sexuality that was perceived by African-American men were believed to be a main barrier for men to attend screening.	Moderate
Blocker et al. (2006) Knowledge, Beliefs and Barriers Associated with Prostate Cancer Prevention and Screening Behaviors among African-American Men	To explore the knowledge and beliefs of African-American men and their spouses about prostate cancer, behaviour change to reduce prostate cancer risk, and increase prostate cancer screening	Qualitative	Focus groups (n=4)	Purposeful	Adult men and women from an African-American church-based population (n=29)	North Carolina (USA)	Spiritual beliefs and church support identified as important in cancer prevention. African-American men demonstrated a reasonably good level of general knowledge and awareness about prostate cancer. Despite the fact that most men held a negative perception of the Digital Rectal Examination, participants understood the importance of cancer screening.	Moderate

Bloom et al. (1989) Physician induced and patient induced utilization of early cancer detection practices among black Americans	To explore general health-related attitudes and beliefs and to assess specific attitudes and beliefs about cancer among black Americans	Quantitative	Face-to-face interview/ survey	Randomly selected	Black individuals, 20 years old and over (n=1137)	California (USA)	Participants did not believe that dietary habits influenced or affected cancer health. Age is a more important factor than gender in negative attitudes toward cancer. Women were more willing to have a Digital Rectal Examination. Participants believed that cancer is a death sentence and negative attitudes towards cancer were significant barriers to taking preventative measures. 65.3% believed that cancer treatment is worse than the disease. Older individuals over 50 were reported to have given up smoking.	High
Carter et al. (2010) Increasing Prostate Cancer Screening among African American	To identify enablers and barriers to prostate cancer screening; and to promote screening behavior in African-American men	Qualitative	Quasi-experimental focus groups (n=6)	Convenience	African-American men aged 40 and over and their spouses/significant others (n=76)	Alabama (USA)	Findings suggested that men were reluctant to talk about their health condition with others. 48% of the participants who had not been screened within the last 12 months were screened after attending the education session.	Moderate

Chan et al. (2003) Informed Consent for Cancer Screening with Prostate-Specific Antigen: How Well Are Men Getting the Message?	To examine knowledge about prostate-specific antigen (PSA) screening among African-American and white men	Quantitative	Survey questionnaire	Purposeful	African-American and white men, attending the general internal medicine outpatient clinic for a routine check-up (n=271)	Houston, Texas (USA)	African-Americans appeared less knowledgeable than white men, but the differences were a result of differences in educational level and previous experience with prostate cancer screening. 60% of African-American men and 37% of white men knew that the risk of getting prostate cancer is higher amongst African-Americans. 22% of African-Americans thought that the Digital Rectal Examination is a blood test for prostate cancer. African-Americans were generally less knowledgeable than their white counterparts about treatment options for early prostate cancer.	High
Clarke-Tasker & Wade (2002) What we thought we knew: African Males' perceptions of prostate cancer and screening methods	To assess African-American men's knowledge, attitudes, and perceptions of prostate cancer and early detection methods.	Qualitative	Focus groups (n=2)	Purposive sampling	African American men, aged 38-80 (n=12)	USA	Participants understood the importance of early detection. Participants felt their doctors did not adequately screen them or recommended prostate cancer screening. Men between 40-50 years of age concerned about possible change in their sex life if diagnosed with prostate cancer.	Low
Consedine et al. (2009) Physician, affective, and cognitive variables differentially predict 'initiation' versus 'maintenance' PSA screening profiles in diverse groups of men	To evaluate the relevance of demographic, physician, and psychological characteristics to PSA screening in ethnic sub-populations	Quantitative	Survey questionnaire/face-to-face interview	Stratified cluster-sampling	African-American, European-American, Jamaican, Trinidadian and Tobagonian men, aged 45-70 (n=533)	New York (USA)	PSA screening was low; 29% amongst Jamaicans and 21.1% amongst Trinidadian or Tobagonians. Lack of knowledge, worry, and embarrassment were the main reasons for the low rate of screening. Jamaican, Trinidadian, and Tobagonian men also had lower efficacy perceptions.	High

Consedine et al. (2011) Gender and ethnic differences in colorectal cancer screening embarrassment and physician gender preferences	To examine colorectal cancer screening embarrassment among men and women from three ethnic groups and to explore patient's preference of physician's gender and ethnicity.	Quantitative	Survey/ Questionnaire	Purposeful	European American, African-American, and immigrant Jamaican men and women, aged 45-70 (n=245)	New York (USA)	Although embarrassment generally was higher among Jamaicans and men, the gender-by-ethnicity interaction suggested that rectal embarrassment was particularly high among Jamaican men. Jamaican men reported greater examination intimacy embarrassment regarding a physician of the opposite gender; but also for Jamaicans, examinations by men may elicit embarrassment because they constitute a more profound violation of norms, and in turn, be taken as evidence of homosexual behaviour. Ethnic differences were stronger regarding fecal or rectal embarrassment.	Moderate
Demark-Wahnefried et al. (1995) Knowledge, beliefs, and prior screening behavior among blacks and whites reporting for prostate cancer screening	To assess prostate-cancer-related knowledge, beliefs, and prior screening behaviour	Quantitative	Survey/ Self-administered questionnaire	Convenience	Black and white men who attend free DRE and PSA testing offered during prostate cancer awareness week (n=1504)	Southeast (USA)	72% of participants reported that their doctor never discussed a prostate cancer test to them. There were similarities among black and white men regarding knowledge and beliefs about prostate cancer. Differences in access to screening, perception of the disease, and knowledge of risk factors existed between black and white men; differences representing a significant barriers to early detection amongst African-Americans.	Moderate
Elmubarak et al. (2005) Focused interviews with Sudanese Americans: perceptions about diet, nutrition and cancer	To explore Sudanese-American perceptions regarding diet and cancer	Qualitative	Focus groups (n=4)	Purposeful	Sudanese-American women and men, aged 20 and over (n=18)	Alabama (USA)	Men did not believe that diet affected cancer. Culture was perceived as a barrier to changing eating and food choice habits. Participants described cancer as death from God but they showed positive attitudes towards cancer prevention ideas.	High

Fearing et al (2000) Prostate screening health beliefs and practices of African American men	To investigate the health beliefs and practices of African-American men regarding prostate cancer screening	Quantitative	Survey/ Self-administered questionnaire	Convenience	African-American men aged 45 and over (n=59)	USA	Most participants had a high level of knowledge regarding prostate cancer and early detection, and had prostate screenings on a regular basis. Participants believed prostate cancer treatment would be painful and would harm sexual function. Spirituality and reliance on faith reported as helpful to participants in taking preventative measures.	Moderate
Ford et al. (2006) Factors influencing behavioral intention regarding prostate cancer screening among older African-American men	To assess factors associated with perceptions of prostate cancer screening amongst African-American men	Qualitative	Focus groups (n=2)	Randomly selected	African-American men aged 55 and over (n=22)	USA	Lack of knowledge regarding cancer, fear of cancer, confusion between prostate cancer screening and prostate cancer diagnostic tests. Encouragement by family member was a key motivator for cancer screening. Minimal utilisation of health information and cancer screening clinic combined with lack of health insurance were barriers to prostate cancer screening and treatment.	Moderate
Forrester-Anderson (2005) Prostate Cancer Screening Perceptions, Knowledge and Behaviors among African American Men: Focus Group Findings	To explore the knowledge, perceptions, attitudes, and behaviour of African-American men concerning prostate cancer and screening for the disease	Qualitative	Focus groups (n=12)	Convenience	African-American men aged 40 and over (n=104)	Maryland (USA)	Limited knowledge about the disease, lack of access to screening services, embarrassment, and fear of a positive diagnosis. Belief that prostate cancer is related to sexual behaviour. Men reported suspicious views towards the government, such as deliberate distribution of cancer in black communities by adding things to food. Positive beliefs, hope, and familiarity with the disease were enabling factors for prostate cancer screening.	Moderate

Friedman et al. (2009) African American Men's Understanding and Perceptions about Prostate Cancer: Why Multiple Dimensions of Health Literacy are Important in Cancer Communication	To assess black men's functional health literacy in in relation to prostate cancer	Qualitative	Focus groups and interview	Purposive	African-American men aged 45 and over (n=25)	Southeast (USA)	Participants demonstrate limited understanding, and misconceptions about prostate cancer risk factors. Many wanted information about prostate cancer delivered via word-of-mouth, by African-American women and church pastors.	High
Friedman et al.(2012) It Takes Two to Talk about Prostate Cancer: A Qualitative Assessment of African-American Men's and Women's Cancer Communication Practices and Recommendations	To explore African-American men's and women's current practices, barriers, and recommended strategies for Prostate cancer communication	Qualitative	Focus groups (n= 22)	Purposive sample	African-American men and their spouses/female relatives (n=81)	South Carolina (USA)	A majority of men had discussed prostate cancer more frequently with the women in their lives, especially wives, than they did with their doctors. Older male participants were more open to discussing prostate cancer with other men than were younger male participants. Fear of cancer, discomfort of DRE screening, embarrassment/pride, masculinity, and cultural factors emerged as key barriers to talking about cancer. Men recommended churches and barbershops as preferable locations for accessing information about cancer.	High
Fyffe et al. (2008) Knowledge and barriers related to prostate and colorectal cancer prevention in underserved black men	To explore the cultural perceptions of colorectal cancer among three ethnic subgroups of black men	Qualitative	Focus groups (n=2)	Convenience Stratified randomly selected	Black male, aged 18 and over (n=24)	Newark, NJ (USA)	Fear of discomfort, stigma, embarrassment, and mistrust of healthcare professionals were reported as barriers associated with prostate and colorectal cancer screening. Black men are sensitive to rectal examinations because this type of procedure may lead black men to question their sexuality and manhood. Participants' most commonly reported healthcare system barriers were insurance coverage and negative experiences with healthcare professionals. Decision to have prostate and colorectal cancer screening was triggered by family history of cancer and cost-benefit (health and money) analysis.	High

Green & Kelly (2004) Colorectal Cancer Knowledge, Perceptions, and Behaviors in African Americans	To explored low-income African-American men's and women's knowledge, perceptions towards, and screening behaviours of colorectal cancer	Quantitative	Survey questionnaire/face-to-face interview	Convenience sampling	African-American men and women aged 50 and over (n=100)	USA	Respondents demonstrated inadequate knowledge of colorectal cancer with a significant difference between males and females; men had better knowledge than women. Valued the benefit of screening; positive attitudes towards colorectal screening.	Low
Gwede et al. (2010) Exploring disparities and variability in perceptions and self-reported colorectal cancer screening among three ethnic subgroups of U.S. Blacks	To assess perceptions of colorectal cancer and identify self-reported screening behaviours in three black subgroups	Mixed-method	Semi structured, in-depth qualitative and structured quantitative interviews	Purposeful sampling	Men and women aged 50 and over, African-American, English-speaking Caribbean-born, Haitian-born (n=62)	Hillsborough (USA)	Awareness of colorectal cancer screening tests, risk perception and use of screening were low across all subgroups. Distinct barriers to screening existed among subgroups. 95% of Caribbean-born participants reported that they rarely or never worry about developing cancer, compared to 64% for African-Americans, and 65% for Haitian-born participants.	Moderate

Gwede et al. (2011) Perceptions of colorectal cancer among three ethnic subgroups of US Blacks: A Qualitative Study	To explore knowledge and attitudes of African-Americans about colorectal cancer	Mixed-method	Semi structured, in-depth qualitative and structured quantitative interviews	Purposeful sampling	Men and women aged 50 and over, non-Hispanic black or African-American, English speaking Caribbean, Haitian (immigrants must have lived in the USA at least two years) (n=62)	Hillsborough (USA)	There were no vast differences among the three ethnic subgroups in their overall perceptions of cancer as well as their attitudes related to barriers, motivation and resources for CRC screening. However, there were differences in perceptions of curability, preventive practices, and preferred sources of information.	Moderate
Janz et al. (2003) Colorectal cancer screening attitudes and behavior: a population- based study	To assess attitudes and practices regarding colorectal cancer screening	Quantitative	Telephone survey	Random digital dialing	Black and white, men and women aged 50-79 (n=355)	Michigan (USA)	Adherent rates of screening were: black men 37.8%, white men 24.8%, black women 19.2%, and white women 26.5%. Physician recommendation was a powerful motivator to screening behaviour, but over 50% of black participants reported never receiving a recommendation from their physician	High

Jones et al. (2005) Prostate cancer knowledge and beliefs among black and white older men in rural and urban counties	To assess prostate cancer knowledge and beliefs in older black and white men and to compare knowledge and beliefs with perceived personal risk	Quantitative	Survey/computer assisted telephone interview	Random digital dialing	Black and white men aged 50-75 (n=235)	Georgia and Alabama (USA)	Black men in rural and urban areas were less knowledgeable about risk factors of prostate cancer than white men. 10% of black participants perceived their risk for prostate cancer as high. Black men in rural area had lower level of knowledge than their urban counterparts. 75% of men wanted to know more and 80% said they would undergo screening if their doctor recommended it.	Moderate
Jones et al. (2009) How African American Men Decide Whether or Not to Get Prostate Cancer Screening	To explore how and when African-American men decide about prostate cancer screening	Qualitative	Interview (n=17)	Convenience	Men, aged 40 years or over, self-reported as African-American, never been diagnosed with prostate cancer (n=17)	USA	Family and friends played an important role in the men's decision-making process. It was essential for the men to have a trusting relationship with their healthcare provider to have screening.	High
Kumar et al. (2009) comparing dietary and other lifestyle factors among immigrant Nigerian men living in the US and indigenous men from Nigeria: potential implications for prostate cancer risk reduction	To evaluate and compare differences in behavioural variables that are implicated in contributing to prostate cancer mortality and morbidity among Nigerian men living in the USA and men living in Nigeria	Quantitative	Survey questionnaire /face-to-face interview	Convenience	Nigerian men aged 35-70 (n=249)	Houston (USA) and Abeokuta (Nigeria)	Immigrant Nigerian men had high intake of meats, oils, and alcohol, and minimal fish intake, which may contribute to increasing the risk of getting prostate cancer. However, immigrant Nigeria men had significantly healthier diets, used less tobacco, and engaged in purposeful physical activity, compared to their counterparts in Nigeria.	High

Lee et al. (2011) Barriers and facilitators to digital rectal examination screening among African-American and African-Caribbean men	To explore the effect of race/ethnicity and fear characteristics on the initiation and maintenance of digital rectal examination screening	Quantitative	Survey questionnaire /face-to-face interview	Stratified cluster sampling	Black and white men aged 45-70 (n=533)	New York (USA)	Black men had greater prostate cancer worry and screening fear. Black men were less likely to maintain annual digital rectal examination.	High
Magnus (2004) Prostate cancer knowledge among multiethnic black men	To assess prostate cancer knowledge among African-American, English speaking Caribbean, Haitian-American and African men in America	Quantitative	Survey/ Questionnaire	Convenience	Black men from different black ethnic group (n=528)	Florida (USA)	Participants' knowledge about prostate cancer was adequate. There is no significant difference in knowledge among men of different black ethnicity. However, income and family history of prostate cancer were significantly related to high level of knowledge.	High
Odedina et al. (2009) Prostate cancer cognitive behavioral factors in a West African population	To understand the prostate cancer cognitive-behavioral factors among Nigerian men in Nigeria and Nigerian immigrants in America. To explore the impact of emigration from Nigeria to the US on these characteristics.	Quantitative	Survey/ Questionnaire	Convenience	Nigerian men aged 35-79 (n=249)	Texas (USA) and Abeokuta (Nigeria)	The findings showed significant difference of knowledge and attitudes between these two groups: knowledge of prostate cancer among Nigerian men in the US was higher than among respondents in Nigeria. Participants from the US showed willingness to get tested for prostate cancer but participants from Nigeria were less keen on this idea. Men living in Nigeria ranked their chance of getting prostate cancer as low whereas Nigerians in America ranked neutral on the scale.	High

Odedina et al. (2011a) Modifiable prostate cancer risk reduction and early detection behaviors in black men	To explore the personal factors related to modifiable prostate cancer risk-reduction and detection behaviours among black men	Quantitative	Cross – sectional Survey/Questionnaire	Non-probability and purposeful sampling	Black men aged 40-70 (n=3430)	Florida (USA)	Participants' risk-reduction behaviour was very low. Findings also suggested a low early detection behaviour by participants. Less than 30% of participants reported that they received recommendation for screening from their doctor. The men's attitude towards screening was favorable.	Moderate
Odedina et al (2011b) Within-group differences between native-born and foreign-born Black men on prostate cancer risk reduction and early detection practices	To explore the ethnic variations among USA-born black men, African-born black men, and Caribbean-born black men relative to prostate cancer risk reduction and early detection behaviours	Quantitative	Survey questionnaire /face-to-face interview	Non-probability sampling	Black men aged 35 and over (n=3400)	Florida (USA)	There were significant differences among the three groups. The US-born black men were most likely to have health insurance and had the highest knowledge compared to the other two groups. African-born black men's knowledge was lowest among the three groups, but they were most likely to use chemoprevention products and discuss prostate cancer risk-reduction and early detection with African doctors.	High
Oliver (2007) Attitudes and Beliefs about Prostate Cancer and Screening among Rural African American Men	To describe personal attitudes and beliefs of rural African-American men related to prostate cancer and prostate cancer screening	Qualitative	Interview	Convenience sample	African-American men (n=9)	Alabama (USA)	Disparity, lack of understanding, traditions, mistrust of the system, fear, and threat to manhood were identified as core to the attitudes and beliefs among African-American men.	High
Parchment (2004) Prostate cancer screening in African American and Caribbean males: Detriment in delay	To investigate the health beliefs surrounding prostate cancer among African-American and Caribbean men in USA	Quantitative	Survey	Convenience	Black African-American, Caribbean, and African men aged 37-89 (n=100)	Miami (USA)	80% of men stated that it is embarrassing to have digital rectal examination; 75% of participants reported that the information they get from their doctors did not convince them to attend a screening. 60% of participants said that if diagnosed with cancer they fear impotence and incontinence after cancer treatment. Men who had been diagnosed with prostate cancer delayed treatment.	Moderate

Pedersen et al. (2012) Perceptions of prostate cancer in Black African and Black Caribbean men: a systematic review of the literature	To appraise research on knowledge and perceptions of prostate cancer among black men	Systematic review	Literature search from databases and hand search of relevant papers	-	Papers published in the English language (n=33 papers)	UK	Black men's awareness of personal risk of prostate cancer varied between studies. Black men's awareness of, and willingness to be tested for prostate cancer are influenced by individual, cultural and social factors. Mistrust of the healthcare system, health professionals, and limited access to healthcare also frequently reported as major barriers.	High
Powe et al. (2009) Comparing Knowledge of Colorectal and Prostate Cancer Among African American and Hispanic Men	To compares the relationships among knowledge of prostate and colorectal cancer, perceptions of cancer fatalism, common sources of cancer information, and awareness of cancer resources screening between African-American and Hispanic men	Quantitative	Survey Interview	Convenience	African-American and Hispanic men aged 18 or over, able to communicate in English or Spanish (n=119)	USA	African-American men were more knowledgeable about cancer and had less fatalistic attitudes towards cancer than Hispanic men. Most men were more likely to get cancer-related information from the television and/or radio, with few accessing the Internet.	Moderate
Rajbabu et al. (2007) Racial origin is associated with poor awareness of prostate cancer in UK men, but can be increased by simple information	To assess the level of prostate cancer awareness and attitudes in black and white men, and to see if written information would modify awareness	Quantitative	Survey/ Questionnaire	Opportunistic convenience and randomly selected	Black and white men aged 40-75 (n=871)	London, Leeds, Birmingham, and Sandwell (UK)	Black men were unaware of their increased risk of developing prostate cancer, demonstrated poor knowledge about the symptoms of the disease, and held more negative attitudes about its control and treatment. After intervention (targeted education), there were significant improvements in their knowledge, risk awareness, and attitudes.	High

Richardson et al. (2004) Uncovering myths and transforming realities among low-SES African-American men: implications for reducing prostate cancer disparities	To assess the knowledge of a cohort of low-SES African-American men regarding prostate cancer and to uncover myths/misinformation as barriers to prostate health decisions and behaviours	Qualitative	Focus groups (n=2)	Convenience	African American, men aged 33-47 (n=15)	Virginia (USA)	Participants knew very little or nothing about prostate cancer, its symptoms, and risk factors. They did not perceive themselves at high risk if a close relative had prostate cancer. Fear of screening, possible consequences of a prostate cancer diagnosis, including impotence, the loss of masculine appeal, suffering, and death.	High
Ross et al (2005) Awareness and use of the prostate-specific antigen test among African-American men	To explore awareness of the prostate-specific antigen (PSA) test among African-American men	Quantitative	Survey/ Questionnaire	Purposeful sampling	African-American men aged 45 and over, with no history of prostate cancer (n==736)	USA	63% of participants had heard of the PSA test and 48% had been tested. Men with high levels of education, married, living in a metropolitan area, and having private or military health insurance were more likely to be aware of prostate cancer screening.	High
Shavers et al. (2009) Race/Ethnicity, Risk Perception, and Receipt of Prostate-Specific Antigen Testing	To examine men's perception of the general and relative risk of developing prostate cancer and its association with the receipt of PSA testing among a population-based sample	Quantitative	Cross-sectional Survey	Random digit dialing	African-American, Hispanic, and non-Hispanic white males aged 45 and over, with no history of prostate cancer (n=1075)	USA	17.5% of African-American men perceived that they were more likely to develop prostate cancer. 13.2% of African-American men indicated that they worry about developing prostate cancer often or all of the time.	High

Taskila et al. (2009) Factors affecting attitudes towards colorectal cancer screening in the primary care population	To identify which factors most strongly contributed to negative attitudes to colorectal cancer screening in the primary care population	Quantitative	Survey/ Questionnaire	Randomly selected through GP	Men and women aged 50-69 (n=21,488)	West Midlands (UK)	People with black-Caribbean ethnic background were more likely to have positive attitudes towards colorectal screening.	High
Waller et al. (2009) Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England	To explore the differences of awareness among ethnic minority groups towards cancer warning signs and their impact on delaying cancer diagnosis	Quantitative	Survey/ Questionnaire, face-to-face interview	Quota sampling	Men and women from six minority groups (Indian, Pakistani, Bangladeshi, Caribbean, Africa and Chinese), aged 18 and over (n=1500)	England (UK)	Awareness of cancer warning signs was low across all ethnic groups but it was significantly low in the African participants. African participants reported that they would see their doctor in less than two weeks if they noticed unusual symptoms.	High
Weinrich et al. (2007) Knowledge of Hereditary Prostate Cancer among High-Risk African American Men	To measure knowledge of hereditary prostate cancer in a group of high-risk African-American men	Quantitative	Cross-sectional survey/Telephone interviews	Randomly selected	African-American (n=79)	Detroit, Houston, Chicago, and Columbia (USA)	Knowledge of hereditary prostate cancer was low.	Moderate

Winterich et al. (2009) Men's Knowledge and Beliefs about Prostate Cancer: Education, Race, and Screening Status	To compare education, race, and screening status to determine how each factor alone or together shapes men's knowledge of prostate cancer and screening	Qualitative	Interviews	Convenience	African-American and white men with diverse education backgrounds, aged 40-64 (n=65)	North Carolina (USA)	Knowledge about the prostate gland, prostate cancer symptoms and screening tests, and attitude like fear of prostate cancer were not associated with race or screening status. Rather, they depend on the participant's education level.	High
Woods et al. (2004) Culture, black men, and prostate cancer: what is reality?	To explore general and cancer-screening-related health behaviors	Mixed- method	Phase I: Interviews (n=15) and focus groups (n==2) Phase II: Survey self-administered questionnaire	Purposive convenience sample	Black American men aged 40 and over, no diagnosis or symptoms of prostate cancer and no evidence of mental illness (n=277)	Southern California (USA)	Lack of knowledge, communication, social support, quality of care, and sexuality were identified as factors that pushed black men away from the healthcare system and contributed to non-participation in prostate cancer early detection activities.	High

Appendix 3: Correspondence with Professor Pierre Pluye regarding SMSR Assessment Tool (Pluye et al., 2009)

Betselot Mulugeta
Wed 05/06/2013 11:53
Sent Items
To: pierre.pluye@mcgill.ca;

Dear Professor Pluye

I am a PhD student based in the UK and currently undertaking the literature review for my research. I am using your SMSR tool (Pluye et al., 2009) to assess the quality of included papers in the review. I found it to be a very good tool as it can be used to assess all research design types, including qualitative, quantitative, and mixed methods, thereby ensuring consistency. However, I was hoping you may be able to assist with a question I have, namely, how can I classify studies' quality as low, moderate or high quality?

I was thinking to classify the overall rate as 'low', 'moderate', or 'high' quality as follows: studies with a 'quality score' greater than 70% to be classified as 'high', 56-70% classified as moderate, and less than 56% to be classified as low.

I will be very grateful if you advised me or tell me what your thoughts are on this suggestion.

Kind regards

Bete

Pierre Pluye, Dr. <pierre.pluye@mcgill.ca>
Wed 05/06/2013 21:11
Inbox
To: Betselot Mulugeta;
Cc: Hong, Quan Nha <Quan.Nha.Hong@USherbrooke.ca>;

Dear Bete,

Thanks for your interest in our work. These are great comments. I am interested in knowing more about you and your work (title, topic, context).

Scoring: As mentioned in our wiki, "For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using SMSR criteria)". E.g., this gives the same 'weight' to each criterion, which is an issue. Having said this, I agree that scoring may be useful to summarize results of the appraisal in a table for instance. For scoring, I include 'I cannot tell' (e.g., no companion paper with appropriate information, no answer from authors), i.e., the criterion is not met.
In our experience, few studies meet all MMAT criteria. In one of our systematic mixed studies review, we decided for instance to distinguish studies with all MMAT criteria met vs. other studies. Your decision may reflect your included studies.

Note: I share this email with one of my PhD students. Quan is working on the MMAT, and may contact you for further information.

Best regards,
Pierre

Pierre Pluye, MD, PhD
FRQS Research Fellow, Associate Professor
Department of Family Medicine, McGill University
517 Pine Avenue West, Montreal, QC, Canada, H2W 1S4
Phone: 514-398-8483
Fax: 514-398-4202
Email: pierre.pluye@mcgill.ca

Betselot Mulugeta
Thu 06/06/2013 08:30
To: pierre.pluye@mcgill.ca;

Dear Dr Pluye

Thank you for taking time to replay for my email. In response to your question about me, I don't have much to say about myself, I am a PhD student, working under the supervision of Professor Kinta Beaver, Dr Susan Williamson and Dr Rob Monks.

The title of my work is '*The views of black African and black African Caribbean men living in the UK towards cancer'*.

I have just added few more things below for your attention and advice, I hope you wouldn't mind. I also would like to mention that it is purely out of my interest and wish for this tool to have more impact in the research world. However, I apologies beforehand if I came across as an arrogant or ignorant. There are 44 papers included in my literature review and I am assessing their quality using your SMSR tool (please see attached document for details), and I am unsure on how to grade their quality. An alternative solution that I can think of might be as follows:

As suggested in your paper [# of yes/relevant criteria x100] is a formula to calculate the quality score. When we calculate using this formula, it always gives us six numbers regardless. The numbers are: - 16, 33, 50, 66, 83, 100(please see the table below). Hence based on this scale what are your thought on classifying 50and < as 'low' , 51-70 'moderate' and over 71 'high' high quality study ?

Again, I think there are quite few criteria which can be used to all kinds of methods (highlighted in yellow). Thus it gives more balanced weight for example the quality of 'Quantitative experimental study' papers could be assessed against seven criteria instead of three (which is the case currently). Finally, if this fundamental aspect is addressed, because of its great advantages (e.g. being able to assess all qualitative, quantitative and mixed method study papers using one tool), I strongly believe that it has a potential to be the most useful tool in assessing the quality of studies by insuring consistency.

Types of Study	Methodological Quality criteria	Quality score scale by %
5. Qualitative	• Qualitative objective or question • Appropriate qualitative approach or design or method • Description of the context • Description of participants and justification of sampling • Description of qualitative data collection and analysis • Discussion of researchers' reflexivity	With 1 yes = 16 With 2 = 33 3= 50 4= 66 5=83 6=100
6. Quantitative experimental	• Appropriate sequence generation and/or randomization • Allocation concealment and/or blinding • Complete outcome data and/or low withdrawal/drop-out	With 1= 33 2= 66 3=100
7. Quantitative observational	• Appropriate sampling and sample • Justification of measurements (validity and standards) • Control of confounding variables	As above
8. Mixed methods	• Justification of the mixed methods design • Combination of qualitative and quantitative data collection-analysis techniques or procedures • Integration of qualitative and quantitative data or results	As above

Source Pluye et al. (2009)

Thank you again for your time and help
Kind regards
Bete

Pierre Pluye, Dr. <pierre.pluye@mcgill.ca>
Wed 26/06/2013 17:00
To: Betselot Mulugeta;
Cc: Hong, Quan Nha <Quan.Nha.Hong@USherbrooke.ca>;

Hello Bete,
Apologies for the delay. The last few weeks were chaotic. Thanks for your comments.
Your classification makes sense to me (50and < as 'low' , 51-70 'moderate' and over 71 'high' high quality study).
You may also consider having only 2 categories for sub-analyses, e.g., lower (70 and <) and higher (over 71) quality studies, as you can argue that the MMAT is based on a little number of basic criteria, which should all fulfilled.
Did you contact authors or look for companion papers when all criteria are not met?
Finally, next version might be more comprehensive.

Best regards,
Pierre

Pierre Pluye, Dr. <pierre.pluye@mcgill.ca>
Fri 19/07/2013 10:23
To: Betselot Mulugeta;

Dear Bete,
I am very pleased to report that Quan Nha Hong has received a 5-year bursary (she was ranked 5th!) from CIHR ($275,000) to do her PhD in our Department. In addition, she received the Elizabeth Dickson Prize ($5,000) for the best 2013 candidate in Knowledge Translation.
This is outstanding, and great news for our MMAT project (Mixed Methods Appraisal Tool). I will supervise her thesis on the validity, reliability and usability of the MMAT. She will contact you as needed for further development and testing of the MMAT.
Best regards,

Pierre Pluye, MD, PhD
FRQS Research Scholar, Associate Professor
Department of Family Medicine, McGill University
517 Pine Avenue West, Montreal, QC, Canada, H2W 1S4
Phone: 514-398-8483
Fax: 514-398-4202

Appendix 4: Quality of Included Qualitative, Quantitative and Mixed Method Studies Based on SMSR[7]

Paper	CR1	CR2	CR3	CR4	CR5	CR6	CR7	CR8	CR9	CR10	CR11	CR12	CR13	CR14	CR15	relevant criteria	number of 'yes'	quality score %
Agho and Lewis (2001)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Allen et al (2007)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Austin et al. (2009)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Bass et al. (2011	1	0	1	1	1	0	0	0	0	1	0	0	0	0	0	6	4	66.7
Blocker et al. (2006)	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	6	4	66.7
Bloom et al. (1989)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Carter et al. (2010)	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	6	4	66.7
Chan et al. (2003)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Clarke-Tasker and Wade (2002)	0	1	0	1	1	0	0	0	0	0	0	0	0	0	0	6	3	50
Consedine et al. (2011)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Consedine et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Demark-Wahnefried et al. (1995)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Elmubarak et al. (2005)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Fearing et al (2000)	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	3	2	66.7
Ford et al. (2006)	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	6	4	66.7
Forrester-Anderson (2005)	1	1	0	1	1	0	0	0	0	0	0	0	0	0	0	6	4	66.7
Friedman et al. (2009)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3

[7] The heading of this table is colour coded to show which criteria are relevant to which type of study; green for qualitative, yellow for quantitative, and red for mixed methods study

Paper	CR1	CR2	CR3	CR4	CR5	CR6	CR7	CR8	CR9	CR10	CR11	CR12	CR13	CR14	CR15	relevant criteria	number of 'yes'	quality score %
Friedman et al. (2012)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Fyffe et al. (2008)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Green & Kelly (2004)	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	3	1	33.3
Gwede et al. (2010)	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	3	2	66.7
Gwede et al. (2011)	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	3	2	66.7
Janz et al. (2003)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Jones et al. (2005)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Jones et al. (2009)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Kumar et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Lee et al. (2011)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Magnus (2004)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Odedina et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Odedina et al. (2011a)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Odedina et al. (2011b)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Oliver (2007)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Parchment (2004)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Powe et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	2	66.7
Rajbabu et al. (2007)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Richardson et al (2004)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Ross et al (2005)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Shavers et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Taskila et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100

Paper	CR1	CR2	CR3	CR4	CR5	CR6	CR7	CR8	CR9	CR10	CR11	CR12	CR13	CR14	CR15	relevant criteria	number of 'yes'	quality score %
Waller et al. (2009)	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	3	3	100
Weinrich et al. (2007)	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	3	2	66.7
Winterich et al. (2009)	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	6	5	83.3
Woods et al. (2004)	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1	3	3	100

- CR1[8]. Qualitative objective or question
- CR2. Appropriate qualitative approach or design or method
- CR3. Description of the context
- CR4. Description of participants and justification of sampling
- CR5. Description of qualitative data collection and analysis
- CR6. Discussion of researchers' reflexivity
- CR7. Appropriate sequence generation and/or randomization
- CR8. Allocation concealment and/or blinding
- CR9.Complete outcome data and/or low withdrawal/drop-out
- CR10. Appropriate sampling and sample
- CR11. Justification of measurements (validity and standards)
- CR12. Control of confounding variables
- CR13. Justification of the mixed methods design
- CR14. Combination of qualitative and quantitative data collection-analysis techniques or procedures
- CR15. Integration of qualitative and quantitative data or results

[8] CR1, CR2, etc. … stands for criteria1, criteria 2... and replace the actual criteria title in the table in order to fit the cells' size

Appendix 5: Correspondence email from Professor Katy Charmaz regarding to Constructivist Grounded Theory

Kathy Charmaz <charmaz@sonoma.edu>
Tue 11/02/2014 20:23
To:
Betselot Mulugeta;
Flag for follow up. Start by 11 February 2014. Due by 11 February 2014.
You replied on 20/06/2014 14:06.

Dear Bete,

Your page is pretty much on target. I made a couple of changes and am also sending you the prepublication version of my 2009 paper. It appeared in 2009 shifting the Grounds: Constructivist Grounded Theory Methods for the Twenty-first Century. In Janice Morse, Phyllis Stern, Juliet Corbin, Barbara Bowers, Kathy Charmaz, and Adele Clarke, *Developing Grounded Theory: The Second Generation* (pp. 127-154). Walnut Creek, CA: Left Coast Press.

Best wishes with your work,

Kathy Charmaz

Appendix 6: The Script for Radio Advertisement

The Views of African Caribbean and Black African men living in UK towards Cancer

Yo ! Listen to this

Do you know black men have high risk of getting prostate cancer than any other ethnic groups?

Wa gwan man?

Bete is from Ethiopia the land of Jah Rastafari, doing his PhD in University of Central Lancashire (Preston)

He is doing research on black men's views towards cancer.

If you are male over the age of 18 and consider to participate in this research you can find out more by calling or texting 07947183012

Yo Yo Check It Out

Appendix 7: Recruitment Poster

Are you a UK- born or African/Caribbean-born black man over the age of 18?

Volunteers needed to participate in a research study.

My name is Betselot Mulugeta (Bete) and I am a PhD Student at the University of Central Lancashire, under the supervision of Professor Kinta Beaver.

I am looking for volunteers who are willing to take part in a research study entitled:

The Views of Black African/African Caribbean Men living in the UK towards Cancer

You **do not** have to have suffered from cancer to participate.
If you decide to take part in this research, I would like to interview you about your views towards cancer, its prevention and screening.

If you would like to take part in this research or simply to find out more about what is involved, you can ask at the community office for an information sheet or contact me on:

Betselot Mulugeta (Bete)
School of Health
Brook Building, Room 247
University of Central Lancashire
Preston
PR1 2HE

You can call or text me on: **07947 183012**
Or email me: Bmulugeta@uclan.ac.uk

The University of Central Lancashire Ethics Committee has approved this research (*reference Number 081*).

Appendix 8: Participant Information Sheet

Participant Information Sheet
Study Title: The Views of Black African/ African Caribbean Men living in the UK towards Cancer

You are being invited to take part in a study on the views of black African and black African-Caribbean men living in UK towards cancer. Before you decide whether you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information sheet carefully and discuss it with others if you wish. Please do not hesitate to ask me if there is anything that is not clear or that you would like to know more about. Take your time to decide whether or not you wish to take part. This study has been approved by the University of Central Lancashire Ethics Committee (BuSH) (Reference number 081).

Why have I been chosen? We are interviewing English-speaking black African and black African-Caribbean men (aged 18 and over) living in the UK who to the best of their knowledge do not have, and have not been treated for cancer. The interview will be used to identify black men's views about cancer and to find out what they know about help that may be available to them and what, if anything, they wish to know more about. As a black man over the age of 18 years, you are invited to take part in this study.

What is the purpose of the study? A review of existing research findings has shown that very little work has been done on this subject in the UK. Hence, cancer prevention strategies may not reflect the views of UK-based black African and black African-Caribbean men towards cancer. The purpose of this study is to understand the views of black African and black African-Caribbean men living in the UK towards cancer. By undertaking this study we intend to inform doctors and nurses working in cancer care in order to enable them to provide services that are suitable to black men and to help increase awareness of early symptoms and signs of cancer. We would like to interview up to 25 people and once this number is reached we will stop recruiting.

I have to take part? No, you do not have to take part. Taking part in the study is entirely voluntary. If you would prefer not to take part you do not have to explain why. Even if you volunteer to take part in this study and then change your mind, you can withdraw at any time without giving an explanation and may ask for the interview (data) to be deleted. However, if you want to withdraw and request your interview (data) to be deleted at a time when the data has already been anonymised, it will not be possible to identify individual data for deletion; however please be assured that it will also not be possible to identify any one person from this data.

What will happen to me if I decide to take part? If you agree to take part in the study you will be asked to take part in a face-to-face interview. The interview will be expected to be last no longer than 60 minutes. An interviewer (Bete) who is a qualified nurse will ask you a number of questions, including your views towards cancer as an illness, its causes, and what help or information you might look for to prevent cancer. You will NOT be obliged to answer all the questions, just the ones you are comfortable with. With your permission, the interview will be audio- recorded and typed up (transcribed). This is common in this type of research and it will help us to analyse the data (information collected from participants). If you wish, a transcript of the interview will be provided to you, so you can check that the transcript is an accurate account of what you have said. The interview will take place at a mutually convenient place, date and time. With your agreement, you may be contacted again for one further interview, only if it is needed to help us to understand better some of the points raised in the first interview.

What are the possible disadvantages and risks of taking part? For the majority of people, it is unlikely that the study will cause upset or distress. However, it is possible that some issues may be raised during the course of the interview that you may find upsetting. If this is the case, we will stop the interview if that is what you wish to do. If you require, further help, you could contact your General Practitioner (GP) or the Macmillan helpline (telephone 0808 808 0000, web- www.macmillan.org.uk), the Mind helpline (telephone 0300 123 3393, web- www.mind.org.uk/help), or the Cancer Research UK (telephone 0808 800 4040 web- http://www.cancerresearchuk.org/cancer-help/) to seek further advice.

What are the possible benefits of taking part? No financial or any other material incentive will be given for participating in this study. However, the findings of this research may benefit black men and health care professionals in developing and delivering care with regards to cancer care/health in the future.

Will my taking part in this study be kept confidential? Yes, the identity of people who take part (participants) will remain confidential. Additionally all information obtained from participants will be handled with great caution in the following manner. All personal information will be removed from typed up interviews. A code number will be allocated to each typed up interview. Any information stored on a computer will be on a password-protected system. All other materials and/or information on paper will be kept in a locked cabinet.

What will happen to the results of the research study? The results of the study may be written up and published but we will not use your name or include any identifiable references to you.

Who is organising and funding the research? This study is being conducted as a PhD research study in the School of Health at the University of Central Lancashire (UCLan). The research is not funded by any other groups or organisations.

Who has reviewed the study? This study has been reviewed by my academic supervisory team at the University of Central Lancashire and also by a user and carer research advisory group. The research project has also been approved by the University of Central Lancashire (UCLan) Ethics Committee.

What do I do if I have questions or concerns as the result of my participation in this research? If you have any questions or concerns feel free to ask, Mr Betselot Mulugeta (Bete), the person who will be conducting the study. If you are not satisfied or if you have still concerns or questions you can contact my supervisor Professor Kinta Beaver and/ or Dr. Nigel Harrison who is the Dean of the School of Health using the address below.

Thank You!

If you need further information or for any query, please contact:

Betselot Mulugeta **(Bete)**, PhD student, School of Health, University of Central Lancashire, Brook Building, Preston, PR1 2HE. Tel 07947183012, E-mail Bmulugeta@uclan.ac.uk

If you have any complains please contact

Research Supervisor: **Kinta Beaver, Professor** of Cancer Nursing, School of Health, University of Central Lancashire, Brook Building, Preston, PR1 2HE. Tel: 01772 893715, E-mail: KBeaver@uclan.ac.uk

Nigel Harrison: Dean of the School of Health, University of Central Lancashire, Brook Building, Room BB430, Preston, PR1 2HE. Tel: 01772 893700, E-mail: NHarrison@uclan.ac.uk

Appendix 9: Interview Topic Guide

Interview Topic Guide

➢ Welcoming participant and introduction:

Ensure they understand the purpose of the study
Explain the presence and purpose of recording equipment
Discuss issues regarding consent and confidentiality prior to each interview and obtain informed consent.

➢ Begin with asking general questions about cancer

In your home country is cancer an issue of concern for you personally?
What was it like to talk about cancer in your home country?'
What is it like to talk about cancer in the community where you live now?

➢ Explore how and from where information is accessed and its accessibility

If you would like to get information about cancer, where would you get it?[9]
How easy was it to find information about cancer?
What information were you trying to get **(w***hat did you want to know)?*
What did you think of the information you found?

- ❖ *If they have never tried to find out about cancer, then ask*
  Why have you never tried to find out about cancer?', then (unless they say they are not interested):
  What would you like to know?'
  Where would you look for information?'
  Where would you like information to be provided?'

- ❖ *If the reason they have never tried to find out about cancer is that they didn't know where to look,*
  What would you like to know?'
  Where would you like information to be provided?'

➢ Explore general views and opinions:

What do you think of when you hear the word cancer?
Do you think since living in England, your views about cancer have changed in any way?
Would you like to know if you had cancer?
Would you tell to your family and friends?

➢ Explore awareness of risk factor and public health campaigns

What do you think causes cancer?

- *Prompt (if responds yes). What could you do to lower your risk of getting cancer?*
- *What do you do?*

If the respondent does not know anything about risk factors and wants to know about the risk ,the following website links will be given at the end of the interview as information sources:- www.cancerresearchuk.org www.prostate-link.org.uk/information/risks/risk-factors/ www.cancerquest.org/lung-cancer-risks and www.breastcancercampaign.org/breast-cancer-risk-factors

Which types of cancers are you most concerned about?
Do you know about cancer screening programmes?

- *Prompt (if responds yes) Have you or would you take part in a cancer screening programme?*

What public information about cancer have you seen in the media or on a poster?

- *If they've seen any, prompt what they thought about them*

➢ Asking participants' demographic data

Length of residency in the UK, age, occupation, education level and country of birth

➢ Is there anything that has not been discussed that you consider being important? Then thanking participants

Appendix 10: Participants Detailed Socio-demographic Characteristics
Participant's Demographic Characteristics by their Background Group

Participant	Age	Place of birth	Study area	Employment	Occupation	Education level	Length of time resident in the UK	Marital status	Background
01[10]	58	Jamaica	Manchester	Full time	Teaching assistance	Diploma	50	Divorced	1stBAC
02	38	Sudan	Manchester	Full time	Hair stylist	Degree	10	Never Married	1stBA
03	42	Eretria	Leeds	Full time	Healthcare assistance	Degree	12	Separated	1stBA
04	52	England	Birmingham	Part time	Driver	No qualification	52	Never Married	2ndBAC
05	54	Jamaica	London	Full time	Shop owner	No qualification	51	Married	1stBAC
06	38	S. Africa	Birmingham	Full time	Nurse	Degree	14	Married	1stBA
07	35	Lesotho	Manchester	Full time	Nurse	Degree	10	Married	1stBA
08	19	UK	Manchester	Student	Student	Vocational Q	19	Never Married	2ndBAC
09	69	Trinidad	London	Full time	Natural healer	Vocational Q	25	Married	1stBAC
10	40	Nigeria	London	Part time	Care assistance	Degree	4	Never married	1stBA
11	54	UK	Leeds	Full time	Computer Engineer	Degree	54	Divorce	2ndBAC
12	42	Togo	Birmingham	Student	Student	Degree	12	Never married	1stBA
13	53	Ethiopia	London	Full time	Sales manger	Degree	19	Married	1stBA
14	51	Ethiopia	London	Full time	Housing officer	Degree	20	Never married	1stBA
15	26	Liverpool	Liverpool	Full time	Software Eng.	Degree	26	Never married	2ndBA
16	52	Jamaica	Birmingham	Full time	Nurse	Degree	46	Divorced	2nd BAC
17[11]	54	Birmingham	Birmingham	Full time	Musician & writer	Vocational Q	54	Co-habiting	1stBAC
18	51	Leicester	Liverpool	Full time	Support worker	NVQ	51	Married	2nd BAC
19	34	Nigeria	Manchester	Full time	Driver taxi	Degree	9	Never Married	1st BA
20	38	Leeds	Leeds	Part time	Tenancy Officer	A level	38	Divorced	2nd BAC
21	24	Sheffield	Sheffield	Student	Student	Degree	24	Never Married	2nd BA
22	35	Zimbabwe	Sheffield	Full time	Youth officer in Church	High School	11	Never Married	1st BA
23	39	Kenya	Birmingham	Full time	Logistics Manager	Degree	13	Married	1st BA
24	46	Zimbabwe	Manchester	Student	Student	Degree	15	Married	1st BA
25	33	Sudan	Birmingham	Full time	Bus driver / Islamic cleric	Degree	12	Married	1st BA
26	27	London	London	Unemployed	Unemployed / musician	Certificate	27	Never married	2nd BA
27	59	Cameroon	London	Full time	Pastor	High School	22	Married	1st BA

[10] Colour coded in green to indicate participants who were interviewed twice
[11] Shaded rows to indicate the two female participants and also /interviewed together/

1st BAC= 4 2BAC= 6 1BA =14 2BA =3

First Generation BAC (1BAC)

Participant	Age	Place of birth	Study area	Employment	Occupation	Education level	Length of time resident in the UK	Marital status
01	58	Jamaica	Manchester	Full time	Teaching assistance	Diploma	50.	Divorced
05	54	Jamaica	London	Full time	Shop owner	No qualification	51	Married
09	69	Trinidad	London	Full time	Natural healer	Vocational Q	25	Married
16	52	Jamaica	Birmingham	Full time	Nurse	Degree	46	Divorced

Second Generation BAC (2BAC)

Participant	Age	Place of birth	Study area	Employment	Occupation	Education level	Length of time resident in the UK	Marital status
04	52	England	Birmingham	Part time	Driver	No qualification	52 yrs.	Never Married
08	19	UK	Manchester	Student	Student	Vocational Q	19	Never Married
11	54	UK	Leeds	Full time	Computer Engineer	Degree	54	Divorce
17	54	Birmingham	Birmingham	Full time	Musician & Writer	Vocational Q	54	Co-habiting
18	51	Leicester	Liverpool	Full time	Support worker	NVQ	51	Married
20	38	Leeds	Leeds	Part time	Tenancy Officer	A level	38	Divorced

First Generation BA (1BA)

Participant	Age	Place of birth	Study area	Employment	Occupation	Education level	Length of time resident in the UK	Marital status
02	38	Sudan	Manchester	Full time	Hair stylist	Degree	10	Never Married
03	42	Eretria	Leeds	Full time	Healthcare assistance	Degree	12	Separated
06	38	S. Africa	Birmingham	Full time	Nurse	Degree	14	Married
07	35	Lesotho	Manchester	Full time	Nurse	Degree	10	Married
10	40	Nigeria	London	Part time	Care assistance	Degree	4	Never married
12	42	Togo	Birmingham	Student	Student	Degree	12	Never married
13	53	Ethiopia	London	Full time	Sales manger	Degree	19	Married
14	51	Ethiopia	London	Full time	Housing officer	Degree	20	Never married
19	34	Nigeria	Manchester	Full time	Taxi driver	Degree	9	Never Married
22	35	Zimbabwe	Sheffield	Full time	Youth officer in Church	High School	11	Never Married
23	39	Kenya	Birmingham	Full time	Logistics Manager	Degree	13	Married
24	46	Zimbabwe	Manchester	Student	Student	Degree	15	Married
25	33	Sudan	Birmingham	Full time	Bus driver/ Islamic cleric	Degree	12	Married
27	59	Cameroon	London	Full time	Pastor	High School	22	Married

Second Generation BA (2BA)

Participant	Age	Place of birth	Study area	Employment	Occupation	Education level	Length of time resident in the UK	Marital status
15	26	Liverpool	Liverpool	Full time	Software Eng.	Degree	26	Never married
21	24	Sheffield	Sheffield	Student	Student	Degree	24	Never Married
26	27	London	London	Unemployed	Unemployed / musician	Certificate	27	Never married

PARTICIPANT SOCIO-DEMOGRAPHIC DETAILS
The Views of Black African/ African Caribbean men living in the UK towards Cancer

Participant ID Number: _____

Researcher Name: _____

Age (years): _____

Marital Status:

Married/co-habiting/civil partnership ☐ Widowed ☐

Divorced/separated ☐ Never married ☐

Employment status:

Working full time ☐ Unemployed at present ☐

Working part time ☐ Long term sick ☐

Retired from work ☐ other (please state) ☐ _____

Occupation (current or previous) _____

(n.b. Please be as specific as possible)

Education/qualifications (tick all that apply):

No formal qualifications ☐ Vocational qualifications ☐ O level/GCSE ☐

A level ☐ Certificate/Diploma ☐ University degree ☐

Sub Group

African-born black African ☐

UK-born black African ☐

Caribbean-born black African-Caribbean ☐

UK-born black African-Caribbean ☐

Country of birth _____

Length of time resident in the UK _____

Appendix 12: Ethical Approval

11th June 2013

Kinta Beaver & Betselot Mulugeta
School of Health
University of Central Lancashire

Dear Kinta & Betselot

Re: BuSH Ethics Committee Application
Unique Reference Number: **BuSH 081**

The BuSH ethics committee has granted approval of your proposal application 'The Views of African Caribbean and Black African men, living in UK towards Cancer'.

Please note that approval is granted up to the end of project date or for 5 years, whichever is the longer. This is on the assumption that the project does not significantly change, in which case, you should check whether further ethical clearance is required

We shall e-mail you a copy of the end-of-project report form to complete within a month of the anticipated date of project completion you specified on your application form. This should be completed, within 3 months, to complete the ethics governance procedures or, alternatively, an amended end-of-project date forwarded to roffice@uclan.ac.uk quoting your unique reference number.

Yours sincerely

Denise Forshaw
Chair
BuSH Ethics Committee

NB - Ethical approval is contingent on any health and safety checklists having been completed, and necessary approvals as a result of gained.

Appendix 13: Written Consent Form

Written Consent Form for Research Participants

Title: **The Views of Black African/African Caribbean men living in the UK towards Cancer**

	Please put your initials in each box
I confirm that I have read and understood the patient information sheet for the above study, version V 2 dated 31.05.13, and have had the opportunity to ask questions, and have had enough time to think about whether I want to be interviewed or not.	
I understand that I am under no obligation to agree to being interviewed and my participation is voluntary. I understand that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
I agree to the audio-recording of my interview and understand that I can ask for the recording to be stopped and edited at any time during the interview and I can ask for any part of the conversation to be deleted.	
I understand and agree that the information I give and some of my responses can be used in written reports, publications, or presentations that will arise from the research, but that my name and any identifiable information will be removed in order to maintain my anonymity.	
I agree to being interviewed as part of the above study.	
I agree to be contacted for a further interview if the researcher needs to interview me again. I understand that I am under no obligation to do this. I also understand that even if I agree my right to withdraw at any time, without giving any reason is always preserved.	
I agree that if I withdraw, any information that has been collected will not be used without my agreement unless it has already been transcribed and anonymised.	
I would like a summary of the results of the study when it completed (*please tick this box only if you would like to receive the summary of the result*).	

Name of Participant Date Signature

_____ _____ _____

Name of researcher taking consent Date Signature

_____ _____ _____

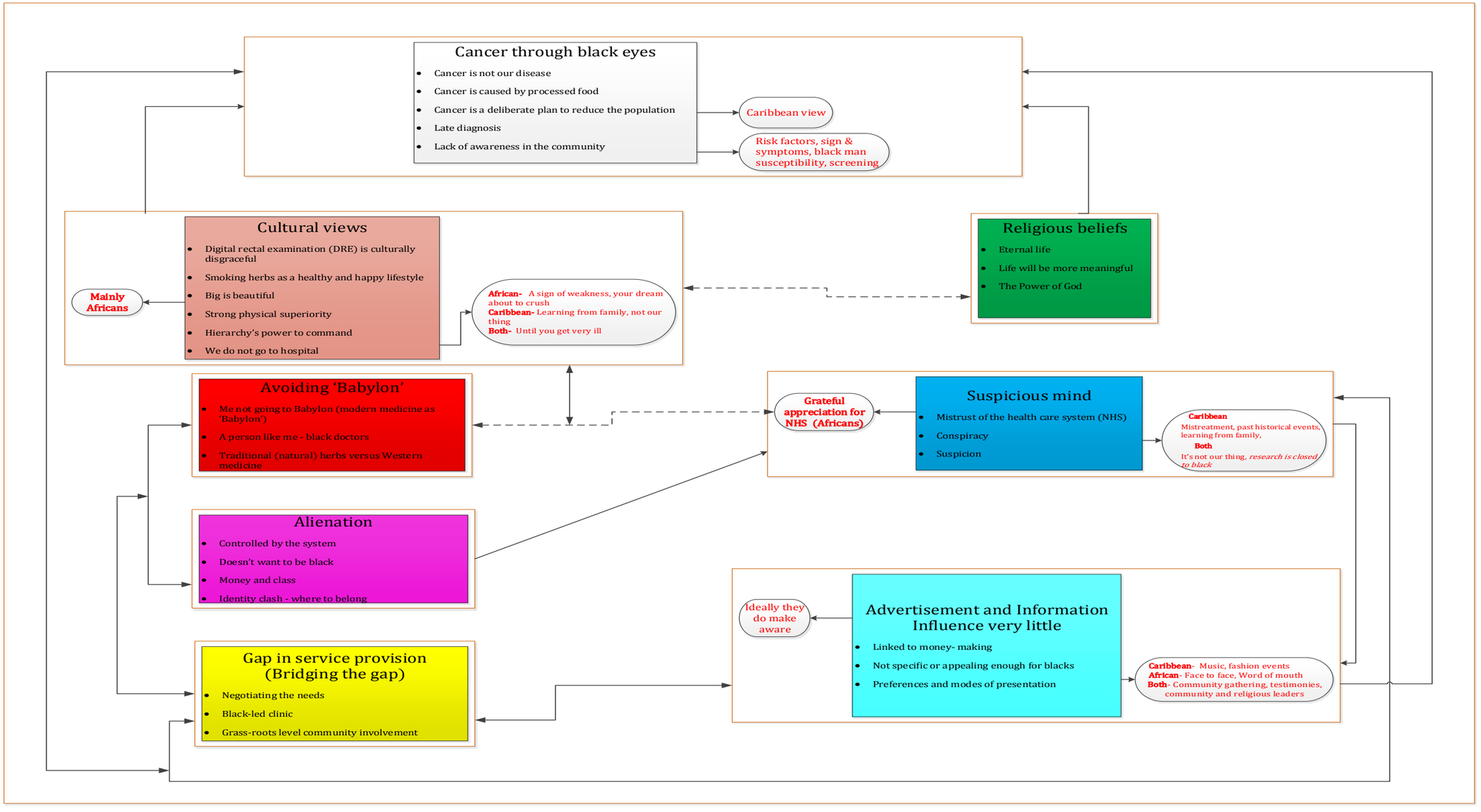
Please fill out the tear off slip form below if you would like a summary of the study.

_____ _____ _____ _____ _____ _____ _____

Name

Address or email account (if preferred) where to send the summary

Appendix 14: Extended Diagram of Core and Sub-categories Including Their Properties



Arrows indicate links between one category and another, there are three types of arrows to indicate the nature of links between categories (see the key)

Key

Overlapping nature ◄- - - - - -►

Contributing factor ——►

Feed each other ◄——►