

**Perceptions of Prostate Cancer Risk in White Working  
Class, African Caribbean and Somali Men Living in South  
East Wales:  
A constructivist grounded theory**

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## Abstract

This thesis presents an in-depth study that explored the differences in perceptions of prostate cancer risk, between Black and White men living in South East Wales. The study grew from the researcher's experience of working in prostate cancer clinics in Wales. During this time, it became apparent that Black men were underrepresented in these clinics. A review of the literature found that African and African Caribbean men have a 1 in 4 risk of prostate cancer, which is twice the lifetime risk of White men. The literature also revealed a worldwide concern about low prostate cancer diagnosis rates in Black men and high mortality rates. It is known that Black men are likely to live in areas of deprivation in the United Kingdom, and this is thought to contribute further to disparities in cancer diagnosis and mortality rates. For this reason, all the men in this research were recruited from areas of deprivation.

This research used a constructivist grounded theory approach to explore how prostate cancer risk perception differs between three distinct ethnic groups of men without a diagnosis of prostate cancer. These men were drawn from Somali, African Caribbean and White Working Class cultural groups. The men took part in semi-structured interviews and focus groups to gain an understanding of how they talked about their bodies and their health, and their understanding of prostate cancer risk. A total of 17 men were interviewed and three focus groups were conducted with men from White Working Class, African Caribbean and Somali communities.

Extensive community engagement was required to gain access to all the men participating in this study, which involved finding novel and imaginative ways to recruit participants to research of this nature.

The findings suggest that the men's perception of prostate cancer risk is formed from their social and cultural background of inclusion or exclusion in relation to the majority population. The findings are explained using the theoretical framework of embodiment and drawing on the habitus and field theory of Bourdieu as well as social constructions of masculinity. From the African Caribbean perspective, the men emphasised risks of emasculation, which has raised the importance of the status of healthy body image as masculine in this community. Similarly, the Somali men talked about the development of community to embody their status as a Somali man and to create a space that reflects their background and country of origin. Conversely, White Working Class men talked about the body in terms of individual experiences of health and illness, rather than being framed by a community structure.

From these insights, this research proposes a grounded theory that emphasises cultural differences in the social construction of the body and how this influences the way the men perceive their risk for prostate cancer. This is based on different expectations of the male body and social constructions of masculinity. These insights should be attended to when providing appropriate health messages, with the greatest cultural impact and relevance.

## Table of Contents

<b>ABSTRACT</b>	<b>II</b>
<b>LIST OF TABLES</b>	<b>IX</b>
<b>LIST OF FIGURES</b>	<b>IX</b>
<b>GLOSSARY</b>	<b>X</b>
<b>CHAPTER 1: INTRODUCTION</b>	<b>1</b>
<b>CHAPTER 2: SETTING THE SCENE</b>	<b>5</b>
<b>2.1: CANCER</b>	<b>5</b>
2.1.1 PROSTATE CANCER	8
2.1.3 CANCER IN WALES	12
2.1.4 PROSTATE CANCER IN WALES	12
2.1.5 CANCER AND SOCIOECONOMIC DEPRIVATION	14
2.1.6 ETHNICITY AND SOCIOECONOMIC STATUS	18
2.1.7 ETHNICITY AND DEPRIVATION IN WALES	19
2.1.8 WELSH HEALTH POLICY	22
<b>2.2 CANCER RISK</b>	<b>24</b>
2.2.1 ETHNICITY AND CANCER RISK	24
2.2.2 PERCEIVED CANCER RISK	26
2.2.3 USING EXAMPLES TO JUDGE PERSONAL RISK	28
2.2.4 CULTURAL DIFFERENCES IN CANCER BELIEFS	30
2.2.5 BLACK MEN AND PROSTATE CANCER RISK PERCEPTION	37
2.2.6 CONCLUSION	42
<b>CHAPTER 3: THEORETICAL UNDERPINNING AND METHODOLOGY</b>	<b>45</b>
<b>3.1.1 CONSTRUCTIVISM AND SOCIAL CONSTRUCTIONISM</b>	<b>45</b>
3.1.2 CONSTRUCTIVISM AND SOCIAL CONSTRUCTIONISM IN THE HEALTH LITERATURE	47
3.1.3 CHARMAZ ON CONSTRUCTIVISM	50
<b>3.2 CONSTRUCTIVIST GROUNDED THEORY</b>	<b>53</b>
3.2.1 GROUNDED THEORY	53
3.2.2 CONSTRUCTIVIST GROUNDED THEORY	55
3.2.1 APPLICATION OF CONSTRUCTIVIST GROUNDED THEORY	59
<b>3.3 THE PHILOSOPHICAL APPROACH OF THIS RESEARCH STUDY</b>	<b>60</b>
<b>4. RESEARCH DESIGN AND METHODS</b>	<b>62</b>
<b>4.1 AIMS, OBJECTIVES AND PURPOSE OF THE RESEARCH</b>	<b>62</b>
<b>4.2 USING CONSTRUCTIVIST GROUNDED THEORY</b>	<b>62</b>
4.2.1 THEORETICAL SENSITIVITY	63
4.2.2 THEORETICAL SAMPLING AND SATURATION	64
4.2.3 PURPOSEFUL SAMPLING IN CONSTRUCTIVIST GROUNDED THEORY	66
<b>4.3 REFLEXIVITY</b>	<b>67</b>
<b>4.4 ACCESS AND RECRUITMENT</b>	<b>68</b>
4.4.1 RECRUITMENT FROM ETHNIC MINORITY GROUPS	70
4.4.2 USE OF KEY STAKEHOLDERS	71

4.4.3 USE OF MEDIA FOR RECRUITMENT	74
4.4.4 CONTACTING THE RESEARCHER	75
4.4.5 RECRUITMENT TO FOCUS GROUPS	75
4.4.6 COMMUNITY ENGAGEMENT	77
4.4.7 SAMPLE CHARACTERISTICS	78
4.4.8 SAMPLE SIZE	80
<b>4.5 DATA COLLECTION TOOLS</b>	<b>82</b>
4.5.1 USING INTERVIEWS	82
4.5.2 FOCUS GROUPS	85
4.5.4 RECORDING THE DATA	90
4.5.5 MANAGING THE FOCUS GROUP TRANSCRIPTS	91
4.5.6 LOCATIONS OF DATA COLLECTION	91
4.5.7 SAFETY OF THE RESEARCHER	92
4.5.8 FIELDNOTES	93
4.5.9 ETHICAL CONSIDERATIONS	94
4.5.10 CONSENT PROCEDURE	96
4.5.11 CONFIDENTIALITY AND DATA PROTECTION	97
<b>4.6 METHOD OF DATA ANALYSIS</b>	<b>99</b>
4.6.1 CODING USING INITIAL LINE-BY-LINE CODES	99
4.6.2 CONSTANT COMPARISON	100
4.6.3 IN-VIVO CODES	102
4.6.4 FOCUSED CODING, THEORETICAL CODING AND CATEGORIES	102
4.6.4 MEMO WRITING	105
4.6.5 CREATING CATEGORIES	106
4.6.6 A WORD ON INCIDENTS AND AXIAL CODING	108
4.6.7 DEVELOPING THEORY	110
<b>4.7 TRUSTWORTHINESS OF THE RESEARCH</b>	<b>112</b>
4.7.1 CREDIBILITY	112
4.7.2 TRANSFERABILITY	113
4.7.3 DEPENDABILITY	113
<b>4.7.4 CHAPTER SUMMARY</b>	<b>114</b>
<b><u>5.0 PRESENTATION OF FINDINGS</u></b>	<b><u>116</u></b>
<b>5.1 INTRODUCTION</b>	<b>116</b>
<b><u>6.0 CATEGORY 1 – IDENTITY BY DIFFERENCE</u></b>	<b><u>117</u></b>
6.1 INTRODUCTION	118
<b>6.2. AFRICAN- CARIBBEAN MEN</b>	<b>119</b>
6.2.1 BEING BLACK	119
6.2.2 IDENTITY BY RESTRICTED OPPORTUNITY	122
6.2.3 SUMMARY	124
<b>6.3 SOMALI MEN</b>	<b>125</b>
6.3.1 IDENTITY BY RELIGION	125
6.3.2 IDENTITY BY DIVIDED LOYALTY	126
6.3.3 IDENTITY BY LANGUAGE	128
6.3. SUMMARY	130
<b>6.4 WHITE WORKING CLASS MEN</b>	<b>131</b>
6.4.1 IDENTITY BY SIMILARITY	131
6.4.2 SUMMARY	133
<b>6.4.3 CHAPTER SUMMARY</b>	<b>133</b>

<b>7.0 CATEGORY 2 – VIEWS OF THE BODY</b>	<b>136</b>
7.1 INTRODUCTION	136
<b>7.2 WHITE WORKING CLASS MEN</b>	<b>136</b>
7.2.1 IMAGES OF THE UNWELL BODY	136
7.2.2 SOCIAL ACCEPTANCE	138
7.2.3 THE BODY AT RISK	139
7.2.3.3 MANAGING PERCEIVED RISK	142
7.2.3.4 THE PRIVATE BODY	144
7.2.3.5 MISCONCEPTIONS	146
7.2.4 SUMMARY	147
<b>7.3 AFRICAN CARIBBEAN MEN</b>	<b>150</b>
7.3.1 BODY IMAGE	150
7.3.2 THE BODY AT RISK	153
7.3.3 THE PRIVATE BODY	158
7.3.4 MISCONCEPTIONS	162
7.3.5 SUMMARY	163
<b>7.4 SOMALI MEN</b>	<b>166</b>
7.4.1 THE MEDICAL BODY	166
7.4.2 THE BODY AT RISK	169
7.4.3 MISCONCEPTIONS	173
7.4.4 SUMMARY	175
<b>7.5 CHAPTER SUMMARY</b>	<b>176</b>
<b>8.0 CATEGORY 3 – THE EVERYDAY BODY</b>	<b>183</b>
<b>8.1 INTRODUCTION</b>	<b>183</b>
<b>8.2 WHITE WORKING CLASS MEN</b>	<b>184</b>
8.2.1 SHARING HEALTH IN A GROUP	184
8.2.2 THE BROKEN GROUP	185
8.2.3 INDIVIDUAL KNOWLEDGE	188
8.2.4 SUMMARY	189
<b>8.3 AFRICAN CARIBBEAN MEN</b>	<b>191</b>
8.3.1 HEALTH AS A COMMUNITY CONCERN	191
8.3.2 COMMUNITY AS A BARRIER	193
8.3.3 COMMUNITY AS ENABLER	196
8.3.4 SUMMARY	200
<b>8.4 SOMALI MEN</b>	<b>202</b>
8.4.1 HEALTH AS A COMMUNITY CONCERN	202
8.4.2 EDUCATING THE COMMUNITY	205
8.4.3 SUMMARY	206
<b>8.5 CHAPTER SUMMARY</b>	<b>208</b>
<b>9.0 CATEGORY 4 – SOCIAL TALK</b>	<b>214</b>
9.1. INTRODUCTION	214
<b>9.2 WHITE WORKING CLASS MEN</b>	<b>215</b>
9.2.1 OUT-ILLING AND TELLING	216
9.2.2 USING HUMOUR	219
9.2.3 SUMMARY	220
<b>9.3 SOMALI MEN</b>	<b>221</b>
9.3.1 INCLUDING AND DELIBERATING	222
9.3.2 USING HUMOUR	225
9.3.3 SUMMARY	226
<b>9.4 AFRICAN CARIBBEAN MEN</b>	<b>226</b>

9.4.1 DEMOCRATIC TALK AND SHARING EXPERIENCE	228
9.4.2 USING HUMOUR AND SHARING EXPERIENCE	231
9.4.3 SUMMARY	233
<b>9.5 CHAPTER SUMMARY</b>	<b>234</b>
<b><u>10.0 A GROUNDED THEORY OF SOCIAL CONSTRUCTIONS OF THE BODY AND PERCEPTIONS OF PROSTATE CANCER RISK</u></b>	<b><u>238</u></b>
<b><u>11.0 DISCUSSION</u></b>	<b><u>241</u></b>
<b>11.1 INTRODUCTION</b>	<b>241</b>
<b>11.2 HABITUS, FIELD, EMBODIMENT AND HEGEMONIC MASCULINITY</b>	<b>247</b>
11.2.1 HABITUS AND FIELD	247
11.2.2 EMBODIMENT	249
11.2.3 HEGEMONIC MASCULINITY	252
11.2.4 SUMMARY	256
<b>11.3 THE BODY</b>	<b>258</b>
11.3.1 SUMMARY	268
<b>11.4 EVERYDAY MASCULINITY</b>	<b>271</b>
11.4.1 SOCIETY AND EDUCATION	281
11.4.2 SUMMARY	284
<b>11.5 OVERALL SUMMARY</b>	<b>285</b>
<b>11.6 STRENGTHS AND LIMITATIONS OF THIS RESEARCH</b>	<b>287</b>
<b>11.7 CONCLUSION</b>	<b>290</b>
<b><u>12.0 RECOMMENDATIONS AND CONCLUDING REMARKS</u></b>	<b><u>294</u></b>
<b>12.1 INTRODUCTION</b>	<b>294</b>
<b>12.2 CONTRIBUTION TO THE LITERATURE</b>	<b>295</b>
12.3 RECOMMENDATIONS	297
<b>12.4 FUTURE WORK</b>	<b>298</b>
12.4.1 IMPLICATIONS FOR FUTURE RESEARCH	298
12.4.2 IMPLICATIONS FOR PRACTICE	298
12.4.3 IMPLICATIONS FOR EDUCATION	299
<b>12.5 DISSEMINATION</b>	<b>299</b>
12.6 AND FINALLY...	301
<b>12.5 PERSONAL REFLECTION</b>	<b>301</b>
<b><u>13.0 REFERENCES</u></b>	<b><u>303</u></b>
<b><u>LIST OF APPENDICES</u></b>	<b><u>318</u></b>
<b>APPENDIX I: SEARCH STRATEGIES FOR LITERATURE REVIEWS 1 AND 2</b>	<b>318</b>
<b>SEARCH STRATEGY FOR LITERATURE REVIEW 1</b>	<b>318</b>
<b>SEARCH STRATEGY FOR LITERATURE REVIEW 2</b>	<b>319</b>
<b>APPENDIX II: EXTRACTS FROM PHD DAIRY</b>	<b>320</b>
<b>APPENDIX III: EXAMPLE OF FIELD NOTES</b>	<b>325</b>
<b>APPENDIX IV: RECRUITMENT FLYER VERSION 1</b>	<b>333</b>
<b>APPENDIX IV: REVISED RESEARCH FLYER</b>	<b>334</b>
<b>APPENDIX V: EXTRACT OF FIELD NOTE FROM TIME SPENT IN AREA B</b>	<b>335</b>
<b>APPENDIX VI: EDUCATION QUESTIONS USED IN NATIONAL CENSUS 2011</b>	<b>337</b>
<b>APPENDIX VII: RESEARCH INTERVIEW SCHEDULE</b>	<b>338</b>
<b>APPENDIX VIII: FOCUS GROUPS CARD GAMES</b>	<b>339</b>
<b>APPENDIX IX: FOCUS GROUP GROUND RULES</b>	<b>342</b>
<b>APPENDIX X: EXAMPLE OF FOCUS GROUP OBSERVER NOTES</b>	<b>344</b>
<b>APPENDIX XI: PARTICIPANT INFORMATION SHEET (INTERVIEWS)</b>	<b>350</b>

<b>APPENDIX XII: FOCUS GROUP PARTICIPANT INFORMATION SHEET</b>	<b>352</b>
<b>APPENDIX XIII: RESEARCH CONSENT FORM</b>	<b>355</b>
<b>APPENDIX XIV: EXAMPLES OF THEORETICAL CODING, SORTING AND THEORY GENERATION</b>	<b>356</b>
<b>APPENDIX XV: EXAMPLE OF MEMO INTEGRATION</b>	<b>357</b>

## List of tables

<b>Table 1: Estimated lifetime risk of developing cancer by year of birth and sex. From Ahmed at el. (2015)</b> .....	<b>7</b>
<b>Table 2 Keywords used for Welsh Government health policy review</b> .....	<b>22</b>
<b>Table 3: Fatalism themes derived from Miles et al. 2011; Powe and Finnie 2003; Powe 1995; Powe 1996</b> .....	<b>35</b>
<b>Table 4 Participant inclusion criteria</b> .....	<b>79</b>
<b>Table 5: Qualifications held by men in this research. Some men have more than one qualification</b> .....	<b>81</b>
<b>Table 7: Personal characteristics of the men interviewed for this research</b> .....	<b>117</b>
<b>Table 6: Extracts from interview and focus group transcripts demonstrating individual and community strategies for raising awareness of prostate cancer</b> .....	<b>213</b>

## List of figures

<b>Figure 1: Distribution of BME population and relationship to WIMD score in South Wales. Source: (Stats Wales 2017; National Statistics 2015)</b> .....	<b>20</b>
<b>Figure 2: Comparison in initial coding from interview transcripts for participant 024 p4 and participant 032 p</b> .....	<b>101</b>
<b>Figure 3: Process followed during theoretic analysis</b> .....	<b>110</b>
<b>Figure 4 Development of category Individual Difference</b> .....	<b>135</b>
<b>Figure 5 Diagrammatic representation of category Views of the Body</b> .....	<b>182</b>
<b>Figure 6 Diagrammatic representation of Social Talk</b> .....	<b>237</b>
<b>Figure 7: Illustrative example of generating grounded theory</b> .....	<b>240</b>



## Glossary

AS	Active surveillance
BME	Black Minority Ethnic
DRE	Digital rectal examination
NHS	National Health Service
PSA	Prostate Specific Antigen
UK	United Kingdom
WIMD	Welsh Index of Multiple Deprivation
WW	Watchful Waiting
Use of capitals	Capitalisation of Black men, African Caribbean men and White Working Class men is used when referring to the groups of men taking part in this research. At other times these terms are not capitalised.

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## Chapter 1: Introduction

*“We’re not talking about men in general, we’re just talking about black people, there’s a difference”*

*(African Caribbean focus group transcript: Participant 04 p.17)*

This thesis presents the findings of research exploring black and white men’s perceptions of prostate cancer risk based on their everyday experiences of the body. Evidence will be given that black men living in South East Wales<sup>1</sup> have created a buffer in the shape of a masculine body image, black community and religious practices, to protect themselves from the apparent racism and marginalisation they faced as young men in a predominantly white country. This is thought to influence their perceptions of risk for the uniquely male health complaint, prostate cancer. Understanding black men’s perceptions of risk for prostate cancer is important; black men have twice the risk of developing prostate cancer in their lifetime when compared to white men (Benarif and Eeles 2016).

The men recruited to this research all lived in areas of deprivation, as recognised by the Welsh Index of Multiple Deprivation (National Statistics 2015). Social deprivation is known to increase risk of cancer diagnosis and mortality (Marmot 2010). It is also known that ethnic minority populations are well represented in areas of social deprivation (National Statistics 2015), and so

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<sup>1</sup> In this research black men have been separated into two distinct groups of men: African Caribbean and Somali. The reasons for this are given in chapter 4. When the men are discussed as one group the term black men is used. At all other times the men are presented by their ethnic identity, Somali and African Caribbean.

to mediate for the effect of deprivation on understanding of cancer risk all the men in this research lived in areas recognised as equally deprived.

This thesis will present the theory that for the White Working Class men in this research living in an area of deprivation seems to draw the men together as members of groups, which they find a useful source of information about health and illness. Conversely, the Black men talk about health and illness as a community concern and value learning about risks to their bodies as a community process. In this research, a group is defined as a space occupied by the men that is linked to an activity, such as an allotment. The community is defined as an area in which the men live that has provided the men with the background to social identity, and which continues to influence their everyday behaviour.

This research has used a constructivist grounded theory approach based on the premise that the body is understood in terms of the social environment in which a person learns about their body image. This theoretical thinking is influenced by the work of Charmaz (2014), and the writing of influential social psychologist and philosopher George Herbert Mead and his understanding of the self in relation to others (Strauss 1977).

Charmaz (1995; 2014) takes the view that data collection and analysis remains flexible to include the experiences and assumptions of the researcher, rather than assuming the researcher is a natural observer in the research process (Charmaz 2014). This was felt particularly important for this research as the

researcher was working as a Clinical Nurse Specialist in prostate cancer at the start of the research process and has many years of experience of talking to men with prostate cancer. It was felt important that the influence of the researcher's assumptions about men's understanding of prostate cancer should be considered during the process of data collection and analysis. The application of a constructivist grounded theory approach has meant the researcher has remained flexible through data collection and analysis, using memo writing to maintain reflexivity.

In the nature of grounded theory, the theoretical framework on which these data are presented was emergent throughout the process of analysis. The emerging framework has been presented in the context of the habitus and field theories of Bourdieu (2007) , and the embodiment of hegemonic masculinity (Bourdieu 2007; Maton 2014; Thomson 2014). These theories are felt to fit with the differences in the way the men talk about their bodies based on their experiences of the body in a social context. It is argued that for the men in this research, interactions with other men construct their understanding of prostate cancer risk in terms of their experiences of their masculine bodies, and this is particularly salient for the African Caribbean men.

Recommendations have been given as to how these findings can help support work to better inform men at the most risk of prostate cancer. The contribution of these empirical findings to existing literature has been presented as adding to knowledge of how men identify their body's risk for prostate cancer. The comparison of three distinct cultural groups of men have made these

differences more salient than that which has been previously reported in the current literature.

## Chapter 2: Setting the scene

Chapter 2 presents a review of the background literature, which will introduce the context for this study (literature review 1, p312). Using a grounded theory methodology this review was conducted to establish what is already known about the topic of prostate cancer and African, African Caribbean men and White Working Class men. A further review of the literature was carried out for the discussion chapter (literature review 2, p313), to establish the position of the proposed grounded theory in current theory and empirical evidence. The strategies used for literature reviews 1 and 2 can be seen in appendix I.

### 2.1: Cancer

Worldwide, a person's risk for developing cancer in a lifetime is increasing (Connell 2005; Cancer Research UK 2012). In 2012 the GLOBOCAN project collated data from countries holding cancer registers, and concluded that internationally there were 14.1 million new cases of cancer and 32.6 million people living with cancer (International Agency for Research on Cancer 2012). In the same year there were 8.2 million deaths from cancer worldwide. In addition, these international cancer statistics show that the burden of cancer is predominantly shared by highly developed countries despite these countries making up only 17% of the population (International Agency for Research on Cancer 2012). This statistic is likely to be multifaceted, due to the effects of Western lifestyle, access to health care and education as well as better cancer detection and record keeping (Bray et al. 2012).

The GLOBOCAN project (2012) also found that the international age-standardised rate for risk of all cancers was 25% higher in men than in women; cancer trends show that both genders are now at greater lifetime risk (0-99 years) of a cancer diagnosis (see table 1), but that men born in 1960 have a lifetime risk for cancer of 1 in 2 (53.5%), whereas for women the risk is below this at 47.5% (Bray et al. 2012).

The overall increase in cancer incidence can also be explained by changes in cancer detection. In recent years there have been advances in diagnosis due to better screening procedures; routine mammography for breast cancer, screening for cervical and colon cancer and the introduction of prostate specific antigen (PSA) blood test to aid prostate cancer detection (Ahmad et al. 2015). Academics speculate that increases in cancer diagnosis may also be explained by longer life expectancy, with some hypothesising that if people lived long enough most people would be diagnosed with cancer in their lifetime (Ahmed et al. 2015). In addition to increases in cancer diagnoses, advances in cancer treatment mean people will be living longer with cancer. Maddams et al. (2012) predict the numbers of people surviving cancer will rise to 2.9 million in 2020, from 2.1 million in 2010, if current rates of cancer survival continue.



Based on these facts, it is reasonable to accept that cancer is fast becoming a global health problem and that due to advances in treatment and detection, cancer is starting to be viewed as a chronic condition. This positive change in the outlook of cancer means people have begun to live with the side effects of cancer treatment, or with the uncertainty of routine monitoring of an indolent cancer (O’Callaghan et al. 2014) . Approaches to cancer management have begun to accommodate these lifelong uncertainties, such as cancer survivorship programmes and cancer support groups (O’Callaghan et al. 2014).

Year of birth	1930	1935	1940	1945	1950	1955	1960
Male %	38.5	42.2	45.4	47.8	49.8	51.5	53.5
Female %	36.7	39.7	42.6	44.2	45.3	46.4	47.5

**Table 1: Estimated lifetime risk of developing cancer by year of birth and sex. From Ahmed et al. (2015)**

### 2.1.1 Prostate cancer

Prostate cancer is now the most common cancer in men in the United Kingdom (Maddams et al. 2012). Each year, 34,000 new cases are diagnosed and approximately 10,000 men die from prostate cancer (Mackie 2010). The lifetime risk of developing prostate cancer is 1 in 8, or 11.1%, and prostate cancer is now the second most common of all cancers in the United Kingdom (Mackie 2010). Mortality rates from prostate cancer have fallen in recent years but diagnosis rates have increased (Cancer Research UK 2017). The increase in diagnosis rates are likely to be partly due to the introduction of the prostate-specific antigen blood test (PSA), following research by Catalona et al. (1991).

Catalona et al. (1991) compared the usefulness of the PSA test as a screening tool for prostate cancer, alone or in combination with a digital rectal examination (DRE) and ultrasound biopsy. Their findings found a correlation between an elevated PSA (over  $4\mu\text{g}$ ) and a positive prostate biopsy (a PSA of over  $10\mu\text{g}$  had the most significant correlation). However, Catalona and colleagues were unable to conclude that the PSA blood test, when used alone, was sensitive enough to be used as a screening tool due to the risk of a false positive result; PSA can be elevated because of benign changes to the prostate and also increases the risk of finding indolent prostate cancers (Catalona et al. 1991).

Despite concluding that the PSA blood test could not be used as screening for prostate cancer, Catalona et al. (1991) recommended the use of the test in combination with the DRE to increase efficacy of prostate cancer detection. Consequently, since 1991 the use of the PSA test has led to an increase in prostate cancer detection. The tolerance of discovering indolent prostate cancers has changed in recent years, with the introduction of Active Surveillance (AS) and Watchful Waiting (WW) (O'Callaghan et al. 2014). AS can be offered to men who are diagnosed with a low-risk prostate cancer that does not need immediate radical treatment, and WW is used for older men with a low-risk prostate cancer, who are unlikely to need treatment for their prostate cancer in their lifetime (O'Callaghan et al. 2014).

However, there remains controversy about the use of the PSA test as a screening tool for prostate cancer, and therefore there is currently no screening available (National Institute for Health and Care Excellence 2014). In spite of this, uro-oncologists argue that every man is entitled to a PSA blood test after counselling from their healthcare practitioner about the associated risk of a false-positive result, and in the United Kingdom the test is offered to men who are concerned about symptoms of prostate cancer (National Institute for Health and Care Excellence 2014).

It is known that some men have a higher risk for prostate cancer than others, such as black men and those with a family history, but there is still some debate amongst clinicians about the use of the PSA blood test as a screening tool for these men (Schröder et al. 2012). Benarif and Eeles (2016) identified genetic risk factors

for prostate cancer, and as such believe that for men diagnosed under the age of 60 years the risk to their first-degree relatives is four-fold that of men diagnosed over the age of 60. Benarif and Eeles (2016) also recognise that there is an increased risk for African and African Caribbean men, possibly due to genetic risk factors.

Unfortunately, for some of these high-risk men the on-going debate about the PSA blood test has led to avoidance in seeking advice from a healthcare professional (Corben et al. 2017). These men receive conflicting advice from healthcare professionals, about the usefulness of the PSA blood test, and some are being told that the blood test is not available, despite recommendations that all men are entitled to the test (Corben et al. 2017).

Of interest to this research is the increased risk for prostate cancer in black men. There is a growing body of evidence that ethnicity is important in prostate cancer. For example, black African and African Caribbean men have a lifetime risk of prostate cancer of 1 in 4, compared to 1 in 8 in other men (UK National Screening Committee 2014). These men are also more likely to be diagnosed with an aggressive form of prostate cancer and have a mortality rate 2.4 times higher than white men (Benarif and Eeles 2016). The highest risk for prostate cancer is amongst African-American men (Benarif and Eeles 2016) and the majority of the research examining and understanding of risk for prostate cancer in black men has been conducted in the United States, as further discussed in chapter 11. In the United Kingdom (UK) research in 1992 studied cancer occurrence in immigrants to the UK by matching ethnicity to cancer diagnosis between the years 1970-1985 (Grulich et al. 1992). The research by Grulich et al (1992) was the first to provide

evidence that men of African and African Caribbean origin living in the UK were more than three times more likely to be diagnosed with prostate cancer, compared to white men also living in the UK. Statistical adjustments were made for social class differences that may affect these results. The effects of socioeconomic status on cancer diagnosis and mortality rates are discussed on page 19.

Grulich et al. (1992) understood the significance of their findings to help target resource for cancer prevention to those most at risk. Unfortunately, there has been limited UK-based research on this topic since 1992, although more recent research using retrospective analysis of all incidents of prostate cancer in four areas of England has identified that black African and African Caribbean men are still at a significantly higher risk of developing prostate cancer than white men (Jack et al. 2007; Ben-Sholmo et al. 2008; Nanton and Dale 2011).

Despite recent advances in genetic research and the discovery of a susceptibility gene for black men, the cause of the increased risk in black men is complex, due to the effects of migration (Benarif and Eeles 2016). The effects of a diet rich in fat and starch, preferred by African and African Caribbean men is also thought to contribute, although the process of acculturation to a western lifestyle make attributions of risk more complex (Benarif and Eeles 2016). This will be discussed further in section 2.2.4.

Of interest to this research is prostate cancer risk in black men who have migrated to Wales. Wales is a small country in the United Kingdom, which has a high sense of nationalism largely brought about by the widespread use of the Welsh language

and devolved powers given to Wales in a referendum for a Welsh Government in 1997. The history of this devolution is discussed further in section 2.1.8 with a review of Welsh health policy.

### **2.1.3 Cancer in Wales**

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) collects data on cancer diagnosis from pathology and death certificates for individuals resident in Wales (Welsh Cancer Intelligence and Surveillance Unit 2016). This information is used to inform trends of cancer diagnosis, mortality and survival in Wales. The Wales Cancer Network (2016) reports that cancer diagnosis rates have been increasing by 1.5% per year and this is expected to increase by 2% per year over the following 4 years, so that by 2020 there will be approximately 150,000 people living with cancer in Wales. Similar to other developed countries, the most commonly occurring cancers in Wales are breast, prostate, lung and bowel cancers (Williams et al. 2015). Compared to other counties in the United Kingdom, Wales does not perform well on diagnosing cancer early and this is thought to be related to the behaviours of people who are most at risk of cancer, and their relationship with primary care (Welsh Cancer Intelligence and Surveillance Unit 2016). This will be discussed in more detail in section 2.1.5 when the relationship of cancer and socioeconomic deprivation is considered.

### **2.1.4 Prostate cancer in Wales**

For men in Wales, data from 2001 to 2014 show that incidence rates of prostate cancer diagnoses have remained stable (Wales Cancer Network 2016). This is

likely to be due to fluctuations in diagnosis rates during this time, and because of this the Wales Cancer Intelligence and Surveillance Unit conclude that overall more men are being diagnosed each year (Welsh Cancer Intelligence and Surveillance Unit 2016).

The reasons for this are thought to be the same as those discussed in section 2.1.1; better prostate cancer detection since the use of the PSA test to aid diagnosis. Wales has also seen an increase of 31.6% in five year survival rate for prostate cancer, and this is thought to be because of on-going research into effective prostate cancer treatments (Wales Cancer Network 2016).

In Wales there is anecdotal evidence, including personal experience of the researcher from working in prostate cancer clinics, that men of African and African Caribbean origins are not currently being seen in prostate cancer clinics despite their increased risk. In 2011, in the recruitment area used for this research, there were 10,605 black African and African-Caribbean people resident and 700 were males who fall within the age-range for the highest incidence of prostate cancer (60-84 years) (Wales Cancer Intelligence and Surveillance Unit 2017), 25% of whom are at risk of developing cancer in their lifetime. Unfortunately cancer registers in Wales do not collect ethnicity data (White 2017), so it is difficult to know if there is a difference across ethnic groups in presentation and investigations for prostate cancer.

What is known about African and African-Caribbean men in Wales is that they mainly live in areas of social deprivation (Office for National Statistics 2011). It is,

therefore important to this research to consider the effects of social deprivation on a cancer diagnosis.

### 2.1.5 Cancer and socioeconomic deprivation

People with higher socioeconomic position in society have a greater array of life chances and more opportunities to lead a flourishing life. They also have better health. The two are linked: the more favoured people are, socially and economically, the better their health (Marmot 2010, p. 4)

The Marmot Review (2010), commissioned by the Department of Health to survey how the social determinates of health affect life expectancy, concluded that on average people living in the poorest areas of England would die seven years earlier than those living in the most affluent areas (Marmot Review 2010). The reasons for this are complex and in Wales the gap between health and wellbeing between the least deprived and most deprived areas continues to grow (Welsh Assembly Government 2011; White 2017) . In the United Kingdom, Wales trails behind England, Scotland and Northern Ireland in the levels of inequality affecting 11-15-year olds (Welsh Assembly Government 2011). Marmot (2010) considers deprivation amongst children a key indicator of deprivation across the life course; deprivation at this age increases the negative effects in skills development employment and work. The inequality affecting 11-15-year olds in Wales is an indicator of lifetime deprivation in this country.

In research comparing cancer outcomes and socioeconomic status, level of deprivation is recorded using multiple indices of deprivation, which include domains such as income, employment, health, education and crime (Morgan et al.



2013). In Wales, the Welsh Index of Multiple Deprivation (WIMD) assesses deprivation level based on: Income, employment, health, education, access to services, community safety, physical environment and housing. Using these measurements, people can be deprived in more than one domain, creating a robust view of deprivation to inform government policy (Welsh Assembly Government 2011).

Evidence relating to cancer and health inequality suggests that cancer diagnosis rates are lower in areas of high socioeconomic deprivation, compared to areas of least deprivation, whilst the risk of dying from cancer is higher (Surbone and Halpren 2016). A recent study of recorded cancer incidence (National Statistics 2015) matched postcodes to cancer diagnosis and mortality from the National Cancer Data Repository in England, and findings support the disparity of cancer diagnosis rates found by Surbone and Halpren (2016). The reasons for the difference in cancer diagnosis and mortality rates, between areas of high and low deprivation, are complex. Multiple co-morbidities related to lifestyle risk factors, such as poor nutrition and inactivity have been linked to an increased risk of cancer diagnosis, and low literacy levels and attitudes towards illness contribute to lower rates of cancer diagnosis among the most deprived (Marmot 2010; Noor et al. 2013; National Statistics 2015; Eylert et al. 2016).

In research examining a young person's cancer risk behaviour, as an indicator for future cancer risk, Wardle et al. (2003) conducted a 5-year longitudinal study of children aged 11-12 years in 36 schools across London. The children had anthropometric measures (e.g. height and weight), demographic data (including

deprivation status), and a record of health behaviours collected (e.g. diet and exercise). Wardle et al. (2003) found that children living in areas of deprivation were likely to have tried smoking, have a high-fat diet and an increased risk of obesity, and they conclude that when their measures are used as predictors of cancer risk, individuals living in deprived areas put themselves at an increased risk for cancer as early as adolescence. More recent research, using the same longitudinal approach, also found a relationship between low socioeconomic status and health related behaviours that are likely to increase risks for cancer (Eylert et al. 2016). Conversely, research conducted on a cohort of men living in an area of mixed socioeconomic status in Wales, has found that after thirty years of data collection, only smoking was thought to significantly increase cancer risk, despite only 1% of the men adopting five recommendations for a healthy lifestyle over the 30-year period (Elwood et al. 2013). However, Elwood et al (2013) used an amalgamation of socioeconomic status during data analysis, which is likely to have affected the overall findings of this research.

However, these findings indicate that risks, which are not being directly measured, such as familial cancer history, also impact on cancer diagnosis rates. The research by Elwood et al. (2013) seems to suggest that if smoking behaviour was the only recorded behavioural risk for cancer, other lifestyle factors may be difficult to extrapolate from risks beyond a person's control. This is of interest to this research because of the unknown cause of increased risk for prostate cancer in black men, and the possible genetic contribution as identified by Benerif and Eeles (2016).

With regards to risk from deprivation for cancer diagnosis rates, multiple indexes of deprivation also measure quality of and access to local services, including education. Eylert et al. (2013) suggest that individuals from areas of deprivation are less likely to have access to effective education, reducing the capacity of the individual to make effective decisions about a healthy lifestyle and, in the future, effectively discuss treatment options for cancer. As treatments for cancer continue to improve and new treatments become available, patients are often asked to make a decision about their preferred treatment at the point of diagnosis Wardle et al. (2003). In a review of cases where multiple treatment options were available for patients with prostate cancer, Eylert et al. (2016) found that patients from areas of deprivation were unlikely to question the doctor's choice of treatment. Lamb et al. (2014) express concerns that for some patients, such as those from areas of deprivation, discussions about cancer treatments could be confusing, and Noor et al. (2013) found that patients from the most deprived areas were significantly less likely to be referred to take part in a cancer clinical trial, compared to those from least deprived areas. Noor et al. (2013) suggest this is due to poor levels of education amongst people living in areas of deprivation, reducing their ability to understand complex treatment decisions.

A position of equipoise tells us that outcomes for cancer patients taking part in clinical trials could extend life expectancy; trial treatment may be more beneficial than standard treatment in extending life expectancy (Noor et al. 2013).

Therefore, the low uptake of clinical trials in people from disadvantaged areas adds to the complexity of worse cancer outcomes among people with a low socioeconomic status.

### 2.1.6 Ethnicity and socioeconomic status

There is agreement among research exploring ethnicity and health, that people from Black Minority Ethnic (BME) communities are disproportionately represented in areas of social deprivation, compared to their white counterparts (Shi et al. 2013; Longhi 2014; Di Pietro et al. 2016). In the UK, poverty is higher amongst BME populations than among the white population (Shi et al. 2013).

A review of the evidence relating to poverty and ethnicity for the Joseph Rowntree Foundation in 2011, highlighted difficulties for BME individuals in finding work and once in work these individuals experienced inequality of opportunity, access to training and promotion (Barnard and Tucker 2011). The reasons for this are complex, particularly because of the differences in cultural beliefs and practices amongst BME communities, such as honouring Muslim prayer times and the wearing of the hijab amongst Muslim women (Lamb et al. 2014). The Equality Act of 2010 has made some progress in protecting employees with particular religious beliefs from discrimination, but there are still difficulties in equity faced by BME individuals in work (Longhi 2014).

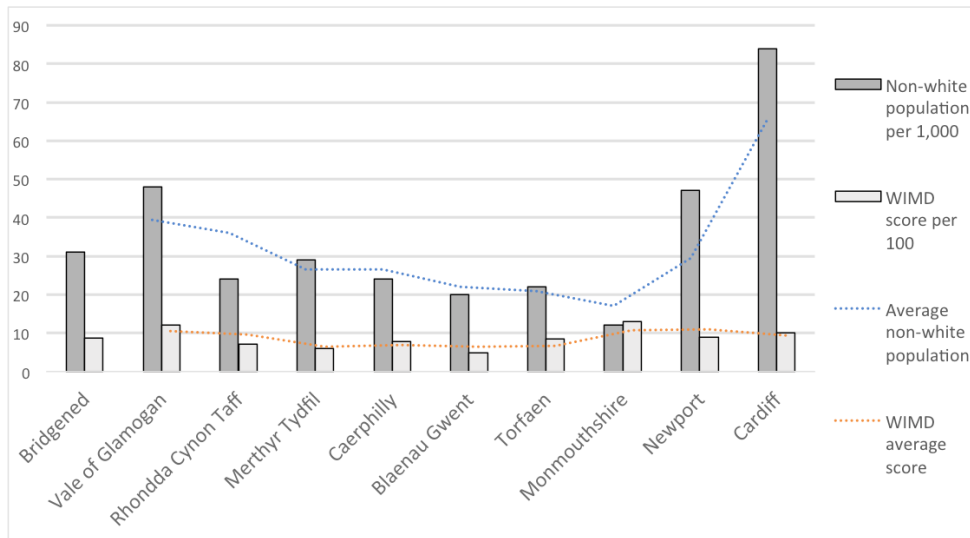
To try and understand the effect of poverty on BME individuals, Longhi (2014) modelled the effect of cultural diversity on subjective wellbeing, comparing a surveyed measure of wellbeing to the English Indices of Multiple Deprivation. Longhi (2014) found that despite the difficulties faced by BME individuals, such as those discussed above, the majority of the BME families involved in her research

did not display low subjective wellbeing whilst living in areas of deprivation. Longhi (2014) concludes that this is because of proximity to friends, family and cultural norms. This provides an insight into how socioeconomic status should be understood for BME families. These families may find value from social capital, and so efforts to improve health education could focus on maintaining this worth. In an interview and focus group study of immigration and inclusion in Wales, Threadgold et al. (2008) comment on the importance of social capital for migrant families, and the difficulties facing these families living in towns and cities in Wales. These findings suggest that migrant families work hard to protect their children from influences of Western culture (such as excessive alcohol), and attempt to preserve the best of the cultures from their countries of origin, which could hinder integration and social mobility (Longhi 2014).

### **2.1.7 Ethnicity and deprivation in Wales**

In Wales, ethnic minority groups usually live in the most deprived areas of the largest towns and cities and also in some of the most deprived areas of Wales, the South Wales valleys, although the overall population from a non-white background in the valley areas is relatively low (Office for National Statistics 2011). This is important for this study; the distribution of ethnic minorities in Wales could mean that health policy directed at improving the health of individuals from deprived areas may actually miss the needs of ethnic minorities hidden in our towns and cities, where the division between deprivation and affluence is less clear. Figure 1 shows the relationship between areas of deprivation and numbers of ethnic

minorities living in these areas, using data from the Welsh Index of Multiple Deprivation and the 2011 National Census. The Welsh Index of Multiple Deprivation uses a ranking system for each index, with a lower overall rank indicating an area of most deprivation (Threadgold et al. 2008). The average WIMD score is higher for areas of least deprivation.



**Figure 1: Distribution of BME population and relationship to WIMD score in South Wales. Source: (Stats Wales 2017; National Statistics 2015)**

Qualitative research examining influence of ethnicity on levels of poverty in Wales (Holtom et al. 2013) explored the experiences of poverty in ethnic minorities recently migrating to Wales, using in-depth interviews with families from five ethnic groups living across Wales representing the most commonly occurring ethnic groups in the country, (Bangladeshi, Pakistani, Somali, Polish, White British/Welsh). Holtom et al. (2013) found that the circumstances of migration changed the perceived experiences of poverty for the BME families. Those who migrated under traumatic circumstances experienced greater poverty and uncertainty. This experience left individuals with fragmented social networks,

which contributed to depression and feelings of powerlessness (Holtom et al. 2013). Like Threadgold et al. (2008) and Longhi (2014), Holtom et al. (2013) found that strong family links and community ties were particularly important to BME individuals, which adds to the rich complexity of integration faced by BME individuals and families in Wales.

The 2011 census has shown that, in Wales, the total population of individuals from black and minority ethnic backgrounds has increased from 2.1% of the total population in 2001, to 4.1% in 2011 with the majority of this population living in towns and cities (Holtom et al. 2013). For historical reasons, such as the annexation of Wales by England in the 13<sup>th</sup> century (Threadgold et al. 2008), Wales has had an ongoing debate about nation and national identity, focused more sharply since devolution in Wales in 1997 (Longhi 2014). Williams (2015) considers that post-devolution tolerance to immigrants has lessened in Wales, reducing cohesion between the white Welsh/British and immigrant ethnic groups. The National Assembly of Wales is only now establishing policy on multiculturalism and racial tolerance, and this leaves the country some way behind England on attitudes towards integration (Williams et al. 2015). The vote for Britain to leave the European Union in June 2016, and the subsequent surge of new racially aggravated hate crimes (Sharman and Jones 2017) will add to this complexity; only time will now tell how this change will impact on the lives of ethnic minorities living in Wales.

### 2.1.8 Welsh health policy

In 1997 the people of Wales voted in a referendum for a devolved government and a 'yes' vote was returned with 50.3% of the vote (Williams et al. 2015). The National Assembly for Wales was formed in 1999, which was given devolved powers for legislation, including control of the NHS in Wales (Williams et al. 2015). In 2006 a second referendum was passed to allow the creation of legislation on devolved issues in the form of Assembly Measures, and the National Assembly for Wales was reformed as the Welsh Government and the Welsh Assembly to create a more parliamentary structure.

The following review of Welsh Government health policy, from 1999-2017 (since devolution), has provided an understanding of how policy is influencing cancer care and the needs of BME individuals. Policy documents published during 1999-2017 were word searched according to themes generated from a review of the literature relating to ethnic minority health, and specifically cancer. See Table 2 for keywords used in this review.

Theme		
Cancer	Inequality	BME
Cancer	Equality	Ethnic
Cancers	Inequality	Minority
Screening	Deprived	Ethnic minority
	Disadvantaged	BME
		Excluded
		Socially excluded

**Table 2** Keywords used for Welsh Government health policy review



There has been very little reference to black minority ethnic groups in health policy documents since devolution. The exceptions to this are: One Wales: A Progressive Agenda for the Government of Wales (Welsh Assembly Government 2007) and Fairer Outcomes for All (Welsh Assembly Government 2011), which make reference to ethnic minority groups not enjoying social, cultural and health benefits, and that language and literacy competence may provide barriers to accessing healthcare. This indicates that the policy agenda has started to recognise the need for culturally specific healthcare for black minority ethnics living in Wales.

With regards to the social determinants of health, policy has reflected the recognition that deprivation affects health outcomes for some of the people of Wales. In relation to cancer, Fairer Outcomes for All (Welsh Assembly Government 2007) recognised the inequalities in cancer diagnosis and death and the important relationship with social deprivation. An action point in this document is to create a database to help establish an evidence-based programme to raise awareness of cancer risk in disadvantaged communities. In an update of this document, The Cancer Delivery Plan for Wales 2016-2020 (Wales Cancer Network 2016), deprivation is still recognised as a barrier to an early cancer diagnosis, particularly through poor screening uptake, and action has been planned to improve engagement and education with these areas. There is no mention of ethnic minorities and their specific risks and health needs relating to cancer.

## 2.2 Cancer risk

Risk: (Exposure to) the possibility of loss, injury, or other adverse or unwelcome circumstances; a chance or situation involving such a possibility (Oxford English Dictionary 2017a, p. online)

In relation to cancer, risk is defined in medical literature as a problem of epidemiology and genetics (Eeles and Easton 2013). Genetics and cancer risk have received research attention in recent years, as familial risks for cancer have become more salient (Walker et al. 2014). A recent meta-analysis of familial risks collated data from a selection of studies for over 200,000 individuals with breast, ovarian and prostate cancer, has found over 70 new susceptibility genes for breast, ovarian and prostate cancer (Eeles and Easton 2013). This finding could lead to more targeted screening and treatment for individuals at most risk, and particularly those at risk of aggressive disease (Eeles and Easton 2013). This research has provided exciting new evidence to support targeted screening. How this information is understood by those at risk (for example, prostate cancer risk in black men), and translated to a change in health behaviour is the focus of interest for this research.

### 2.2.1 Ethnicity and cancer risk

There has been steady migration to the United Kingdom in the 20<sup>th</sup> and 21<sup>st</sup> centuries, and as social demography changes it is important to understand how cancer differently affects ethnic populations, to help deliver culturally sensitive health care services and health promotion campaigns to improve health and outcomes from illness.

Disparities in cancer burden have been found in studies analysing data on ethnicity and cancer incidence (Ward et al. 2004; Wild et al. 2006; Jack et al. 2007; Lane et al. 2007; Oxford English Dictionary 2017a). A study of mortality from all cancers by country of birth, for people resident in England and Wales in 2001, used data from cancer registers for all cancer deaths in adults over the age of 20 years, from 2001 to 2003 (Wild et al. 2006). There were a total of 399,000 deaths for this period. Cancer mortality was highest for men and women born in Scotland, Ireland and West Africa and low for men and women born in East Africa, Asia, China and Hong Kong. Prostate cancer mortality was significantly higher for men born in West Africa and the West Indies and breast cancer deaths were high in women from West Africa (Wild et al. 2006).

In the UK, a longitudinal study of cancer risk and ethnicity used a single database created from 12 factories and 4 churches in Birmingham over an 18-year period, and included a follow-up period of 4.8 years (Lane et al. 2007). Data was collected on cancer diagnosis and mortality from white European, African, Caribbean and Asian communities. Participants were traced through the Office for National Statistics for records of cancer diagnosis and cancer site, which had been classified according to ICD-10 (International Classification of Disease and related health problems) (Lane et al. 2007). Lung cancer was the most common cancer diagnosis for men and women and the most common cause of cancer death. There was a low incidence of cancer amongst African and Caribbean women and South Asian men, compared to white European men and women. For African and African Caribbean men, prostate cancer was the most commonly occurring cancer (Lane et al. 2007).

Other studies have similar findings to Lane et al. (2007), documenting that lung cancer is the most commonly occurring cancer when all cancers are combined (Harding and Rosato 1999) Wild et al. 2006; Jack et al. 2011). However, analysis of cancer registry data has shown that for men from South Asia and West India there is a low incidence of lung cancer (Harding and Rosato 1999; Jack et al. 2011) and conversely a higher incidence of prostate cancer in these men (Harding and Rosato 1999).

For women, breast cancer is the most commonly occurring cancer with the exception of Irish women who have a higher incidence of lung cancer and cancer of the oral cavity and pharynx combined (Harding and Rosato, 1999, Jack et al. 2011).

### **2.2.2 Perceived cancer risk**

Perception of risk is considered a key indicator of health behaviour and therefore our understanding of how we perceive risk, and how this perception influences our behaviour, can help identify ways to encourage risk-reducing behaviour (Kelly et al. 2012). It is presumed that being in possession of the facts about risk for illness, in this case cancer, will motivate an individual to change their health behaviour in order to minimise their risk (Leventhal et al. 1999; Ward et al. 2004; Wild et al. 2006; Jack et al. 2007; Lane et al. 2007; Cancer Research UK and National Cancer Intelligence Network 2009; Jack 2009; National Cancer Intelligence Network 2009). Unfortunately changes in health behaviour of this type are complex and are often influenced by readiness to accept risk based on, for

example: age, gender, work, enjoyment of life and involvement in decisions about screening (Leventhal et al. 1999).

Access to knowledge of health risks have also been found to mediate perceptions of individual risk for cancer (Harding and Rosato 1999). In trying to understand low uptake of cervical screening in the United States, Kelly et al. (2012) conducted research with Appalachian women who appeared to have a higher incidence of cervical cancer than women in the United States as a whole. Kelly et al. (2012) conducted interviews with 571 women based on their perceived risk for cervical cancer. Those women who had the most knowledge about cervical cancer and the screening process were the most worried about their risk, as well as those women who had previously been involved in risky health behaviour, such as having multiple sexual partners (Kelly et al. 2012). Contrary to this, Ferrer et al. (2012) and Rice et al. (2015) found that in the general population people high in worry about cancer risk was negatively associated with protective health behaviour, such as eating more fruit and vegetables.

This complexity of risk perception, and the relationship to knowledge and health behaviour, has a substantial presence in academic literature. Studies have found complex relationships between risk perception and health behaviour (Orom et al. 2010; Kelly et al. 2012). McDowell et al. (2013) suggest that this complexity is based on the subjectivity of risk perception, related to personal beliefs and experiences. Personal experiences may include a cancer diagnosis in the family, and this exposure to cancer is related to an apparent enduring relationship for high cancer risk perception.

### 2.2.3 Using examples to judge personal risk

Theories of perceived risk assert that individuals are influenced by the experiences of others around them and that perception of risk is adjusted if peers, friends or relatives experience illness or a threat to livelihood (Leventhal et al. 2003). The construction of individual risk perceptions for cancer can be based on exposure to familial cancer, which has been found to have increased perceptions of individual risk (Rice et al. 2015). McDowell et al. (2013) cite evidence that individuals reduce the complexity of understanding of their personal risk for cancer by using information from their immediate environment to make risk decisions. Their research, specifically related to prostate cancer and familial risk, found that men who understood their family history of prostate cancer reported the greatest overall perception of risk and were more likely to have discussed prostate cancer with their General Practitioner (McDowell et al. 2013). However, this study used a sample of men in employment, educated and receiving an average salary. Following earlier discussion about deprivation and understanding of cancer risk, it could be argued that the research by McDowell et al. (2013) was not representative of all men with prostate cancer, and how these men may act on knowledge of familial cancer risk.

Forbat et al. (2013) surveyed men with a diagnosis of prostate cancer in 2008 and 2009 and found that men with a family history of prostate cancer perceived their risk to be high, when compared to those men without a family history. However, this difference did not reach statistical significance. Forbat et al. (2013) also found

that men who had experienced a friend with prostate cancer perceived themselves to be at higher risk than those without a friend with prostate cancer, and this did reach statistical significance. These men were also more likely to have requested a PSA blood test, and Forbat et al. (2013) conclude that men are more likely to perceive themselves at high risk if they have had interpersonal experience of prostate cancer.

A caveat to these findings is that Forbat et al. (2013) recruited men for their research from a clinical trial with a large database of men with newly diagnosed prostate cancer. It is likely that the men in this research did not represent men from areas of low socioeconomic status, whom Noor et al. (2013) believe are significantly less likely to be offered a clinical trial. This could mean that cancer risk perception in these men may already be different to all men with prostate cancer.

If the sample used for their research had been more representative of all men with prostate cancer, Forbat et al. (2013) may have found that fewer men in their sample requested a PSA blood test, despite experiencing a friend with prostate cancer. This could be because of the complexity of asking for the PSA blood test due to the uncertainty related to the use of the test. Lamb et al. (2014) believe that complex conversations with healthcare professionals could be difficult for men living in an area of deprivation, with a history of poor access to education.

In recent research Peretti-Watel et al. (2014) studied the interaction between smoking, cancer related-risk knowledge and socioeconomic status. Collecting

interview and survey data to assess how smokers perceived their risks for cancer, Peretti-Watel et al. (2014) found that smokers who identified as low socioeconomic status, measured using household income, food deprivation and poor access to healthcare, judged themselves to be low in terms of smoking-related cancer risk. Those with low socioeconomic status used their family and friends as sources of knowledge and felt that they smoked too few cigarettes per day to be at risk of cancer (Peretti-Watel et al. 2014). This is compared to those of a higher socioeconomic status, whose main source of information was television, news media and healthcare professionals. These individuals perceived themselves at high risk of smoking-related cancer (Peretti-Watel et al. 2014). This research supports the findings of Lamb et al. (2014), when considering educational level, socioeconomic status and access to information about cancer risk.

#### **2.2.4 Cultural differences in cancer beliefs**

In recent years the use of population-based screening for cervical, breast and colorectal cancer has increased cancer diagnosis rates, and also has the potential to decrease deaths and long-term health complications from these cancers (Crawford et al. 2016). In the United Kingdom screening is offered through the National Health Service (NHS) for breast, cervical and colorectal cancers, and there is evidence that the uptake of screening varies across ethnic groups (Robb et al. 2010). Some studies have found that there is no difference between ethnic groups (Gonzalez et al. 2008), while other studies have reported lower uptake of screening in ethnic minority groups (Jack 2008; Szczepura et al. 2008). Research examining uptake of screening for breast and bowel cancer, over five rounds of a



national screening programmes (1989 – 2005), found that in Asian ethnic minority groups breast screening uptake was significantly lower for the first three national screening programme (Szczepura et al. 2008). However, by the fifth round the uptake had increased in Asian women showing the inequality in breast cancer screening slowly decreasing (Szczepura et al. 2008).

Szczepura et al. (2008) also found that there were differences in sub-groups of the Asian women in uptake of breast cancer screening, dependant on identified ethnic group. Muslim women had the lowest uptake of breast and bowel screening over the five rounds of screening opportunities, exhibiting an enduring and significantly lower screening uptake. Szczepura et al. (2008) do not offer an explanation for these sub-group differences, but this will have implications for strategies used by third-sector organisations and healthcare professionals, when providing education about national screening programmes.

Robb et al. (2010) explored the low uptake of cancer screening in BME groups in more depth. In their research Robb et al. (2010) collected data from the Office of National Statistics Opinions Survey in 2008, and an Ethnibus survey also in 2008. Both surveys collected data on attitudes to cancer screening, and the Ethnibus survey included questions on non-existent cancer screening programmes (lung, testicular, prostate, and skin), to test for propensity to believe all cancers are screened for through the NHS. Robb et al. (2010) found that Caribbean men demonstrated a high level of knowledge about cancer screening, but also had the highest score on the propensity to assume all cancers are screened. This perhaps

highlights a lack of knowledge in this group and also over-reliance on healthcare professionals taking responsibility for managing risk.

#### *2.2.4.1 Effect of acculturation and duration of residence on cancer beliefs*

In the 21<sup>st</sup> century acculturation is studied in the context of stress and associated health problems, experienced by new migrants who try to adapt to a strange new culture (Rudmin 2009). Acculturation is largely concerned with the assimilation of new cultural practices and the cognitive processes that need to take place for a person or persons to accept a new culture, or assimilate cultures, to become multicultural (Rudmin 2009).

The importance of acculturation to this research is the effect of this process on the health beliefs and behaviours of migrants as they assimilate Western medicine and health behaviours. The literature focusing on cancer is mainly concerned with the process of acculturation on the acceptance of cancer screening amongst BME communities, as they engage in becoming competent in their second culture (Rudmin 2009). As discussed in section 2.1.6, recent migrants prefer to stay living within their cultural groups, even in this means living in areas of deprivation (Longhi 2014). Rudmin (2009) would profess that this preference is to protect themselves from acculturative stress, caused by trying to assimilate with a new culture. This can lead to a lack of integration, which could explain the low uptake of cancer screening by older generation migrants, compared to those born to migrant parents (Gany 2006).

Acculturation affects uptake of cancer screening as well as changes in health behaviour leading to an increased risk for cancer (Harding 2003; Zaman and Mangtani 2007). In 2003 Harding found that duration of residence in the UK is associated with three times the risk for all cancers (hazard ratio 3.1), and in 2007 Zaman and Mangtini discussed literature addressing cancer risk and length of stay in the UK, and found an association with increased levels of cancer risk amongst BME people adopting a Western lifestyle (sedentary habits, smoking and a high fat diet). However, Wild et al. (2006) challenge the usefulness of these statistics, when making judgements about elevated risks for cancer related to timing of migration, because of difficulties in being certain of a person's country of origin and the influence of this on cancer risk, such as the increased prostate cancer risk in black men.

The following section discusses research examining population risk for cancer since time of migration based on the understanding and beliefs of cancer risk in BME communities. A common finding in this evidence is feelings of fear associated with a cancer diagnosis, referred to as cancer fatalism, affecting acceptance of cancer screening and receiving a cancer diagnosis (Gany et al. 2006; Miles et al. 2011).

#### ***2.2.4.2 Culture and cancer fatalism***

It is believed that individuals who come from communities perceived as socially isolated and deprived use availability heuristics to judge their own health risks,

creating a culture of health poverty from negative beliefs about diagnosis and treatment outcomes (Wen et al. 2003).

In relation to cancer, studies of ethnic minority groups have identified a higher incidence of cancer fatalism (Powe & Finnie 2003). There are some differences in the definition of cancer fatalism but broadly the term refers to the belief that death is inevitable when cancer is present (Powe & Finnie 2003), and the antecedents to fatalism include fear, pessimism and death (Powe and Finnie 2003). Fatalism is difficult to conceptualise as it involves multiple themes that influence health behaviour (see table 3). In an attempt to extrapolate these theories and focus on fatalism and health behaviour, Powe (1995) developed a fatalism index based on a review of the literature and subsequent development of a quantitative questionnaire used in two pilot studies. Factor analysis of the data resulted in 13 questions loaded onto one factor (Cronbach  $\alpha$  of 0.87), showing a high level of consistency in this measure of fatalism. The index has been widely used to study fatalism (Harding 2003; Gany et al. 2006; Zaman and Mangtani 2007; Miles et al. 2011; Crawford et al. 2016; Vrinten et al. 2016)

Fatalism	
Theme	Sub-topics
Socioeconomic status	High vs Low Social deprivation Isolation Minority ethnic group Conforming to social norms
Knowledge	Education/literacy Access to appropriate messages
Self-efficacy	Depression Ability to control outcome Motivation to stay well
Health beliefs	Cancer = death Experience of illness (negative or positive outcome) Cultural norms for accessing healthcare (behaviour) Trust in healthcare professionals Acceptance of risk
Self-rated health	Negative outlook on health outcomes High vs Low

**Table 3: Fatalism themes derived from Miles et al. 2011; Powe and Finnie 2003; Powe 1995; Powe 1996**

In early research examining cultural differences in cancer fatalism, Powe (1995) used the Powe Fatalism Index to study the African American and white populations, and their attitudes to screening for colorectal cancer. The index was given to 192 participants who were either white or black African American with a mean age of 76 years. Participants completed the questionnaire and were then educated on colorectal cancer screening and invited to take part in screening with a free test. Powe (1995) found a significant difference in fatalism scores between the white and black participants; the black African American participants had a higher fatalism score, and displayed a more fatalistic outlook. In relation to participation in colorectal cancer screening, 29% of the African American sample took part in the screening, after receiving education, as compared to 33% of the white sample. Powe (1995) concluded that cancer fatalism was a predictor for uptake of cancer screening and a significant indicator of health behaviour (Powe 1995). This

research is dated, but more recent research by Shen (2009) has demonstrated that fear of a cancer diagnosis mediates the uptake of colorectal cancer screening.

However, Shen (2009) tested a revised version of the Powe Fatalism Index on a multi-ethnic population in the United States, and found that ethnicity was not strongly associated with levels of fatalism. The strongest demographics linked to fatalistic beliefs were education and income, and Shen (2009) suggests that these are areas that should be targeted in interventions for changing health behaviour, rather than focusing on ethnicity. Relating cancer fatalism to socioeconomic status (Miles et al. 2011) conducted a postal survey on older adults (50-70 years), to assess the relationship between self-rated health, socioeconomic status, perceived risk for cancer and beliefs about efficacy of treatment and cancer fatalism. The results found that high levels of cancer fatalism were associated with low uptake of cancer screening, and this was mediated by low socioeconomic status, low levels of self-rated health and low levels of risk reducing behaviours, such as fruit and vegetable intake. Like Shen (2009), Miles et al. (2011) did not find a relationship between ethnicity, cancer fatalism and uptake of cancer screening.

Examining ethnicity and fatalism in more detail, (Vrinten et al. 2016) conducted research with migrants living in the UK, and found a significant difference in cancer fear and cancer worry between ethnic groups, with Indian and African migrants having the highest fear of cancer. Vrinten et al. (2016) found that cancer fatalism, measured using the Powe Fatalism Index, was higher in participants who were significantly more likely to state that cancer was not curable. Vrinten et al. (2016)

also found that those who were not born in the UK and whose main language was not English were more likely to display fatalistic beliefs.

#### **2.2.5 Black men and prostate cancer risk perception**

Men of African and African Caribbean origin have a high risk for prostate cancer and are 1.2 times more likely to die from prostate cancer compared to white men (Odedina et al. 2011). The literature focusing on perceptions of prostate cancer risk in black men is largely a discourse of cancer knowledge amongst this group of men, their experiences of cancer in the family and their cultural beliefs, as well as their judgements of personal risk. The evidence is divided between qualitative and quantitative methods and so there is some depth to the understanding amongst these men.

Odedina et al. (2011) used a conceptual framework to test personal factors related to modifiable risk behaviours and the relationship between acculturation, cancer fatalism, religion, and perception of immediate risk (temporal orientation), in men without a history of prostate cancer. This complex research, using a cross-sectional survey method, found that risk reduction behaviour was influenced by knowledge, perceived severity, control and acculturation (Odedina et al. 2011). In this research, knowledge was greater in men with a friend or relative with prostate cancer and Odedina et al. (2011) found this created a significant association with risk reduction behaviour. This is similar to the findings of Forbat et al. (2013) in the use of a friend's personal experience of cancer for men to internalise their own cancer risk.

In research examining the differences in prostate cancer awareness between black and white men in the UK, Rajbadu et al. (2007) conducted a postal survey of 871 men living in three locations in the UK: London, Leeds and Birmingham. Men either received or did not receive information about prostate cancer before they received the survey. Rajdadu et al. (2007) found that black men were less likely to have heard of prostate cancer compared to white men, although there was no difference in the understanding of overall risk factors for cancer. The group that received information about prostate cancer, before they completed the survey, displayed greater understanding of prostate cancer symptom and there was no difference between the black and white men.

As the authors acknowledge, this finding is not surprising as the men in the information group had the information to hand when they completed the survey, and so their research could not say if the provision of information had an enduring effect. A further criticism of this research is the recruitment strategy used by the researchers; approaching men in community groups and GP's surgery in London, and through County Council staff newsletters in Leeds and Birmingham. The researchers do not report collecting data on socioeconomic status, and it can be assumed that those receiving a staff newsletter, in Leeds and Birmingham were in work. The difference in recruitment methods across study areas, and the likely difference in participant demographic, casts doubt on the comparability of the data sets.



More recent research in the UK, comparing white and black males' willingness to have an examination for possible prostate cancer, has also recruited participants through GPs' surgeries (Martins et al. 2015). The researchers in this study approached men waiting for an appointment, asking them to take part in an electronic vignette-based survey. The vignettes used men with varying symptoms of prostate cancer, examinations needed for a diagnosis, and varying prognosis (risk level) if prostate cancer was detected (Martins et al. 2015). The findings of the research show that black men were significantly less likely to opt for further investigations, based on the vignette with the lowest risk level, and this was related to the perceived low risk for cancer in this group of men. Martins et al. (2015) speculate that the lower preference of the black men to pursue a prostate cancer diagnosis could indicate why black men are often diagnosed with an advanced prostate cancer, and have an increased mortality.

Non-UK based research examining the difference between black and white men used survey data to measure cancer knowledge and health behaviour, in a cross-cultural design (Orom et al. 2010). Orom et al. (2010) found that, compared to Caucasians, black men were more likely to underestimate their risk for prostate cancer. Orom et al. (2010) believe this is because black people are less likely to know if they have cancer in their family and therefore, unlike whites, do not use family history as a predictor of cancer risk. However, research by Blocker et al. (2006) using focus groups with black men to study knowledge and beliefs about prostate cancer, found the men spoke about their relative's experiences of prostate cancer, or other types of cancers, and how negative outcomes encouraged the men to engage in risk reduction behaviour. In the case of prostate cancer, the men taking

part in the focus groups related negative outcomes to late diagnosis and recognised that if their male relative had gone to the doctor earlier they might have experienced less suffering (Blocker et al. 2006).

This research supports the findings of Odedina et al. (2011), that an awareness of family history may motivate these men to be more protective of their own health. The research also supports that of Forbat et al. (2013) but similar criticisms can be made about participant recruitment for the study. In the research by Forbat et al. (2013) participants were recruited from men taking part in a clinical trial for prostate cancer, who may not have been representative of all men with prostate cancer. Blocker et al. (2006) recruited their participants from a local church congregation using pastors to identify men they felt would have an interest. Having been identified as men interested in their risk for prostate cancer, these men may also not be representative of the general population.

Differences in methodological approaches of the research discussed above could account for some of the differences between these research findings, but the findings also add to the complexity in understanding risk reduction behaviours in black men.

In an attempt to add clarity to these complexities, Corban et al. (2017) used a mixed-methods approach to examine fears and facilitators for prostate cancer screening in black men. Corban et al. (2017a) used survey, focus group and interview methods to collect data on fears and facilitators, which may enable or hinder a prostate cancer diagnosis. Corban et al. (2017a) found that black men were influenced by

the health behaviours and health histories in their families. The men talk about the older black generations not going to a doctor, unless seriously unwell, and this history contributing to reluctance to engage with healthcare professionals. Corban et al. (2017a) also used a modification of the Powe Fatalism Index (Powe 1995) to measure cancer fatalism in their participants, and found that the men were fearful of receiving a diagnosis of prostate cancer because of the uncertainty this would bring.

The uncertainty surrounding the diagnosis is talked about in terms of not being able to protect the family and continue to be a source of stability and income (Corban et al. 2017). In research considering the male body and the acceptance of illness, the concern about providing for the family is also seen in white men and is considered a universal characteristic of the male, often provided as a reason for not accepting illness (Williams 2007). Therefore, the findings of Corban et al. (2017a) are not unique to black men; rather they may transcend concerns of all males.

Empirical research addressing the beliefs, expectations and needs of black men to increase knowledge and improve health behaviour in relation to prostate cancer, have used a myriad of methodologies to find an answer to the problems of under diagnosis (Gany et al. 2006; Allen et al. 2007; Cosma et al. 2015; Le et al. 2016). In an attempt to summarise the research addressing perceptions of prostate cancer risk in black men Pedersen et al. (2012) conducted a systematic review of the literature on this topic. A total of 33 papers were eligible for review, which used both qualitative and quantitative research methods. Studies were included that

explored knowledge and awareness of prostate cancer, and papers solely focusing on uptake of screening and experiences of treatment were excluded.

Pedersen et al. (2012) found that black men displayed little knowledge about the prostate itself, but that those educated to graduate level were knowledgeable about prostate cancer. They also note that knowledge of individual risk varied, and that research comparing black and white men found that black men had less overall worry about prostate cancer compared to white men. Black men were more likely to fear prostate cancer and this was related to their concerns about being able to provide for their families, in their role as a husband and father (Pedersen et al. 2012).

### **2.2.6 Conclusion**

This chapter has provided background statistics about global cancer incidence and the incidence of cancer in the study area. The chapter has also considered the growing trend in prostate cancer diagnosis and the reasons for this. The lack of formal screening for prostate cancer, and the on-going debate about this for men at high risk, has been recognised.

The disparity of prostate cancer burden in African and African Caribbean men has been considered. The relationships of ethnicity and cancer risk have been discussed in relation to migration, acculturation and living in areas of low socioeconomic status. There is a clear understanding that living in an area of deprivation increases risks for cancer, for reasons ranging from access to healthcare services, poor

education and lifestyle choices affecting longevity. A large number of BME migrants in the United Kingdom live in some of the most deprived areas, and for black men this could add to the increased prostate cancer risk.

Wales has some of the most deprived areas in the United Kingdom, and early detection rates for all cancers are low. There appears to be less integration of BME individuals in Wales, compared to other areas of the UK, and this could mean that health policy directed at the most deprived areas misses the needs of BME migrants to Wales, who are hidden in areas of towns and cities. It appears that Welsh health policy, since devolution, may not be addressing the health needs of those from a BME background.

It is known, from personal experience, that black men at high risk for prostate cancer are underrepresented in cancer clinics in South East Wales, and it appears from a review of the literature that the reasons for this are complex. Findings relating to the differences in understanding of prostate cancer risk between black and white men are varied. Black men judge their risk based on personal experience and appear to be less concerned about risk, compared to white men. This seems to be related to wanting to maintain their status as a man, including providing for their families, possibly leading to a rejection of illness. It is not clear, from the literature reviewed if there is a difference in this belief between black and white men.

It is, however, clear that individuals from BME groups are less likely to attend screening programmes and that this seems to change over time. The process of acculturation increases uptake of screening for some individuals, although those

who have stayed close to their cultural identity and have reduced use of the English language are the least likely to attend. There is also an increase in cancer fatalism and fear amongst some BME individuals, and this is also seen in the African and African Caribbean men involved in research relating to prostate cancer. Black men have also been found to be less knowledgeable than white men, about prostate cancer, and it is thought that this might contribute to this feeling of cancer fear.

It appears that the reasons for the low representation of African and African Caribbean men in prostate cancer clinics is multifaceted. This research will explore the differences in perceptions of prostate cancer risk between black and white men, to guide in our understanding of how third sector organisations can effectively access the men at most risk. The literature reviewed for this chapter has explored possible reasons for cancer disparities in ethnic minority groups. There is a gap in our understanding of how black and white men construct their understanding of risk for prostate cancer when compared to each other at a similar moment in time and whilst living in similar social situations.

## Chapter 3: Theoretical underpinning and methodology

### 3.1.1 Constructivism and social constructionism

This research explores how African, African Caribbean and White Working Class men perceive their risk for prostate cancer and how this is constructed in a social context. The approach is intended to investigate how men construct their understanding of prostate cancer risk through their individual and social experiences.

The constructivist paradigm assumes that what is real is an individual construct, created by an individual's knowledge and experiences within the real world (Guba and Lincoln 1989). Reality is constructed from a variety of languages and symbols, such as experiences of the body in a social context, which impact on the production and organisation of differences in society (Denzin and Lincoln 1998). This is seen as important to this research because of the symbolic relevance of being black in a predominantly white country, and the differences this may create in the organisations of risk perceptions in Black and White Working Class men. It is assumed that there are multiple realities, as previous experience and belief systems will influence individual perception (Guba and Lincoln 1989).

Constructivism is concerned with how we develop meaning from what we know based on individual learning within a particular social context (Young and Collin 2004; Thomas et al. 2014)

Often used interchangeably with constructivism, social constructionism is the discussion of acquisition of knowledge through the purposeful activity of groups or individuals (Thomas et al. 2014). Early understanding of the sociology of knowledge purports that one individual can experience multiple realities, related to the need of a reality at a certain time and in a social context (Berger and Luckman 1966; Denzin and Lincoln 1998). For example, a person may need to know how to type with accuracy to enable them to work in the reality of their workplace, whereas later they may need to use knowledge of their body's capability to successfully take part in a sporting activity. In this example, a person is actively seeking knowledge in a flexible and dynamic process to be used at the time and place in which that reality is created. This is important to this research in understanding the construction of risk perception and the effect of social context in how this is embodied at a moment in time. In a seminal text on constructionism, Berger and Luckmann (1966) wrote about the social construction of reality through the paradigm of social constructionism. Berger and Luckmann (1966) discuss realities as part of everyday life but acknowledge that experiences are part of these everyday lives and the influence of these experiences should be considered when challenging a person's understanding of reality. In the view of Berger and Luckmann (1966) a person's views of reality are talked about in the present moment to enable a person to maintain everyday knowledge without interference from the past.

Conversely, social constructivism argues that to fully understand reality, consideration of the background against which a person is born provides a different view of the world, in which individual experience and knowledge shape



reality (Patton 2002; Young and Collin 2004; Thomas et al. 2014). In this study constructivism and constructionism are seen to influence the realities created by the men in this work and the way in which they perceive their risk for prostate cancer. For these men, the construction of reality is thought to be based on their individual experiences and the background against which they were born, as well as the moment in time in which they are interviewed and the influence of the researcher on their portrayal of reality. This is believed to be particularly important for the black men<sup>2</sup> who may create their realities based on the social role of the man, which may have been constructed alongside their experiences of migration.

### **3.1.2 Constructivism and social constructionism in the health literature**

In a discussion on the application of a social constructivist paradigm to health research, Labonte and Robertson (1996) argue that understanding what is real for an individual is always socially constructed through lived experience and the social history in which the experience is located. This has added to theoretical thinking in this study by placing perception of risk in the context of the individual construction of the body. In their writings on empowerment through health promotion, Labonte and Robertson (1996) propose that examining reality using constructivism, keeps the data real to the individual experience and not abstracted

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<sup>2</sup> In this research, black men have been separated into two distinct groups of men: African Caribbean and Somali. The reasons for this are given in chapter 4. When the men are discussed as one group the term Black men is used. At all other times the men are presented by their ethnic identity, Somali and African Caribbean.

from original experiences, as is often the case using conventional methods, such as surveys. Their writing demonstrates an early adoption of a constructivist approach, instead of the positivist research approach traditionally used to examine the usefulness of health promotion practices.

Labonte and Robertson (1996) discuss researchers' approaches to examine community-based health-promotion efforts, using a constructivist approach involving members of the community in generating their own health promotion agenda. They conclude that the generation of knowledge through the empowerment of the community is better suited to the acquisition of enduring knowledge for those individuals most in need. Research has suggested that for ethnic minority groups such a community approach to educating about prostate cancer could be the most effective way of ensuring an enduring approach (Fleisher et al. 2016; Santos et al. 2017).

Fisher and O'Conner (2012) used a constructivist paradigm in their study of motherhood and breast cancer. Individuals given a diagnosis of breast cancer soon after childbirth were interviewed about their experiences of living with breast cancer and coping with their role as a mother. Fisher and O'Conner (2012) used the social constructivist approach to gain an understanding of how experiences can change a person's construct of what is real, which is defined and redefined through interaction with others. This interaction with others leads to exploration using a constructivist paradigm and the data analysis is based on the reality created by the women in the months after their breast cancer diagnosis.

Fisher and O'Conner (2012 ) based their findings on the biographical disruption framework of Bury (1982) in which chronic illness is described as an event which disrupts structures of everyday life and the understanding of relationships between families and wider social networks. This approach is based in reconstructions of reality at the moment in time in which they occur and it seems that the findings of Fisher and O'Conner (2012) are considered in the immediate experience of cancer and motherhood, as well considering the impact of biographical disruption on their long-term reality of motherhood.

It appears therefore, difficult to separate the role of constructionism with that of constructivism in this research. These theories are seen as related to each other by the individual understanding of reality being influenced by the moment in time in which the reality is understood and the longer-term effects of the disruption of illness on the reconstruction of reality. It is understood that reality, and in the case of this study the reality of the men's perceptions of prostate cancer risk, is influenced by individual experiences of illness as well as the symbolic representation of illness in society, which influences how a person experiences constructions and reconstructions of the reality of the body that may become unwell.

In the research by Fisher and O'Conner (2012) it appears that the understanding of reality is supported by constructivism and constructionism; reality is seen as a social and individual construct. The approach used in the current study is based on the thinking that the men might perceive their risk for prostate cancer based on their individual experiences of illness, which could influence their views of their

body as potentially at risk for cancer. It is also thought that the men's views of the reality of the unwell body are based on their experiences within a social arena.

Discussions in the social science literature have begun to suggest that constructivism and constructionism are often used interchangeably (Patton 2002; Young and Collins 2004) and that these approaches have been subsumed as undifferentiated under the name constructivism, a product of both these approaches to understand knowledge and reality (Young and Collin 2004). It is this approach that is the theoretical underpinning of this research.

### **3.1.3 Charmaz on constructivism**

Kathy Charmaz is well known for her approach to grounded theory and particularly her use of a constructivist grounded theory (Gibbs 2015). In an interview with Kathy Charmaz discussing her views on constructivism and grounded theory, Gibbs (2015) explores her interpretation of constructivism. This interview formed part of a series of interviews at the British Psychological Society Qualitative Social Psychology Conference of that year, and offers listeners an in-depth account of Charmaz's approach to Constructivist Grounded Theory. During this interview Charmaz, explains that the importance of constructivism in grounded theory is that it places the researcher at the centre of the lives of the participant, particularly as the researcher pays attention to the implicit meaning of the language of the participant (Gibbs 2015).

The approach to constructivist grounded theory used by Charmaz (2014) is influenced by symbolic interactionism, which informs her interpretation of

constructivism by thinking of how a person interprets their reality of the self, as informed by their interpretation of the past. Influential social psychologist George Herbert Mead introduced the concept of the self as arising through social experience and activity, and has been credited with social interactionist thinking (Strauss 1977). Mead raised the theory that in recognising the reality of the self, an individual responds to the behaviour of others around them, just as others' behaviour is influenced by that of the individual (Strauss 1977). As a pragmatist, Mead applied a practical approach to social science and influenced thinking by social scientists on the identity of the self through the action of deducing social processes and correspondence with others (Strauss 1977).

This sociological perspective of social interactionism is influential in the work of Corbin (1988) and Charmaz (2014), and is also a basis for the application of a constructivist grounded theory in this work. The current study is based on the philosophy that a man's perspective of his risk for prostate cancer is influenced by his social experiences and his application of these experiences to health. This thinking has been induced by Mead's views of the self through social interaction and the views of Charmaz (2014) in her approach to the social construction of knowledge.

Research approaches influenced by symbolic interactionism require a process of data collection that remains flexible so that analysis of interviews reflects knowledge generated by the researcher during data analysis (Guba and Lincoln 1989). Charmaz (1995) used this theoretical framework to study the body during chronic illness. She recognises that the body must be understood in terms of the

self, but also through the influence of the social context in which the body exists (Charmaz 1995).

In her approach to the study of the body in chronic illness, Charmaz (1995) used grounded theory methods to collect and analyse her data. Theory was generated during data collection and analysis, which led to further intensive focused interviews. Charmaz (1995) sees acceptance of a chronically unwell body as a process of integrating the new body into a life that accepts the body's limitations and new social appearance. The individuals in her research adapted to a new social and individual context in which the body would be required to function (Charmaz 1995).

Charmaz (2014) argues that it is the flexibility in data collection, as used in her 1995 research of the body in chronic illness, which allows an analysis of the data based on the interpretation of a person's reality. Charmaz (2014) emphasises that the interpretation of reality is based on the implicit meaning of language use and researcher's interpretation of the social life of their participants (Charmaz 2014). This constructivist approach has previously been criticised for leading to radical relativism in which, 'the notion of specific reality is rejected and what is "real" are simply people's construction' (Labonte and Robertson 1996, p. 434). This positive criticism to the approach of reality is refuted by Guba and Lincoln (1989), who argue that reality will be ever evolving in the presence of new information, therefore, measuring a construct using a rigorous tool for each individual, as used to measure the notion of a specific reality, will not reflect the changing nature of constructs in a person's reality.

Guba and Lincoln (1989) recognise that misconstructions can happen when an individual is ill informed, when information is inconsistent or the construct is derived without adequate sophistication to fully appreciate all the assets of the phenomenon in question. Charmaz (2014) agrees that this is a possible weakness in the approach and maintains that the researcher must collect data until they are sure that data collection is saturated, which enables the researcher to be confident they have produced a concept based on their full understanding of the field in which they study (Gibbs 2015). In the current study the use of theoretical sampling, constant comparison of the data and reflexivity have limited the possibility of generating an inadequate construction of reality. This constructivist grounded theory approach is applied where a full consideration of the construct is central element of data analysis (Charmaz 2014).

## **3.2 Constructivist grounded theory**

### **3.2.1 Grounded theory**

Grounded theory was first discussed in the 1960s as a response to pressure in the qualitative research field to create a clear methodology of data collection and analysis, which allowed new theory generation and prevention of theory stagnation (Howard-Payne 2016). Grounded theory has been used to explore realities created by individuals, which are then raised through data analysis to find an underlying pattern presented in these individual realities (Glaser 1992). Early work by Glaser and Strauss (cited in Glaser (2002) developed grounded theory, which took the ontological position of critical realism, in which reality is assumed

to exist but is imperfect because of the flawed human ability to understand a phenomenon being explored (Guba and Lincoln 1994). In other words, reality cannot be viewed as a linear process; realities are generated as theory but aspects of reality may be under-researched or undiscovered because of the ever-changing nature of the human experience.

The position of this study is that reality is an ever- changing concept, influenced by the experiences and social interactions of an individual. It is not felt that a person has a flawed understanding of the phenomenon under examination, as it is that person's understanding that creates reality. In the case of perceptions of prostate cancer risk, the realities of the men in this research may inform their beliefs about their interpretation of risk. Collection and analysis of this data, using a constructivist grounded theory approach, will be a starting point for understanding the way in which men from distinct cultural groups construct their perception of prostate cancer risk.

In order to fully appreciate the grounded theory method employed in this research, it is necessary to have some understanding of the background to the approach. After development of this approach, Glaser and Strauss soon faced a difference of opinion on their position of realism (Howard-Payne 2016). Strauss began to take on a position of pragmatic realism, which places reality in a particular place and time so that multiple realities are possible at the same time (Howard-Payne 2016). Realism, in this context, is understood as a perception held by an individual that is understood in the context of the person's situation (Sosa 1993). This leads to the theory that multiple realities are possible, depending on



the person and the contextual basis of their understanding of reality.

Alternatively, Glaser took the approach of critical realism, in which reality can be understood from the data without consideration for the contextual nature of the data generated (Howard-Payne 2016). The approach of this study follows the thinking of Strauss, that multiple realities are possible and influenced by the everyday experiences of the individual.

### **3.2.2 Constructivist grounded theory**

In 1990 Kathy Charmaz used grounded theory to understand how people with chronic illness live with chronicity as a construction of their experience and the situations in which these experiences arise (Charmaz 1990; Howard-Payne 2016). In this work, she introduced a social constructionist grounded theory, in which she is persuaded by the views of Strauss on the construction of reality. Charmaz believes that multiple realities can be present and that it is incumbent on the researcher to co-construct reality with the participants, paying attention to the time, place and context of data collection (Gibbs 2015).

Constructivist grounded theory uses an approach that leads us to learn how, when and to what extent experience is embedded in networks, situations, and relationships, and during data analysis differences and distinctions between people become visible (Charmaz 2014). The constructivist grounded theory method is about discovery but it is also about flexibility in data collection. This allows the researcher to be central to theory generation by taking account of the

influence of the researcher's preconceptions and experience during data analysis (Charmaz, 2014).

Although Charmaz has taken a new approach to grounded theory, the basic premise remains that analytic power comes from a well-constructed analytic approach, which meets four basic criteria: fit, work, relevance and modifiability (Glaser 1992). Glaser (1992) believes that analytic power comes from constant comparison during analysis of the data, which later leads to theoretical sampling to test theories derived from the data. The data are further analysed to find fit with the realities of the research participants (Charmaz 2014). The constructionist influence on grounded theory came when the influence of the researcher and their interaction with the data was made more central to the resulting theory generation (Charmaz 2014). Charmaz (1990) believes the researcher has an interaction with the data, which impacts on the resulting discovery of the themes, and this may be based on the researcher's own experiences and interests that shape the data collected and the themes generated.

For the current study, it is important to recognise the researcher's area of expertise (prostate cancer), and how a clinical background in this area might influence questioning during interviews. An example of this is the misconceptions many men had about the symptoms of prostate cancer, which are explored further by the researcher with knowledge that these were, in fact, misconceptions. In this research, I have asked the men "*What are you basing that knowledge on?*", because of my interest in how they are articulating incorrect ideas about prostate cancer symptoms. I have also been influenced by men I have seen in my clinical practice

talking about their interactions with other men, and have phrased questions such as *“Some men talk to each other about prostate cancer, if this something you would do?”*, based on my knowledge of how men in the clinical environment talked to me about the nature of their talk to friends. The possibility of using knowledge from clinical experience to guide research questions, such as the example given above, is acceptable if the influence of this knowledge on data collection does not affect the outcome being attended to so that theoretical analysis is built on what is within the data Charmaz (1990).

However, Glaser (1992) cautions that this type of researcher influence on data collection and analysis could generate bias. Charmaz (1990) and Guba and Lincoln (1994) argue that transparency in the influence of the researcher at the outset reduces bias and creates an opportunity for developing lines of enquiry, which may have otherwise gone unnoticed. Glaser (1992) goes on to criticise Charmaz for not using careful theoretical sampling or the constant comparison method of data analysis to find latent patterns and core categories, in order to find grounded themes (Glaser 1992). Glaser (2002) prefers the constant comparison of incidents, as they appear in the data, and then comparison of incident with category as a method of coding data. He believes this gives the data analytic power to find the true nature of theories emerging from data analysis (Glaser 2002).

Glaser (2002) also criticises the approach of constructivist grounded theory by writing that analysis is the creation of a story without applying the rigour of the grounded theory method. Charmaz (2014) rejects these criticisms; she believes that the researcher is a co-constructer of meaning in the data analysis process, and

that data are reconstructions of experiences and therefore should not be viewed as a version of realities. Charmaz maintains that realities are individual; researchers cannot recreate accurate representations of these realities, rather a construction of them (Charmaz 2014). By accepting that data are a reconstruction, Charmaz (2014) asserts that the presence of the researcher needs to be transparent in the data analysis process through reflective memo writing. For Charmaz (2014) memos capture the researcher's thoughts and connections that are being made during the data collection and analysis process. Memos bring to the surface the researcher's own thinking, as a reference in relation to the outcome of data analysis. In this study, this has been seen as an important step in data analysis by providing reassurance that the researcher is paying attention to their preconceptions and development of thinking throughout the research process.

In criticising the approach of Charmaz and the role of the researcher, Glaser (2002) does not discuss the important fact that many users of the grounded theory method have been practitioners in the field they are studying, such as nursing, where grounded theory has had some popularity in the past. Glaser (2002) writes that most researchers he has worked with, 'take great pains not to intrude their views on the data' (Glaser 2002, p4), but when a researcher is conducting a study of their clinical speciality this objectivity becomes more difficult. A constructivist approach places the researcher in a better place to allow theories to emerge from the realities of the participants and researcher alike (Charmaz 2014). This has been true in the present study; the adoption of Charmaz's approach to this study limited the risk of the researcher of not attending to her clinical discussions about

prostate cancer, and understanding the influence these may have on representing the voice of the men in this research.

### **3.2.1 Application of constructivist grounded theory**

A constructivist grounded theory approach has been used in research by (Holtslander and Duggleby 2009) in which they explored the experiences of hope in older women caring for a spouse with terminal cancer. A constructivist approach was chosen because of the paucity of research in this area. This led the authors to believe a theoretical framework could not be applied prior to data collection, rather the data would articulate the theory (Holtslander and Duggleby 2009). Multiple interviews were conducted with 13 women over a 12-month period, with data also being collected from participant diaries documenting hope.

Using a constructivist grounded theory approach, data were analysed immediately after each interview to allow for theoretical sampling and analysis (Holtslander and Duggleby 2009). Theoretical coding was applied to the data to specify the relationship between categories and find an emerging theory of a caregiver's experience of hope (Holtslander and Duggleby 2009). Through this process of data analysis Holtslander and Duggleby (2009) generated the theory that bereaved women go through a social process of finding new hope. The researchers believe their grounded theory of a trajectory of hope for bereaved women could contribute to programmes of support and interventions of care.

The research of Holtslander and Duggleby (2009) mirrors the analytic strategy used in the current research, particularly because of the paucity of literature about differences in men's perceptions of risk for prostate cancer between cultural groups. A departure to the study by Holtslander and Duggleby (2009) is that data collection techniques have emerged as the data have been analysed and theoretical sampling was developed from purposive sampling. Holtslander and Duggleby (2009) followed a structure for data collection, using multiple interviews and diary entries, which did not appear to be reactive to the data and perhaps not allowing for flexibility in data collection and analysis. The methodology of the current study allowed for flexibility in the methods of data collection, to be reactive to theory generation during data analysis.

Other reasons for interpreting their research findings with caution include the homogenous sample used (all women were recruited to the research from the same palliative care centre), perhaps limiting application of their work.

Holtslander and Duggleby (2009) understand that their findings provide a starting point to explain the experience of bereavement in caregivers. The careful process of data analysis, leading to theoretical sampling, have added depth to their work and additional research with a more heterogeneous sample could provide a useful insight into supporting bereaved caregivers.

### **3.3 The philosophical approach of this research study**

The methodology used in this research is based on constructivism. Constructivism has been used to gain an insight into prostate cancer risk perception in distinct

cultural groups, and how their interpretation of risk differs with external influences and individual life experience. The theoretical underpinnings draw on social constructionism and constructivism to reflect the individual construct of knowledge and the role that shared experiences have on the construct of knowledge, based on the experiences within each cultural group. The ontological approach of this research study is that individuals use knowledge to construct beliefs about the world and that this knowledge is generated from individual experience, but is also reinforced by cultural experiences. Knowledge is not a concept that is measurable without understanding how that knowledge is acquired and then interpreted by individuals to influence action. Therefore, this research is based on the assumption that individuals acquire knowledge of cancer and risk through their individual experience, but this cannot be separated from the experiences of reality based on their cultural and social background.

In this study, data have been collected and analysed using an inductive research process to generate theory on how health beliefs and behaviour influence perceptions for prostate cancer risk, and how this differs between distinct cultural groups. The methodological approach informing this research is a constructivist grounded theory.

## **4. Research design and methods**

### **4.1 Aims, objectives and purpose of the research**

The aim of this research is to understand differences in perceptions of prostate cancer risk perceptions between African men, African Caribbean men and White Working Class men living in South Wales.

The objectives of this research are to:

- Identify knowledge and beliefs about prostate cancer risk in the distinct social groups,
- Identify what barriers and drivers exist in accessing healthcare in the distinct social groups,
- Identify how barriers, drivers and knowledge of risk differ in the distinct social groups.

The purpose of this research is to understand if risks for prostate cancer are differently perceived between distinct social groups. This will add to current knowledge on accessing social groups with a distinct cultural language, and inform third sector organisations, with a focus on cancer education and prevention, of how to tailor education for men at the most risk from prostate cancer.

### **4.2 Using constructivist grounded theory**

Constructivist grounded theory is applied to this research using the approach of Charmaz (2014). The research has been conducted with the researcher at the



centre of the data collection process, taking account of the relationships of the researcher with the participants. This relationship has been documented throughout the research in the form of field notes, which have been used in the findings chapters to help create transparency in the experiences of the researcher during data collection, and the influence of these experiences on the process of data analysis.

In keeping with the constructivist paradigm used by Charmaz (1995, 2014), the approach to this research was to study how the participants constructed their views of risk for prostate cancer, in an individual and social context, and this has involved extensive fieldwork through engagement activities (see section 4.3.6). It is acknowledged that using a constructivist grounded theory approach will generate theory based on the interpretation of reality by the researcher and does not stand outside of this.

#### **4.2.1 Theoretical sensitivity**

Glaser (2002) discusses theoretical sensitivity in grounded theory by using a rigorous approach to data analysis, and particularly the important step of constant comparison of the data. Glaser (2002) believes that this procedure reduces bias from interpretation of the researcher, to reveal a true picture of the reality experienced by the participants. Charmaz (2014) rejects this view, by maintaining that grounded theory reflects the experiences of the researcher and the researched, and acknowledgment of this renders the findings sensitive to theory generation.

Using a constructivist grounded theory means theorising during data analysis and then stopping analysis to consider what needs to be built on using theoretical sampling (Charmaz 2014). Using this approach, theoretical sensitivity has been maintained in this research by collecting additional data using focus groups, and by remaining flexible and responsive to data collection and analysis. Interview schedules were amended during the process of data collection to enable emerging theory to be explored in more depth.

#### **4.2.2 Theoretical sampling and saturation**

Due to the explorative nature and uncertainty of the area to be investigated, sample size would be dependent on saturation of the interview and focus group data. Saturation is appropriate when theories are to be derived from the data (emergent theory) rather than tested against the data using an established research hypothesis (Charmaz 2014). This research would be investigating beliefs about prostate cancer risk in under-researched communities, and the unknown nature of the beliefs and behaviours of these distinct cultural groups. By applying data saturation using a grounded theory approach, the findings would fit with the views of the participants by employing flexibility and responsiveness to the language of the participants (Cutcliffe 2005).

Charmaz (2014) believes that saturation is reached after constant comparison of the data, and if further theoretical sampling does not produce any new properties in emergence of theory then data is saturated. Charmaz (2014) acknowledges that data are collected in a particular time and place, and that the properties of theories may change over time.

Theoretical sampling was applied to this research during and after analysis of participant interviews. During initial data collection, the study area chosen for access to the African and African Caribbean men was quickly recognised to have two distinct cultural groups, African Caribbean men and Somali men (decisions on areas for data collection is discussed in section 4.4). The prevalence of prostate cancer in men of Somali origin in the UK is not documented in the literature, and it is thought that this is due to recruitment to research investigating prostate cancer in black men using the ethnic group Black British (Grulich et al. 1992; Ben-Shlomo et al. 2007).

This is evident in the recent research by Ben-Shlomo et al. (2007), who recruited men based on their ethnicity stated in the 2001 UK census; White, Black, Black Caribbean and Black African. The risk for prostate cancer in all men identifying as black was significantly higher than all white men, in their research. The actual country of origin was not differentiated, and this is the same as research in United States, where the interest is in men who identify as African American (Corban et al. 2017). Therefore, Somali men were included in this research because of the large number of migrants from Somalia in the study area identifying as Black British.

Personal communication with Professor Ros Eeles at the Institute of Cancer Research in June 2017 (Eeles 2017) confirmed that the propensity of risk for prostate cancer in Somali men is unknown from her genetic studies, and that these men should be considered as Black British for the purpose of work on prostate cancer risk. It was therefore felt appropriate that men of Somali origin were included in this research.

It became apparent, during initial contact with the study area, that black men of Somali origin and black men of African Caribbean origin do not live within the same cultural boundaries, and therefore these men were approached as two distinct cultural groups. Developing the theory that these men could have different perceptions of prostate cancer risk, dependant on their perceived cultural influences, allowed the research to develop from a study of two distinct groups, Black and White Working Class men, to three groups: African Caribbean men, Somali men and White Working Class men. This employed the use of theoretical sampling at an early stage of this research.

After initial analysis of the interview data, it was decided that theory generation would be greatly enhanced with the addition of focus group data. It was hoped this would provide a better understanding of how the men talked to each other, to develop the concept of the social construction of prostate cancer risk perception. The sampling for the focus groups therefore involved recruitment of men from the study areas who had not been involved in the interview process, but met the same eligibility criteria (see section 4.4.7).

#### **4.2.3 Purposeful sampling in constructivist grounded theory**

Initial recruitment to the research involved purposeful sampling, to address the central issue to this research: differences in perception of prostate cancer risk between distinct cultural groups. Purposeful sampling was used by Charmaz (Charmaz 1994; 2007) in her exploration of the experiences of chronically ill men.

Men were recruited from an on-going study looking at the situations and experiences of people with chronic illness; 27 men who met the inclusion criteria for the research, were recruited by Charmaz (1994). This exercise of recruitment took Charmaz directly to the men who addressed the central question of her research, what is it like to be a man living with chronic illness (Charmaz 1994).

Holtlander and Duggleby (2009) employed purposeful sampling to study the experiences of bereaved women. Women recruited to the research had recently been widowed and had cared for a spouse in the last year. The use of purposeful sampling narrowed the focus of data collection and led to follow-up interviews to explore categories emerging from the data. The process of theoretical sampling is seen as an important step in refining emerging theory, and this is also the case for Charmaz (1994), where follow-up interviews with the chronically unwell men in her research helped to integrate major themes for final analysis. These examples have informed methods used in this study by providing depth to research findings, which is thought to be valuable in understanding the complexity of differences between the distinct groups of men in this research.

### **4.3 Reflexivity**

Reflexivity is considered as critical practice for researchers undertaking studies of social realism (Adkins 2002). For qualitative researchers, reflexivity is seen as a source of new knowledge; researchers allow themselves to consider discrepancies found during data collection, and question what these mean and what the implications for the research findings could be (Enosh and Ben-Ari 2016). This is

seen as particularly important in nursing research when clinical practitioners may be researching their own area of clinical speciality, such as in this research. The researcher should demonstrate their understanding of their clinical preconceptions on their work through an interrogation their own feelings and beliefs (Arber 2006; Jack 2008).

Charmaz (2014) believes that reflexivity helps the researcher manage preconceptions by finding ways to bring the researcher into the research process. By maintaining a reflexive stance, the researcher provides information on how the researcher relates to the research process and participants, and this is often best achieved by keeping a diary during the research process (Charmaz 2014). For this research, a diary has been kept since 28<sup>th</sup> March 2013. The diary includes extracts about time spent in the research areas, considering how to recruit participants for the study, and thoughts about how the research is influenced by preconceptions (see appendix II for extracts from the PhD diary).

#### **4.4 Access and recruitment**

The study areas used for this research were based on the following criteria:

- Within the catchment area for the cancer centre at which poor representation of black men has been identified in prostate cancer clinics.
- Identified as an area of deprivation according to Welsh Index of Deprivation.

These areas are thought to best represent locations populated by large numbers of the black and minority ethnic community, as identified in chapter 2.

- Identified as having high populations of African, African Caribbean and White Working Class men in 2011 UK Census.

Because of the nature of population distribution in the wider study area, men were not recruited from areas that had a high percentage of Asian men; these men are known to have a lower risk for prostate cancer than any other men (Adkins 2002).

The white men were recruited from areas largely populated with the white working class population, for the same reasons as given above. There was reduced accessibility to white men in the areas largely populated by the black and minority ethnic communities, therefore the white men were accessed from areas of deprivation known to be high in the white British population.

The researcher made personal contact with key stakeholders after spending time visiting community events, which helped with access to the research areas. These included, summer fetes, community open days and education events. For this research stakeholders are defined as people with an involvement in the communities from which the participants would be recruited, and therefore could be affected by the outcome of the research or be supportive of the research due to an interest in health. In this research the key stakeholders were felt to be people who were trusted by the participants as sources of knowledge and advocates for their involvement in research.

To access the Somali men, the researcher went to a male only restaurant/community centre in the Somali area. The researcher was careful to

check the response of the men in the restaurant, who were open to the presence of a female with a nursing background. The Somali men appeared keen to find out about their health risks and the relationship with these men became reciprocal. After collection of the data, the researcher became involved in organising an education event in this area with a local cancer charity (see appendix III for description of the education event).

#### **4.4.1 Recruitment from ethnic minority groups**

Research exploring health in BME individuals has often termed these people as:

Hard to access

Difficult to reach

Underserved

Easy to ignore/overlook

Vulnerable

Marginalised

(Odedina et al. 2011);(Shen 2009; Vrinten et al. 2016).

The use of the terms listed above, for recruiting for research with BME individuals, has become contentious amongst academics. Indeed, during the design stage for this research an email was sent to academics taking part in a group email regarding BME health, to ask for advice about access from hard-to-reach groups (Minority-ethnic-health@jiscmail.ac.uk 2014). A lengthy email exchange followed, concerning the use of such terms, although the use of a correct term was not decided on. The opinion, after recruitment for this research, is that researchers need to make themselves more accessible to the communities so that research can be viewed as



beneficial to the community. It is perhaps the researcher who is difficult to access or hard to reach.

#### 4.4.2 Use of key stakeholders

Research has used varying techniques to access these assumed difficult-to-access groups. These include; use of key stakeholders (Kessing 2013), use of media in socially relevant places, such as cafes and community centres (Kennan et al. 2012), training and using local community workers to recruit to research (Spring et al. 2003; Higginbottom et al. 2015).

Participants in this research were approached in their normal environment, after three key stakeholders had been identified. Each stakeholder was paid £50 for their help with recruitment to this research, which was approved by the University Ethics Committee and paid from research funds.

For the Somali men, a community leader was identified as a key stakeholder. This man was the owner of the Somali male-only restaurant, who was keen for the men he knew to become involved in the research. He expected the men to be educated about prostate cancer in return for their time. The use of this key stakeholder was essential in accessing the Somali men, due to language and literacy difficulties amongst the men, and he was very effective at recruiting to the interviews and focus groups.

The key stakeholder for the African Caribbean men was a caretaker at the local community centre. He was well known to the community and was happy to

promote the research. He was also able to negotiate use of rooms in the community centre to carry out interviews and focus groups, with these men.

For the White Working Class men, the key stakeholder was female. She worked as a volunteer for an organisation that promotes activities for the over 50s (50+ club) living in the research area. This area is described in more detail in appendix III. The organisation was contacted by the researcher as a possible route to recruitment for this research, the key stakeholder responded to the request and found the interview participants and the men for the focus group.

The use of a female as a key stakeholder, rather than a male, did not appear to make a difference to the number of men recruited or the methods used by the stakeholder to promote the research. All stakeholders used word of mouth to gain interest in the study. It is acknowledged that a weakness to this approach is that men were recruited who may already be motivated to learn about their health, although the 50+ Club is intended as a social event for individuals to reduce the risk of loneliness and isolation and not simply for access to health information (Age Connects Cardiff and the Vale 2017).

#### *4.4.2.1 Language barrier*

Communication with the Somali key stakeholder was difficult when compared to the African Caribbean man and the white female stakeholder. The Somali stakeholder, as identified above, spoke enough English to communicate the purpose of the research, although his first language was Somali. He appeared to understand that

the research would involve interviews with men, and this was evidenced with his help in recruiting men to the study. However, use of lay English and therefore the true nature of what would be involved in the research was more difficult. To help with this, and to ensure the safety of the stakeholder and participants, a translator from a Welsh charity with a focus on support services for diverse populations, was asked to help with translation for recruitment, and during the interviews and focus groups. This Welsh charity was active in the area from which the Somali men were recruited and were approached and asked if they worked with translators. The charity was able to make a recommendation and that individual was felt to be suitable to with this research.

The translator was of Somali origin and their work for the charity involved translation of written material giving health advice for diverse populations. The men being interviewed lived in a different area and attended a different mosque to the translator, so they did not know them. It was felt that this was important in allowing the men to feel less inhibited when talking about health and the prostate.

In order to prepare the translator for participating in the interviews and focus groups, the purpose of the research was explained as a study of men's knowledge of prostate cancer and men's health. The interpreter had experience of translating material about health and although clear about cancer they required further information about the prostate, which he was given using prostate cancer literature from awareness campaigns. The Somali version of this literature was also provided to increase clarity. The interpreter was not shown the interview schedule, as they

were not being briefed as a co-producer in the research process, rather as a translator of Somali speech to allow depth to data from the interviews and focus groups.

The interpreter was advised on the format of the interviews and the focus groups. We agreed that the researcher would lead these, and because there would be some discussion in English the interpreter agreed that they would translate only when it became clear clarification was required through translation. The participants themselves led on this process by asking for clarity from the interpreter. This became clear when the men looked at the translator after a question had been asked.

#### **4.4.3 Use of media for recruitment**

The key stakeholders were asked to review flyers drafted for distribution in the study areas (see appendix IV). The Somali and African Caribbean stakeholders were asked if they objected to the use of the word 'black' to describe their ethnicity. Neither man objected and said that is how they would describe themselves. These men wanted the statistics for prostate cancer risk evident on the flyer, as they felt this would be likely to make men respond. The Somali stakeholder was happy that the flyer was written in English. He was unable to read English or Somali and once he fully understood the purpose of the research, with the use of the translator, he was happy to communicate this with the men in his community. After spending time with the Somali men, it became apparent that few men over the age of 40 years, and living in the study area, were able to read Somali. It is thought this is due to the

timing of their migration (during the civil war in the 1980s) and the disruption this had on their education. For this reason, recruitment of the Somali men was most effective when visits were made to the study areas and information given in person. Contact was also maintained with the key stakeholder using the research mobile phone.

The female key stakeholder, for the White Working Class men, was asked to suggest a man who could discuss the content and layout of the flyer. This man was a regular attender at the 50+ club and lived in one of the study areas. He wanted the image of the white man to be placed in-line with the black men. The images used on the research flyer were purchased royalty free with research money from Shutterstock, an organisation that provides royalty free images for use in the public domain (Shutterstock 2013).

#### **4.4.4 Contacting the researcher**

Contact information for the researcher was provided to the stakeholders and was given on recruitment media. The telephone number provided was used exclusively for the research. A pay-as-you-go mobile phone was purchased using research money, to allow participants and stakeholders to contact the researcher; no personal contact information was used.

#### **4.4.5 Recruitment to focus groups**

The decision to include focus groups in this research was made after completion of interview data collection. Once the interviews had been transcribed and these data

analysed for theory generation, it was decided that more information was required about how the men spoke to each other and how this informed their perception of risk. This will be explored further in section 4.5.2.

At this point the relationships with the key stakeholders was very well established and these relationships were effective in recruiting men to the three focus groups. The key stakeholders were asked to raise the possibility of taking part in a focus group at their next convenient community or group activity, such as at Dominoes or 50+ Club group meeting. In conversation with the key stakeholders the researcher arranged a date they would attend a future community or group activity to provide further information about the focus groups and arrange a time and date for the focus group. Due to the apparent unstructured nature of the lives of the Somali and African Caribbean men there were concerns that the process of arranging a group of men to be together at a given time would be difficult. This was not actually the case and the men seemed keen to take part, possibly due to the reciprocal nature of the relationships established with the communities at this time.

The White men were recruited via the 50+ Club, the African Caribbean men via a local dominoes club (of which the key stakeholder was a member) and the Somali men through the stakeholder at the male-only Somali restaurant/community centre. The stakeholder for the African and Caribbean men felt that for the men to meet at the same time, to discuss a health-related matter, they would require an incentive. He recommended using Love2shop vouchers and each man was given a voucher worth £10. This incentive was included in the ethics application to the university ethics committee for the use of focus groups.

The stakeholders for the Somali men and White Working Class men did not feel that there would be a need to incentivise the men and these men were provided with refreshments during the focus group, but were otherwise not reimbursed for their time.

#### **4.4.6 Community engagement**

To collect field notes and maintain reflexivity in this research, a substantial amount of time was spent engaging with the local communities. This work included organising a running event with one of the research areas, which included spending time working with a committee and gaining an insight into the social organisation of the men. Other field activities involved attending activities at community centres, such as health fairs with the black and white communities, taking part in community radio health promotion activities and joining domino clubs with the African Caribbean men. Approximately 237 hours were spent on community engagement activities, many of these at weekends and evenings when the communities were most active. It is considered that these community engagement activities assisted recruitment to this research by allowing the researcher to earn the trust of potential research participants. By showing an interest in the lives of the participant and providing tangible support at health-related events seemed to create a reciprocal relationship, which became important in building a rapport of honesty and openness.

Notes were made on time spent as part of this committee and, using reflexivity, these notes proved useful in informing the data analysis about the social

construction of health knowledge (see appendix V for notes made during this time spent with the community). The use of community engagement as part of this research has also provided the researcher with the opportunity to teach at Cardiff University Graduate College on the importance of engagement when recruiting to research of this kind.

#### **4.4.7 Sample characteristics**

Full inclusion criteria for this research can be seen in table 4 on page 103.

Ethnic group and geographical location were the main identifiers of the men in this research. Sociologists argue that ethnicity is a social phenomenon used to define the basis of diversity within and between social categories, which share cultural and linguistic characteristics (Denzin and Lincoln 1998; Alexander et al. 2006). For this research, this definition suits the purpose of identifying men with the characteristics relevant to the enquiry, and will be the basis of discussions on ethnicity.

As in previous research on cancer and ethnicity (Grulich et al. 1992; Ward et al. 2004; Odedina et al. 2009; Smith 2012)

self-reported ethnic origin was used to screen for participants. Participants were asked to categorise themselves to an ethnic group to ensure consistency in responses. Ethnic group category was the same as that used by the Office for National Statistics in the 2011 census and participants selected their own ethnic category. Anyone falling outside the National Statistics categories was not eligible for the research.



Men were asked how long they had been living in the study areas. Men who had been living in the areas for less than five years were not eligible for the research. It was felt that for reasons of acculturation, as discussed in section 2.2.4.1, men who were recent migrants to the study areas would have a different perception of health risks, based on their migrant status and conditions of migration. Currently, someone seeking British citizenship needs to have lived in the UK for at least five years (Gov.UK 2017) and this was the case at the time of recruitment to this research.

The same criterion was applied to the White men to minimise possible disruption to development of a theory based on the health of men permanently resident within the population.

Eligibility criteria for men of African and African Caribbean origin	Eligibility criteria for White Working Class men
<ol style="list-style-type: none"> <li>1. No previous diagnosis of cancer</li> <li>2. Adult aged over 40 years</li> <li>3. Self-reported ethnic origin Black Caribbean, Black African, Black British</li> <li>4. Currently resident in area of low socioeconomic status, according to Welsh Index of Multiple Deprivation</li> <li>5. Resident in study area for more that five years</li> <li>6. Has permanent residency status in the United Kingdom</li> <li>7. Able and willing to provide informed consent</li> </ol>	<ol style="list-style-type: none"> <li>1. No previous diagnosis of cancer</li> <li>2. Adult aged over 40 years</li> <li>3. Self-reported ethnic origin Welsh, English, Scottish, Irish</li> <li>4. Currently resident in area of low socioeconomic status, according to Welsh Index of Multiple Deprivation</li> <li>5. Resident in study area for more that five years</li> <li>6. Has permanent residency status in the United Kingdom</li> <li>7. Able and willing to provide informed consent</li> </ol>

**Table 4 Participant inclusion criteria**

#### 4.4.8 Sample size

As discussed in section 4.2.2, data were collected until data saturation had been reached. Data saturation was achieved when the process of constant comparison and theoretical sampling did not produce any new properties in emergence of theory (Charmaz 2014).

There were a total of 17 men interviewed for this research.

The total numbers of men from each ethnic group are as follows:

Interviews:

- White men: 8
- Somali men: 3
- African Caribbean men: 6

It is recognised that there is a lower number of Somali men, compared to men in the other groups. This was attributable to reduced communication with the key stakeholder due to reduced English language comprehension. This made it difficult to negotiate places for the interviews and direct communication with the research participants.

A total of 18 men took part in the subsequent focus groups. The distribution of men was as follows:

- White men: 7
- Somali men: 7
- African Caribbean men: 4

To further characterise the sample, data were collected on educational level. It was felt that, in today's economic climate it would be inaccurate to assume that everyone living in an area recognised as deprived would be of a low academic standard. Education data were collected using the 2011 census questions (see appendix VI). Table 5 summarises the educational level of the participants. It is interesting to note that it appears White Working Class men are more likely to benefit from education, compared to the African Caribbean and Somali men. For the Somali men, this could be accounted for because of their age at migration; these men migrated as teenagers during the civil war and may have been given less opportunity to engage in a formal education in the UK. These data were not collected from the men taking part in the focus groups; consent to collect educational data from these men was not given.

Education level	Overall	White men	A/C men	Somali men
4 o'levels/CSE/GCSEs (any grades>, entry level	3	3		
NVQ Level 1, Foundation GNVQ, Basis Skills	2	1	1	
5 + O level (passes) / CSE (grade 1)/ GCSEs Grade A*-C), School Certificate, 1 A Level / 2-3 AS levels / VCEs, Welsh Baccalaureate Intermediate Diploma	1	1		
NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First / General Diploma / RSA Diploma	1		1	
Apprenticeship	3	2	1	
2 + A Levels / VCWS, 4+ AS Levels, Higher School Certificate, Welsh Baccalaureate Advances Diploma	1	1		
NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma	1	1		
Degree (for example BA, BSc) Higher degree (for example MA, PhD, PGCE	3	2	2	
NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level	1	1		
Professional qualifications (for example teaching, nursing, accountancy)	3	3		
Other vocational / work related qualifications	11	9	2	
Foreign qualifications				
No qualifications	4	1		3

**Table 5: Qualifications held by men in this research. Some men have more than one qualification**

## 4.5 Data collection tools

Data were collected using semi-structured interviews and focus groups. Initially, it was thought that all data would be collected using interviews to explore perceptions of risk for prostate cancer. During analysis of the interview data, theory relating to the differences of the body in society and the influence of this on perceptions of prostate cancer risk began to develop. It was decided that in order to generate theory with depth, an understanding of how men in the research areas spoke to each other about health could provide a more thorough understanding. For this reason, men were recruited to focus groups and these were conducted after the interviews to add to theory generation on the importance of understanding the body in the social context.

### 4.5.1 Using interviews

Using interviews in qualitative research is a common method of data collection, and grounded theorists rely on interviews to study people's in-depth experiences and feelings about the phenomenon under study (Charmaz 2014). The influence of symbolic interactionism on constructivist grounded theory also supports the use of interviews; symbolic interactionism depends on understanding human actions in the natural world, such that individual knowledge and interactions can be explained as a way of understanding and guiding beliefs and social action (Denzin and Lincoln 1998; Alexander et al. 2006). This is particularly relevant to this research because the intention is to generate theory of differences in men's perceptions of prostate cancer risk, using the participant's descriptions of their knowledge and experiences.

The research interview is an interaction between the researcher and participant, during which the researcher listens to and interprets participant answers to satisfy theoretical curiosity (Mason 2002) and therefore, knowledge is constructed during this interaction (Kvale 2010). Interviews can be used to seek distinct types of knowledge or experience, and for this reason interviews are difficult to place into an ideal form (Kvale 2010)(Gerson and Horowitz 2002). The skill of a good interviewer in gathering rich data, by clarifying the participants' answers whilst remaining open, is being able to steer the participant to points of interests. This is crucial to the quality of the research interview (Kvale 2010).

In this research, the first interview was short and did not provide depth of knowledge. The inexperience of the researcher meant the answers of the interviewee were not probed for depth. On listening back to the interview, this became apparent; the interview style was amended to ask questions such as, "can you tell me more about that?", or "you said ... can you tell me what you mean by that?". This allowed the generation of rich data by paying attention to the language of the participant and asking them to reflect on this to assist in the construction of a grounded theory (Charmaz 2014). This is particularly important in constructivist grounded theory; the researcher uses the interview to be inquisitive about the participant's experiences and beliefs, which can mean probing for a response through careful questioning (Charmaz 2014).

#### *4.5.1.1 Semi-structured interviews*

Semi-structured interviews are used when a researcher wants to gather rich data, without the constraints of a specific set of questions (Kvale 2010). Specific questions, used without flexibility, lack sensitivity in understanding how the participant is interpreting and understanding the context of the phenomenon under investigation (Mason 2002). However, interviews need a degree of structure to enable the researcher to follow leads in responses and decrease the influence of preconceived ideas (Charmaz 2014). Mason (2002), argues that it is not possible for an interview to be completely unstructured, so that the researcher can freely associate questioning and response, because the assumptions of the interviewer and interviewee will force a framework on the interview process. It is also the case that interviewing with free association is particularly difficult to a novice researcher, who may not be equipped with the skills to tap into elements of the interview that may be unconscious to the respondent but important to the researcher (Charmaz 2014).

It is for these reasons that the semi-structured interview approach was used for this research. This involved building a framework for the interviews (see appendix VII for the interview schedule). The framework was developed from the literature reviewed in order to structure the protocol for this research, and to gain ethical approval for the study.

The approach to grounded theory work, including constructivist grounded theory, is that the researcher allows themselves to be free from preconceptions at the start of the research process, to allow themselves to generate a-priori reason-based theory (Gerson and Horowitz 2002). Chapter 3 has debated the matter of the researcher being free from preconceptions, and in this study, it is acknowledged that preconceptions are inevitable, particularly those studying an area within their clinical experience. For this reason, attention has been paid to the reflexivity of the researcher after the initial review of the literature, which is thought to be inevitable in modern uses of grounded theory (Charmaz 2014; Howard-Payne 2016), due to competition for research funding (Howard-Payne 2016). The researcher should be mindful not to let this literature review stifle their creativity, rather act as a guide for interviews and writing of a grounded theory (Charmaz 2014).

#### **4.5.2 Focus groups**

During collection and analysis of interview data, and on-going collection of field notes, it started to become clear that the men were talking about prostate cancer knowledge and perception of risk in an everyday context. To explore further the emerging category of the 'everyday' view of how and why men make decisions about their health and accessing health care, it was decided that data were needed on how the men spoke to each other about health, illness and prostate cancer.

Focus groups have previously been used in qualitative studies examining men's perceptions of prostate cancer risk (Odedina et al. 2004). Odedina et al. (2004) used a focus group method to gain insight into the preventative behaviour of African-American men in relation to prostate cancer, talking to men without a

diagnosis of prostate cancer. Ten focus groups were used to explore the effect of education programmes on men's screening behaviour. The purpose of focus groups in Odedina's research was to gain breadth of understanding using a large number of participants, a technique often used with interviews in qualitative research to ensure depth and breadth of knowledge (Guest et al. 2017). A respected authority on the use of focus groups (Krueger 1995) advocates focus groups in qualitative research because of the insight they offer on the human experience. To study human experience, Kitzinger and Barbour (1999) discuss the importance of group activity to develop rapport between the researcher and the participants, and this technique was used by Norton et al. (2013; 2017) in their grounded theory approach to health behaviour in adolescents.

For the purpose of this research the focus groups were used to explore an emerging category on the social construction of everyday health knowledge, and so the interest was in how the men talked to each other about their health. Research by Kitzinger (1990) used focus group methodology to help understand audience knowledge of AIDS media campaigns, which she believed should be understood in terms of how interactions in a social environment mediate this knowledge.

To enable the collection of data based on group conversation, Kitzinger (1990) used games as an enabler for group conversation. The 'news game', 'card game' and 'advert game' were used to generate discussion. The participants were asked to use cards to create a news report, reach a consensus about how to rank statements in order of risk and finally to create a slogan for an advertisement (Kitzinger 1990). Kitzinger (1990) warns of potential resistance to this type of approach, by those



people who felt tested against each other, but Kitzinger also believes her research was able to explore sources of knowledge and occurrences of misinformation through the group talk.

#### *4.5.2.1 Using focus groups to explore sensitive topics*

In relation to using focus groups to discuss sensitive topics, such as prostate cancer, Kitzinger and Farquhar (1999) discuss sensitive topics and everyday conversation, and suggest that these topics are dealt with at several levels in group conversation. They believe that groups explore breaking taboos, in which case sensitive topics are accepted as topics of conversation. In their research exploring sex and sexual identity, Kitzinger and Barbour (1999) found that the use of focus groups generated 'sensitive moments', which could be viewed as awkward and that a focus group setting generated discussion that may have been passed over in everyday talk.

In more recent research, Rubin (2004) explored men's attitude to Viagra in a social context by conducting two focus groups with men aged 45-65 years. Rubin (2004) used a semi-structured questionnaire to generate discussion amongst the men, with the intention of replicating, as much as possible, casual conversation the men might have about Viagra in a social setting. Rubin (2004) used a phenomenological analysis of the data and found that the men didn't talk about Viagra in a meaningful way, rather about group views of sexual norms, which were articulated through a pattern of conversation between the men. On a topic that could be regarded as sensitive (impotence), Rubin (2004) found that conversation was easy between the men, but tempered with a lack of depth because of a desire to maintain a macho

image. Rubin (2004) does not acknowledge 'sensitive moments' in the data analysis and this may be because of the topic under discussion, and the relationship of impotence to the image of masculinity.

#### *4.5.2.2 Use of focus groups to analyse talk*

The focus groups in the current study have been used because of an interest in the way men talk to each other about a topic that is considered sensitive because of the relationship of prostate cancer to intimate examinations. This interest was generated from interview data, and the focus groups were structured around this as additional theorising from the interviews. The focus group data collection followed the structure of Kitzinger (1990) by using three 'card games' with the men (see appendix VIII for the card games). The men had four possible responses to questions about prostate cancer and were asked to place in order their consensus on the priority of the responses (ranging from most likely to least likely). One man was asked to read the tasks and possible answers allowed, and this person changed for each question to ensure those that who appeared quiet and less engaged with the group became involved. The card games were translated to Somali for the Somali men to allow depth of talk between the participants. The participants used to read the cards allowed in the Somali focus group was restricted to men who were able to read.

The participants were also shown an image from a prostate cancer campaign based in America (Pennsylvania Prostate Cancer Coalition 2017), who were contacted and happy for their material to be used in the research. The campaign targets the

apparent fear of a digital rectal examination in black men. The image is shown in appendix VIII. The men were asked to discuss the benefit of the image on their understanding of prostate cancer.

Using the card games, the men quickly started discussing their thoughts for each game, and this enabled a dialogue about prostate cancer and health. Kitzinger and Barbour (1999), when discussing the practicalities of running a focus group, warn of participants who speak on behalf of the group which makes it difficult for the quieter members to become engaged. This was somewhat prevented by the sharing of the card games, and also with the establishment of ground rules at the start of the focus groups (see appendix IX). Although it was preferable to include all members of the focus group in the discussion, the reason for the focus group (to study group interactions) meant that manipulation of the participants was kept to a minimum.

The role of the focus group moderator is discussed by Myers and Macnaghten (1999) who refer to the moderator as providing 'back channel' utterances to maintain the flow of the focus group whilst allowing control of the focus group to fall to the participants. This reduces compromising the purpose of the focus group, as one in which the social responses of the group are of particular interest to the researcher (Myers and Macnaghten 1999). By maintaining 'back channel' utterances the moderator can allow normal speech to take centre stage in the focus groups, such as agreement, disagreement, interruption and silence (Myers and Macnaghten (1999). This approach was of particular importance to this study; the focus groups were organised to allow the men to talk to each other in a discussion of

health-related tasks, which led to the natural flow of conversation as outlined by Myers and Macnaghten (1999).

#### 4.5.4 Recording the data

The interview and focus group data were recorded on an Olympus digital voice recorder DM-650. The focus group data were also recorded on a Zoom H2 portable recorder, which has two microphones to ensure all voices were recorded. The microphones were fully charged using a USB charger before the interviews took place.

The recordings were transferred immediately after the interviews and focus groups, to a password-protected computer. The recordings were kept on the recording devices and secured in a locked draw, until the time that the transcription was complete. The recordings were kept on a password-protected computer so they could be listened to as the transcriptions were read for data analysis.

A professional transcriber, used by the university, transcribed the interviews. The recordings were sent using the university's Fast File system and were encrypted for only the receiver to open. The interviews and focus groups with the Somali men took place with the use of an interpreter. To ensure accuracy of transcription of these recordings, the talk between the Somali men and the interpreter was back-translated to English. The recordings of the interviews and focus groups were sent to a second interpreter, using the same Fast File programme as that used for the interviews. These additional transcriptions were matched to those from the original transcriber, where the original transcript stated 'Somali speech'.

#### 4.5.5 Managing the focus group transcripts

Whilst reading the transcripts, the researcher listened to the focus group and interview recordings to check for accuracy and exactness. Listening to the focus group recordings, the researcher was able to place the voices of the participants through recollection of the conversation during the focus group, and using the notes made by the focus group observer (see appendix X for observer notes from one focus group). Each member of the focus group was given a number to identify them. This was important for this research, because as well as being analysed for categories relating to prostate cancer risk perception, the focus groups were also coded for incidence of communication style between the men.

This meant identifying each individual by listening to the transcripts and matching to the locations of the participants as documented by the focus group observer. The observer carefully labelled and documented the position of the participants and made notes of the sequence of talk (see appendix X). This is recognised as an acceptable way to identify participants in a focus group setting (Myers and Macnaghten 1999).

#### 4.5.6 Locations of data collection

Interviews took place in a location of the participants' choosing, to assist in an open conversation during the interview process. Data collection locations were as follows:

Community centre: 9  
Library: 2

Café/restaurant: 5  
University building: 1

The majority of the White Working Class men preferred to be interviewed in a community centre and this could be due to the nature of their recruitment for this research, through a community group. The Somali men were interviewed in an office at the male-only restaurant and the African Caribbean men chose community centres and cafés, with one man preferring to come to an office at the university.

The focus groups for the White Working Class and African Caribbean men were conducted in a community centre, and the Somali men preferred to have their focus group in the office in the male-only restaurant/community centre, in which the interviews had been conducted.

#### **4.5.7 Safety of the researcher**

Due to the intimate nature of the research topic, it was felt that some men would not want to be interviewed in a location where they could be identified. Participants were asked to suggest a suitable venue for the interview, but this was not in the participant's house. The researcher conducted interviews as a lone female, and in accordance with the university's Lone Working policy (Cardiff University 2014), the researcher put in place strategies to protect her safety. The researcher always told someone when she was going to interview a participant and to expect contact when the interview was finished. If the interviews took longer than one hour, a colleague would communicate via mobile phone to ensure the researcher's safety. This

strategy was used during one of the interviews with a Somali man. The flow of the interview was only minimally disrupted.

The focus groups were conducted with a fellow male researcher, as described in section 4.5.2. The lone worker policy did not apply in this case and the presence of a male made the researcher feel more secure.

#### **4.5.8 Fieldnotes**

Fieldnotes were collected during this research because of the assumed complexities of the research question and research field. To have an in-depth understanding of how the men in this research construct their perceptions of risk about prostate cancer, it was felt necessary to also write about the communities in which they conducted their lives and the interactions between people in these communities. Watson (2000) collected field notes in his research on men's health and the articulation of a layperson's idea of health. He felt that writing his thoughts immediately after each interview, and from observation in the community, would provide him with a depth of understanding that could be missed from an interview alone.

This thinking applies to this research, and the writing of field notes was influenced by the work of influential ethnographers, such as by Bourgois (1991) and Wyatt Wyatt (1943). As such, the fieldnotes in this study are descriptive in their nature. Examples of fieldnotes can be seen in appendix III. The fieldnotes were not intended as a method of data collection, and they have been used throughout data analysis to support emerging categories and theory generation. No person can be

identified through the collection of fieldnotes, no names, pseudonyms or place names have been used.

In this study fieldnotes are used to inform the coding process as writings of the researchers experiences with the communities. They were not analysed as data in their own right, but rather to provide a social context to the interview and focus group data. The fieldnotes also informed the analytic process of how my thinking has been informed by immersion in the social lives of the men involved in this research.

#### **4.5.9 Ethical considerations**

The dignity, rights, safety and wellbeing of participants must be the primary consideration in any research study (Research Governance Framework for Health and Social Care in Wales (2009) p8).

Health and Social Care Research Wales (2009) put at the heart of their governance framework the rights of the participants involved in health-related research, whether they are patients, care professionals or members of the public taking part in research to progress the health of the people of Wales (Health and Social Care Wales 2009).

Cardiff University's Research Integrity and Governance framework (Cardiff University 2017), is based on good ethical practice seen in the ESRC guidelines (The Economic and Social Research Council (ESRC) 2015), which follows the principles of



voluntary participation in research, timely informed consent and transparency of the purpose of the research and the use of research findings.

Each School at Cardiff University has its own School Research Ethics Committee (SREC), which reviews the nature of the research within the school and adopts research ethics approval strategies accordingly (Cardiff University 2017). In order to receive ethical approval for this research a Protocol, Participant Information Sheet and Consent Form (see appendix XI), and ethics application form was sent to SREC for The School of Healthcare Sciences. After minor amendments to the wording of the application, the School granted ethical approval in March 2014. There was no need to apply for ethical approval through a NHS ethics committee; the research did not involve patients or staff in the NHS.

The later decision to conduct focus groups led to a further application to SREC. This application was made in early 2015 and was viewed by SREC as a minor amendment to the original ethics application. A justification for the use of focus groups was sent to the SREC and ethical approval was given with a minor amendment to the Participant Information Sheet (see appendix XII).

Specific ethical issues relating to qualitative research and the use of interviews and focus groups include the possibility of the participants laying themselves open to the researcher, reflecting on matters of their life they had left in the past (Patton 2002). Therefore, the researcher needs to have prepared strategies for supporting

the participant; they are not taking on the role of therapist and should not assume to be able to support a participant in these situations (Patton 2002).

The approach used in this research was to establish a relationship with one local and one national cancer charity. These charities were happy to offer support to participants in case of concerns about prostate cancer, or other cancer experiences with family or friends. The support could be offered via telephone, followed by one-to-one support if thought necessary. All participants were given written information about prostate cancer risk in black or white men, provided by a national charity, at the end of the interview or focus group. The information was provided in Somali for the Somali men, if requested.

#### **4.5.10 Consent procedure**

Participants contacted the researcher as discussed on page 98. During this contact, the nature of the research was explained to the participant, including what would be expected of them. They were also informed that they would be contributing to research toward the award of PhD.

Participants were met at a location of their choice, and before the interview commenced they were asked to read the Participant Information Sheet and time was given to ask questions. The Somali men had the information sheet read to them. This procedure was deemed suitable, by the Schools SREC, in order to gain consent from the Somali men, following guidance from the National Patient Safety Agency (2013). Consideration was taken of the fact that some of the Somali men could not read Somali or English.

When the participant was happy to consent to be interviewed for the research, and the researcher was happy that they were fully informed about the purpose of the research, a consent form (see appendix XIII) was signed and dated by the researcher and the participant.

If an individual decided not to take part in the research, they were reassured that there would be no reprisal from this decision. Participants were also informed that they could stop the interview process at any time and that there was no reprisal for this decision.

Informed consent for the focus groups was collected using the same procedure as for the interviews. The key stakeholder involved in the research informed the men about focus groups and the researcher informed the men of the use of card games and established ground rules for the focus group procedure (see appendix IX for ground rules).

#### **4.5.11 Confidentiality and data protection**

Health and Social Care Research Wales (2015) considers confidentiality and data protection to be of paramount importance in research procedures, and this is governed by the Data Protection Act of 1998 (Health and Social Care Research Wales 2015). The ESRC recommends that internal data protection and confidentiality procedures are documented on the ethics application and followed during the consent procedure (The Economic and Social Research Council (ESRC) 2015) .

Cardiff University issues its own guidance on data protection for researchers (Cardiff University 2006), which has been followed in the use of data collected for this study. Participants consented to their personal data being held for research purposes for six months after completion of the research, after which it would be destroyed. This was made clear on the Participant Information Sheet. Participants also consented for extracts from the interview recordings to be used in the write-up of the thesis, and were given the option to allow/not allow for extracts to be used in future publications.

Following Cardiff University data protection guidance (2006), information that could make the participant identifiable, such as name and place of residence, has been removed from the interview transcripts and replaced with (name given) or (place given). For the purposes of the research, the transcript number, such as 010 and 032, has been used to identify participants. The same has been applied to the focus group participants. Only the researcher is aware of the identity of the participant. All personal data, such as consent forms and completed census education questions, have been held securely in a locked drawer on a card-only access floor of the University. Any electronic recordings have been kept on a password-protected computer, and not saved on an electronic 'cloud' (such as Office One Drive), even if this is protected by a password.

## 4.6 Method of data analysis

Data analysis is inductive and strongly based on the data themselves, rather than being influenced by pre-existing theories that fit data into an existing coding framework. The interviews were listened to, and transcripts read, as soon as possible after each interview, to become submerged in the data and start the process of theory generation. Researcher influences on the findings were been kept to a minimum by recognising the experiences of the researcher during the analysis process. This was achieved by maintaining reflexivity and memo writing throughout the process of analysis (see section 4.7.1), and by using multiple methods of data collection to guide understanding of emerging theory in the social and individual context.

### 4.6.1 Coding using initial line-by-line codes

Using the same methods of analysis as Holtlander and Duggleby (2009), this research has used the analytic approach of Charmaz (2014) for data analysis. Charmaz (2014) is an advocate of careful initial coding, commonly used in grounded theory methodology to uncover the data and assist in making sense and finding meaning. In the work of Charmaz (2014) codes are constructed from the types of language used by participants and the actions they are describing. To achieve this, initial data analysis was done using line-by-line coding through the application of gerunds to get closer to meaning from the participants perspective (Charmaz 2014). An example of this technique can be seen in figure 2.

The use of line-by-line coding, rather than initial coding for topics and themes using a theoretical framework, creates a deeper understanding of the data and avoids taking the data at face value (Charmaz 2014). Line-by-line coding has been an important step in data analysis and theoretical sampling, by bringing out the explicit meanings in interviews and focus groups, and forms the basis for how we can understand differences and similarities between the groups of men in this study.

#### **4.6.2 Constant comparison**

Constant comparison is used in grounded theory to fully interrogate the data (Corbin and Strauss 1990). There is some dispute in the literature about the use of constant comparison in grounded theory methodology. In *Basics of Qualitative Research*, Strauss and Corbin (1998) discuss theoretical comparisons as finding patterns and raising questions that will increase the researcher's sensitivity to the data. Glaser (1992) dislikes this technique of comparison, as he believes the technique forces the data by taking consideration of the developing theories of the researcher, rather than the data itself. Glaser (1992) prefers the constant comparison method where comparisons are made between data, incident to incident and data to categories, which he believes will fully interrogate the emerging theory.

With respect to using a constructivist grounded theory, Charmaz (2014) writes about comparison of data in the same terms as Glaser (1992). Charmaz (2014) believes the constant comparative method should be used at every level of analysis to develop analytic distinction, such as comparing participant's words within the

same interview and between interviews to find patterns in the data. An example of this can be seen in figure 2 in which extracts of interview transcripts for participant 032 and 024 are shown. These men are talking about experiences of subtle racism when younger; the extracts demonstrate similarities and differences in the way these participants talk about racism.

<p><b>Interview transcript 024</b>  R: I eat well, certain foods, Caribbean foods that I used to eat and my mother used to prepare them and then I used to eat them. Not too much starch, you know and I was an athlete you know, football, destined for glory, it was difficult in them days because there wasn't any black players so I used to get my fair share of</p>	<p><b>Initial line-by-line codes</b>  Expressing pride in cultural heritage;  Closeness to family; Thinking highly of himself; needing to explain why he hasn't become an athlete; Growing up on a background of racism;  Experiencing aggression because of skin colour. Enduring</p>	<p><b>Comparison of 024 and 032 initial coding</b>  024 and 032 have both experienced racism as children in the UK. 024 is explaining that he didn't fully understand why it felt wrong but 030 knows why people were aggressive towards him. They are both talking about racism as holding them back from reaching their</p>
<p><b>Interview transcript 032</b>  ...he never liked me [teacher], he had a real problem and he actually made racist comments... At the time I remember thinking oh you know...I remember thinking what happened there, do you see what I mean. It wasn't even like I thought oh that's a black thing, I just thought oh what happened there, I just feel really, had a bad feeling about it.</p>	<p><b>Initial line-by-line codes</b>  Receiving racist comments when at school; not understanding that he is being treated differently because of the colour of his skin; knowing that it is not right to be treated this way but not sure why. Having a bad feeling about teacher not liking him. Enduring racism.</p>	

Figure 2: Comparison in initial coding from interview transcripts for participant 024 p4 and participant 032 p3

### 4.6.3 In-vivo codes

In-vivo codes are applied to the initial coding by paying attention to the language that the participants are using (Charmaz 2014). Holtslander and Duggleby (2009) used in-vivo codes to analyse data in their study on hope in caregivers of a spouse with terminal cancer. The use of in-vivo codes in this work allowed the researchers to remain close to the data by coding with the exact terminology of the participant (Holtslander and Duggleby 2009). In-vivo codes are taken as a method of coding to be used alongside line-by-line coding, and need to be integrated into the body of the coding rather than standing alone as a coding strategy (Charmaz 2014).

In-vivo codes are used in this study to identify common terms used by participants, and statements that summarise a participant's thoughts, beliefs or concerns. For example, in a transcription extract from the interview with participant 032, his articulation of his childhood crystallises the views of society when he was growing up. This stands out as an in-vivo code that could have significant meaning to the way these men view themselves in society, *"I thought oh that's a black thing...I just feel really, had a bad feeling about it (Participant 032, p3)"*. This in-vivo code has been used to generate ideas about the effects on black men of growing up in a white country, at a particular time.

### 4.6.4 Focused coding, theoretical coding and categories



Focused coding involves creating codes that are more conceptual than initial codes to allow the researcher to move towards an analytic process (Charmaz 2014). To apply focused coding effectively, decisions have to be made about which initial codes make the most analytic sense to allow the data to be categorised completely and effectively (Charmaz 2014). Focused codes can appear frequently among initial codes. For example in the initial coding shown in figure 2 both participants talk about the difficulties growing up in a predominately white area and this is developed into a focused code 'Enduring Racism'.

Drawing initial line-by-line codes together helps to sort and synthesise the data. Focused coding involves re-coding initial codes once theories start to emerge, to advance theoretical understanding by creating codes for a large amount of data. Holtslander and Duggleby (2009) used focused coding to develop their understanding of their data, and by comparing focused codes with the data a process of refinement took place to help understand the properties of the focused codes. This process creates a clear analytic understanding of how the data fits with the focused codes (Charmaz 2014). This reduces the risk of the researcher forcing focused codes, which only fit their preconceived interpretation of the data (Glaser 1992).

The researcher's engagement with the data through the development of initial codes, focused codes and constant comparison leads to the creation of categories that are grounded in the data (Charmaz 2014). In this study, using manual coding, rather than applying a coding package such as NVIVO achieved engagement with the data, as it was felt this kept the researcher close to the data. Manual coding was

achieved through using an Excel spread sheet format to apply initial line-by-line coding, reducing this to focused coding and then sorting the data to emerging theoretical categories. See an example of coding in appendix XIV.

In constructivist grounded theory focused codes are used to create categories that have significance in the study and can be raised to an analytical level to construct theory (Charmaz 2014). Before categories are created, coding allows the researcher to think about the properties of the focused codes and the context in which these were created. For example, raising 'enduring racism' from a focused code to a category means paying attention to all possible explanations of why the men talk about the struggle of growing up as a black person in a white area, and whether 'enduring racism' is a true reflection of how this has affected their integration as adults, and their beliefs about health and illness. This category was later refined to Identity by Difference, after comparison with the White Working Class and Somali men revealed they had not endured racism in the same way as the African Caribbean men.

The analytic process of raising categories from focused coding involves the application of theoretical coding. Theoretical coding involves putting the pieces back together, from the initial coding and focused coding, which has dismantled the data to allow the researcher to make sense of it (Glaser 1992). Using theoretical codes allows the researcher to explain the data and show relationships through an analytical process, to add precision and clarity (Charmaz 2014).

The application of theoretical coding without the influence of the researcher's preconceptions is achieved through constant reflection of how the focused codes and categories are created (Charmaz 2014). Glaser (1992) advocates that the researcher should 'just not know...so he does not even have to waste time wrestling with his preconceptions' (Glaser 1992, p.50). Charmaz (2014) does not believe this is possible and, as discussed above, the background of the researcher precludes the ability to 'just not know' what is expected from the data. In this study the researcher has discovered their own preconceptions during data collection and initial analysis, such as assuming that all men knew about their prostate and the symptoms that may indicate prostate cancer. This has benefited both the direction of the research, to explore why this misunderstanding exists, and has guided conclusions about how men could be made aware of their body in relation to health. Being attuned to this, and being open to changing preconceptions, has enhanced this work and the relationship of the author with the data.

#### **4.6.4 Memo writing**

Memo writing is a way to express ideas about the data by developing a system to keep track of patterns, questions and categories being raised in the data (Corbin and Strauss 1990). Using explicit writing of how codes and categories are developed, memo writing is used to guide the analytic process without losing conceptual detail and leaving theory undeveloped (Corbin and Strauss 1990). Charmaz (2014) talks about memos being a space to explore your own views and ask questions of your thinking, as well as writing about your comparisons of the data. Memo writing also allows the influence of the researcher on data analysis to remain transparent,

increasing the credibility of the findings. This study has used a research diary that includes thoughts about development of the analytic approach to this research, alongside memos about how focused codes are developing. Below is an example of early memo writing in the development of the focused code 'enduring racism'.

The black men talk about growing up as a black child in a white country. Their parents moved most of the men interviewed here when they were about 10yrs old. The participant's talk about the struggles their parents had adapting to a country where the colour of their skin influenced the way they were treated in society, the amount of money they could earn and the areas they could live in. The men talk about being held back at school because the teachers singled them out as lacking intelligence and this curtailed the amount of opportunities they had to join in with school activities. Spending time with the black community they have told me that they have had to fight hard to find their place in society they say this might create an impression that they are difficult to approach. The white men don't talk about this, they have not had to try and fit into a community that did not want them and I wonder how this has influenced the black men's approach to accessing health care and their relationship with healthcare professionals who, in the study area, are mostly white. Has this created a closed community, which decreases the influence of health literature (such as prostate cancer information leaflets) because this is generated outside the community they have fought for?

**Memo writing for development of focused code enduring racism.**

#### **4.6.5 Creating categories**

Categories are ideas created from the coding process that can be tested against the data through a process of induction and abduction, used when surprising and puzzling data cannot be explained from initial coding (Charmaz 2014). This process allows data that may support or contradict the initial coding process to be checked for theoretical contribution to the research findings and prevent description.

Glaser (Corbin and Strauss 1990; Glaser 1992) maintains that qualitative data analysis can fall into the trap of providing a detailed description of the data, without an analytical approach. He reasons that grounded theory allows the researcher to

create analytical categories, which can later be compared to existing models of theory in a review of the literature to check for the contribution to the research field (Glaser 1992). Corbin and Strauss (1990) agree that grounded theory provides a process of analysis to prevent description, but maintain that the position of the researcher is to remain flexible in the development of categories because of the temporal changing nature of a person's behaviour and beliefs.

This approach is used by Charmaz (2014) who maintains that from a constructivist standpoint, categories are explained by understanding the context in which the category arises, such as the social environment of the participants. This approach also allows categories to be grounded in the data through constant comparison with the empirical data during the coding process (Charmaz 2014).

In this work, categories are compared for similarities and differences to create a core property that belongs to all categories generated from initial and focused coding. Glaser and Strauss (1967), in their initial introduction to grounded theory, introduced the idea of finding the analytic core of a category through constant comparison of the data. This approach to data analysis has been maintained by alternative uses of grounded theory, such as that used by Charmaz (2014), and in the analysis of data in this study. This approach to category generation is seen in the work of Corbin and Strauss (1990) through a process of unifying all categories around a central core, in which categories can be explained in more detail through their relationship with the core property. Charmaz (2014) emphasises that this process involves creating balance between categories and theoretical statements

about categories, including integration of memos. See appendix XV for diagrams of memo integration and memo writing in the integration process.

During data analysis research categories were generated through a process of constant comparison leading to the discovery of patterns in the data and differences between the groups of men. Of importance to this work is the development of categories leading to a grounded theory of how men from distinct cultural groups understand their risk for prostate cancer. Challenging the data has led to categories that were unexpected and this has created a broader view of the lives in the men involved in this research.

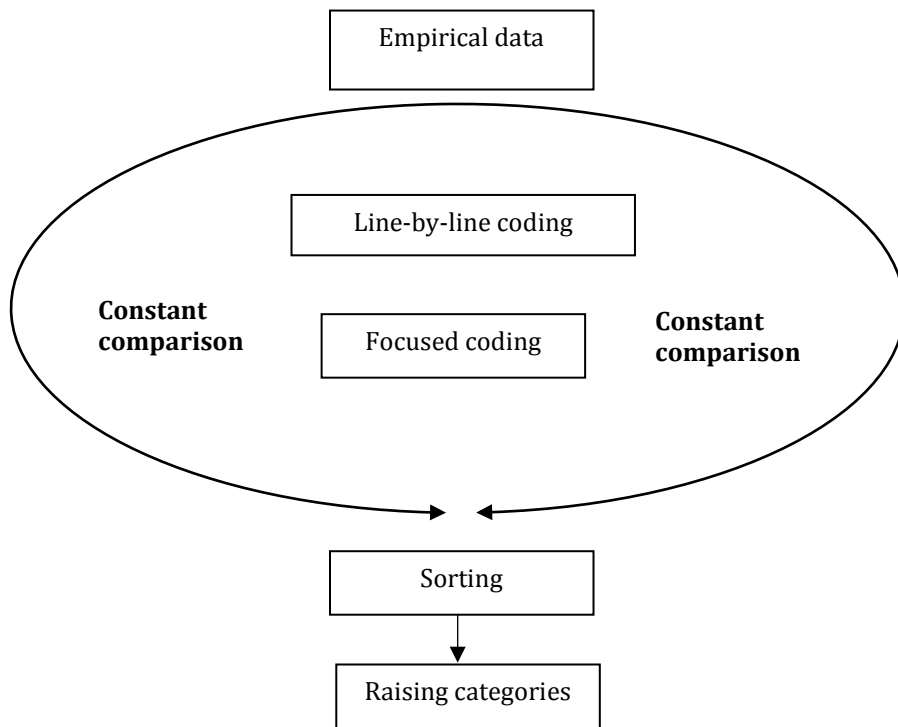
#### **4.6.6 A word on incidents and axial coding**

Incidents are segments of empirical data that explore the experiences of participants. For example, Charmaz (2014) compares incidents of young women receiving bad news in which they will endure physical loss, and Holtslander and Duggleby (2009) compare incidents of women talking about the loss of their spouse to cancer. The focus of the current study is on men's perceptions of their risk for prostate cancer and how this is informed by society, knowledge and access to information. Some of the participants have talked about their own interactions with healthcare professionals and experiences of family members being diagnosed with cancer. These were coded as incidents, during the initial coding process, and compared to understand the relationships between the incidents.

Axial coding is used in grounded theory to place a framework around the data and put the data back together after open coding (Glaser 1992). Axial coding is the process of relating categories to their properties to fully understand the category by linking terms of the category at its axis (Corbin and Strauss 1990). According to Strauss and Corbin (1998) this is done by the application of a paradigm applying conditions to locate the data in a conditional structure. Using a paradigm during analysis, the research is able to create properties of a category relating to structure and process. For example, when a participant talks about their environment and how this has influenced their actions, Strauss and Corbin (1992) apply structure (environment) and process (action) to explain the conceptual components of a category. Glaser (1992) rejects this contemporary use of axial coding as he feels this creates forced coding, resulting in a description of the data, which lacks theoretical sensitivity.

From a constructivist viewpoint axial coding creates a frame around the data and risks limiting interpretation of the data and accepts ambiguity (Charmaz 2014). The argument is that this limits emergence of categories by forcing the data into a paradigm, which limits exploration. For Charmaz (2014), having no explicit framework during the analytic phase, allows further explanation of the data for the researcher who is able to tolerate ambiguity. In this study data has been collected and analysed to follow the leads that the research has taken and therefore, to avoid forcing the data into a paradigm, axial coding has not been applied.

Figure 3 is a diagrammatical representation of the data analysis process used for this research, to the point of raising categories. What follows in this thesis is a description of the process of theory development used in this study.



**Figure 3: Process followed during theoretic analysis**

#### **4.6.7 Developing theory**

*Theory: The conceptual basis of a subject or area of study. Contrasted with practice (Oxford English Dictionary 2017b)*

In grounded theory the focus is on generating theory outside of a theoretical framework, through the use of inductive analysis of the data (Glaser and Strauss 1967). This is in contrast to other qualitative approaches, which use a theoretical



framework applied to analysis. For example, a phenomenological approach focuses the researcher on the lived experiences of their participants (Patton 2002), whereas grounded theory allows the researcher the freedom to acquire knowledge about any aspect of a person's life (Charmaz 2014).

Using a constructivist grounded theory approach, theory is generated through interpretation of the data to provide an abstract theory that will not at first have been obvious (Charmaz 2014). This involves gaining an intimate knowledge of the data before raising categories to theory (Charmaz 2014). For Corbin and Strauss (1990) developing theory involves bringing broad conditions into the analysis to develop enduring theory. For this study, a broad category has been the concept of being black, and the role this has had on the men's views of their bodies, as well as the influence of community on the men's views of their bodies.

In their research examining the experience of caregivers after losing a spouse to cancer, Holtlander and Duggleby (2009) used the analysis approach of a constructivist grounded theory to raise the theory of hope after bereavement to suggest a new paradigm for creating new hope. Holtlander and Duggleby (2009) arrived at their theory using the experience of the participants and the careful consideration of their language during bereavement. In this study, the careful process of analysis of the language used by the participants about their social worlds and their understanding of the body, as well as the contribution of researchers' observations and reflexivity, theory has been generated about the influence of views of the body and the influence of society on perceptions of prostate cancer risk.

## 4.7 Trustworthiness of the research

### 4.7.1 Credibility

The use of reflexivity to ask questions of emerging themes, as well as recognise preconceptions that may have existed from clinical experience, have helped maintain an objectivity in data collection and analysis. Glaser (2002) challenges the ability of the researcher to remain objective using a constructivist grounded theory because of his concerns that Charmaz describes the constructivist approach as “telling a story about people, social processes, and situations” (Glaser 2002, p4). Glaser’s concern is that the constructivist grounded theory may not capture the rigour of data analysis used in a traditional grounded theory. Watson (2000) also has concerns about credibility of qualitative data analysis because of the diverse ways of analysing qualitative data, but agrees that grounded theory can produce credible findings if the analytic process is followed and well documented to allow transparency.

The approach of Charmaz (2014) creates transparency in research findings, by taking account of the influence of the researcher in the analysis process using explanations of researcher preconceptions and reflexivity. The use of constant comparison of the data has informed the credibility of the research findings by finding similarities and differences between the men in this study. Transparency has been maintained through the use of memo writing in data analysis, which provides insight into the thinking of the researcher during the development of categories and

emerging themes. The addition of field notes has added depth to the data and allowed for clarification of the interview and focus group data in the social context.

#### **4.7.2 Transferability**

Qualitative research has been criticised for having a lack of transferability (Blaikie 2010). Often a small number of participants are studied, and a lack of control over individual variables may influence research findings (Blaikie 2010). However, some qualitative researchers argue that it may not be meaningful to search for generalisations in qualitative research, as complex social organisations do not operate in a consistent set of rules (Guba and Lincoln 1989). This is particularly true of the constructivist approach, which rejects the idea that human activity is predicted by one universal set of ideas (Guba and Lincoln 1989). For this research, the process of thematic sampling through the theoretical process of data collection has produced depth in the research data, and the writing of the findings offers what Guba and Lincoln (1989) call 'thick description'. Writing a thick description enables a person interested in the research to decide how well the research findings will transfer to their area of interest (Morse 2015).

#### **4.7.3 Dependability**

Dependability concerns the ability to obtain the same or similar results if this research was conducted again (Morse 2015). The use of dependability has been questioned in constructivist grounded theory because of the view that what has been studied captures a time and place for the participants (Charmaz 2014), therefore obtaining the same results at a different time seems unlikely. However, dependability is important in qualitative research, if the findings are going to be

used to guide changes in behavior or health literature used by third sector organisations.

Rather than dependability, Charmaz (2014) uses the term resonance. Resonance asks if the categories created through data analysis have created a full portrayal of the participant's reality and offered deeper insights into the world lived by them. This has been achieved in this study by using multiple methods of data collection (interviews and focus groups) and through prolonged engagement with the study areas. Resonance is also achieved through the careful process of data analysis and close scrutiny of the data. Coding the data by hand, rather than using coding software, allowed the researcher to become submerged in the data by reading, re-reading and listening to the interviews to gain a deep understanding of the participants' language.

#### **4.7.4 Chapter summary**

This chapter has presented an overview of the design and methods used in this study. The aims and objectives of the research have been discussed and the design used to examine these has been outlined.

This research has been approached using the guidance of Kathy Charmaz (2014) and her position on the application of a constructivist grounded theory. This approach has been used to inform the methods applied to recruitment of the men to this research and the use of fieldnotes to support the generation of theory from interview and focus group data. The use of flexibility and reflexivity, outlined in the

work of Charmaz (2014) has been applied to this study to accommodate for the researcher's clinical background and the influence this may have on theory generation.

The regulatory approaches to data collection and analysis have been described to ensure safety of the researcher, and that of the research participants with regards to consent procedure, involvement in the research and confidentiality. This chapter has also provided a description of the methodological approach to data analysis, based on the work of Charmaz (2014). An adapted approach to this has been used, excluding axial coding to avoid forcing the data into a paradigm early in the analysis process. The following chapters will present the findings of this analytic strategy.

## 5.0 Presentation of findings

### 5.1 Introduction

This research is influenced by constructivism (using approaches of constructionism and constructivism), and so takes into account the individual and social experiences of the participants. Analysis of the data quickly revealed the importance of understanding the ways in which the men identify themselves and the relationship of this to their perceptions of prostate cancer risk.

The findings chapters are separated into four categories, which have been developed through a careful process of data analysis and theoretical sampling. The chapters are separated into discussions of each cultural group before an overall summary of the category is given. These findings are discussed for each group of men before drawing on constant comparison of the data to present the similarities and differences between these groups. Comparisons between men in each group are provided during the individual group discussions.

Findings are presented using extracts from participant interviews and focus groups, as well as extracts from memo writing and field notes. It is recognised that the findings are based on the views of the men taking part in the research at the time and place they inhabited during data collection. To help locate the findings discussed in these chapters in the lives of the interview participants, table 7 provides a summary of the characteristics of the participants who took part in the interviews for this research. These characteristics were not collected from the men taking part in the focus groups. The men participating in interviews gave the characteristics seen in table 7 during the interview process, as a rapport was

established between the interviewer and the interviewee. During the focus groups the relationship between the researcher and the participants was that of group conversation, and the characteristics seen on table 7 were not shared between the men in the focus groups.

<b>Participant number</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Length of time in UK</b>	<b>Marital status</b>	<b>Employment</b>
10	54yrs	Black Caribbean	Lifelong	Cohabiting	Community Caretaker
13	66yrs	White British	Lifelong	Married	Not given
14	56yrs	White British	Lifelong	Divorced	Train conductor
15	42yrs	Somali	27 years	Married	Runs Somali community centre
16	60yrs	Black British	45 years	Separated	Works in business registration office (role not clear)
17	65yrs	Somali	14 years	Separated	Unemployed
18	45yrs	Somali	30 years	Single	Unemployed
19	54yrs	Black British	Lifelong	Married	Pastor and radio DJ
22	64yrs	White British	Lifelong	Divorced	Volunteers for charity
24	56yrs	Black Caribbean	50yrs	Divorced	Worker in a chemical plant
27	40yrs	White British	34 years	Cohabiting	High-ropes engineer
30	50yrs	Black African	Lifelong	Single	Youth Worker
32	51yrs	Black Caribbean	48 years	Married	Third sector health worker
33	70yrs	White British	Lifelong	Married	Retired from British Army
34	82yrs	White British	Lifelong	Divorced	Retired builder
35	71yrs	White British	Lifelong	Married	Retired from British Army
36	78yrs	White British	Lifelong	Married	Retired NHS kitchen porter

**Table 7: Personal characteristics of the men interviewed for this research**

## 6.0 Category 1 – Identity by difference

### 6.1 Introduction

The following chapter explores social identity created from codes raised during theoretical analysis. The chapter examines the way men talked about their experiences of being identified by differences and similarities to the common perceptions of social norms, as held by the majority. The African and Caribbean men commonly talked about being black and the Somali men about their shared experiences of migration and their desire to return to Somalia.

The White Working Class men didn't identify themselves as different in the same way as the black men. On the contrary, these men talked about their similarities, by talking about health problems that are common to the older population (e.g. diabetes). In this context, the White Working Class men did not create a reality based on their differences to the majority population, reality was based on what is similar between these men and what is expected of the body as these men age.

The focus of this chapter is how the men articulate their differences and similarities in relation to their bodies and their place in society. This provides a background for the everyday experiences of the body and the influence of this on perceptions of prostate cancer risk. This chapter is important because it is an essential part of the development of the grounded theory generated through this research.



## 6.2. African- Caribbean men

### 6.2.1 Being black

The African Caribbean men identified themselves by the colour of their skin, in a way that the White Working Class and Somali men did not. The African Caribbean men referred to themselves as being black and related this to their pattern of migration to the United Kingdom, and how their parents' experience of migration created a social reality of being lower class and isolated by their difference to the white population. Participant 032's parents migrated from (place name) to the UK to look for work, and he talked about his parents' expectations before migration and the reality they faced when they arrived in the UK:

*I don't think they were aware of the class structure (laughs)...they expect the same... they didn't realise that coming to the UK, obviously they're going to be in a worse class area... so the UK was a huge shock to them ... coming to the UK my Dad was a blue collar worker (Participant 032 IT: p2).*

Participant 032 recalled the lower status his parents had to accept when they arrived in the UK and, by referring to his father as a blue-collar worker, the reality of the manual paid-by-the-hour work he was offered. This man did not talk specifically about his parents living in the same area as other black immigrants, but participant 024, another African Caribbean man, made reference to this when he talked about his parents' experience of migration:

*I think they were down here, sorry when I say down here because it's a black area, they were living in the (place name) area (participant 024 IT: p1).*

He went on to say that his father wanted to live somewhere “*more prestigious (participant 024 IT: p1)*”, and they moved to an area, which he called more integrated, by using the term assorted:

*My father didn't like that at all [living in a black area] so we were the first black family to live in an assorted area so to speak (participant 024 IT: p2).*

Participant 019 also made reference to the black population and the white population traditionally being segregated when he talked about black and white people starting to mix:

*Yeah but they [black people] used to keep to each other don't they, I mean it's only recently that they've been, they've been spreading you know that don't you? (Participant 019 IT: p14)*

This man used the term ‘spreading’ to talk about social changes between the black and white populations. It is assumed that this is based on changes in social attitudes towards interracial relationships, and participant 024 referred to this when he talked about the views of black women towards a black man’s body in an interracial relationship:

*R: If it was just you and me walking down the street a long time ago it would be difficult.*

*SF: Because I'm white and you're black?*

*R: Yeah, but now it's great, seeing that. However, there was a period where I didn't like it, seeing a black girl going down the street with a white guy.*

*SF: Okay, that's interesting, why didn't you like it?*

*R: Because I assume, it just didn't look right, black girls some of them wouldn't go out with me because I've been out with a white girl.*

*SF: Oh right, okay. So once you make that connection with someone that's white it breaks down a bit of*

*R: A lot of true black women feel that we're tarnished, yeah, so they would never date you.*

(Participant 024 IT: p30)

This man used the word 'tarnished' to describe how black women would feel about his body. Using this word, he seems to refer to black women thinking his body was dirty or blemished, and their changed perceptions of his attractiveness. Participant 019 also made it clear how he felt white people view the black population:

*White people, they're always sort of made out that we're stupid...and we're down the food chain and stuff like that and evolution and all that rubbish. So we like to be proud of ourselves, black people are very proud people you know*

(Participant 019 IT: p25).

In this extract Participant 019 refers to black people having a sense of pride, and in this research this has often been implicit in the time spent with the community, which has influenced creation of the category Identity by Difference. The memo below explains the thought process during data analysis:

*Identity by colour and experiences of racism were originally coded to create two separate categories. During the process of theoretical sorting it was discovered that these categories represent each other. Men either did or did not experience racism based on the colour of their skin, and for some of the men in this research this has led to the colour of their skin being an important part of their socially created identity. Therefore, these categories have been brought together under the term Identity by difference. The black men also talk about being suppressed and restricted in their opportunities by the white population, whom they feel view them as of lower status. As victims of racism these men have chosen to focus on the positives in their community, which has developed a sense of pride in their black heritage. These men live their everyday lives through the pride they feel at being black but have to balance this with the feelings of suppression they have experienced. These data are showing The African Caribbean men are coping with the opposing feelings of worthlessness and pride. Of interest to this research is how this affects the views of their body in relation to illness and health.*

**Memo writing September 2016**

### 6.2.2 Identity by restricted opportunity

The Black men talked about their experiences of restricted opportunities as children and young men because of the colour of their skin. The men described not being able to join sports teams or being overlooked by teachers at school. Participant 032 recalled his experiences at school when the teacher congratulated pupils on their achievements. He talked about his teacher dismissing his achievements by asking all pupils to put their hands up if they had done well, but asking participant 032 to put his hand down despite being at the top of his class for English:

*I know by the time me and my three sisters left school a lot of the aspirations had been kicked out of us ... I went into O-level years and I had a new teacher ... he had notes for everybody on how well they'd done and he was literally saying put your hand up and he would say oh keep up the good work...I was always top for English at that point and he said put your hand down ... I put my hand up and he went (gesture) and he went on to the next person (participant 032 IT: p2-3).*

This participant went on to say, “... it wasn't consciously barracking and having a go. A lot of it was a total lack of acknowledgment (participant 032 IT: p3)”. This experience of being unnoticed seems to have been interpreted by participant 032 as being something he should accept when he says, “oh, that's a black thing (participant 032 IT: p3)”. It appears he is trying to explain his feeling about these experiences, and contextualise them into something normal and to be tolerated.

It appears that for the majority of the African Caribbean men in this research, being black has created a mixture of negative and positive outlooks on how they interpreted being black. Participant 019 talked about celebrating his blackness

through interactions on social media, through which he can make contact with  
'anything black':

*If somebody black dies it's like my family or whatever... people put things on my page [Facebook] or you know and I like reading about anything black, I do yeah  
(Participant 019 IT: p23).*

The men seemed to talk about being black with developing a sense of pride in the colour of their skin. Participant 024 recalled being black and his restricted opportunities with a negative voice, but he still talked about what he had been able to achieve despite being black. He appears to have developed his sense of pride through his sporting prowess, rather than acquainting his experiences with other black people. He recognised that the colour of his skin made it difficult to be accepted by his white peers when he talked about his sporting ability:

*I was an athlete you know, football, destined for glory ... it was difficult in them days because there wasn't any black players  
(Participant 024 IT: p3).*

This man explained that he finally overcame this difficulty by being good at sport and tougher and stronger than other men:

*The average guy thought that for some reason we didn't belong, yeah, and that was a massive barrier... what broke that barrier is that I was tougher, better athlete than them, that's what broke that barrier (Participant 024 IT: p6).*

These three men have found different ways to overlook their experiences of being restricted, such as: understanding, celebrating being black and finding a way to be better than white men. The men have developed a sense of pride that is embodied in the way they view their social interactions as a black person. It appears that their constructions of the reality of being identified as a black man are dependent on the

men's strategies for coping with the discrimination and restrictions they faced during their early days in the UK.

Conversely, participant 016 did not make reference to being black and experiencing restricted opportunity. This man appears to have had every opportunity to develop; he told me he came to (place name) in 1989 to go to university to do a PhD:

*I've been here since 1989 so I've been here for about 18, 19 years. I just came down here ... I started working as a research assistant and then when I was doing my PhD (participant 016 IT: p5).*

He did not talk about whether or not he completed his PhD, and it is not clear from his talk during the interview. He did not make any reference to his career beyond university but he did refer to belonging to the black community (Participant 016 IT: p7) and this is explored further in chapter 8.

### **6.2.3 Summary**

The African Caribbean men in this research talked about their experiences of racism and the strategies they have had to adopt to accept racism as part of their everyday lives. They recognise that the colour of their skin has restricted their opportunities after migration to the UK and this has enhanced their feelings of being different, as well as developed a sense of pride. For one man, this created a positive experience; his black identity has allowed him to access a social network that celebrates and identifies black matters. For other men, finding strategies to accept experiences of racism meant belittling the prejudice they have faced, by calling it a 'black thing', or using physical prowess and aggression to find a place in a white society.

The embodied experience of being black is articulated for these men through their interactions with the wider society and the influences of these interactions on their identity as a black man. The influence of these constructions of reality on the men's perceptions of their bodies and their acceptance of the unwell body is discussed in chapter 8

## 6.3 Somali men

### 6.3.1 Identity by religion

The Somali men in this research identified themselves as Muslim; they follow Islam although it is not clear if they are Sunni or Shi'a. They did not state their religion directly, but whilst helping to organise an educational event for these men there was some concern about not interrupting prayer times, as expected by Islam. Below is a field note made on the day of this organised education event:

*I contacted MY (community contact) two days before the event and he had set-up access to RSH but was vague about what time would be best. We had arranged for the talk to be at 2pm but this would now not suit the community because prayer times had changed. Prayers are determined by the position of the sun in the sky. Prayer had been at 12.20 and was not happening again until 2.41, the men had to eat before next prayer. The prayer times for this day were:*

*Fair Sunris Zuhr Asr Mahhrib Isha  
05:41 07:18 12:10 2.41 5.12 6.43*

*Prayer times from <http://www.islamic-relief.org.uk/prayer-timetable> [accessed 12.02.15]*

*(FN 29:p.2/4)*

The men made reference to religion when talking about health behaviour, and particularly the environment in which they would like to be educated, "you can't talk those things [prostate] in the mosque (participant 018 IT: p11)". These men seemed to be bound by their religious practices and this influences their everyday lives and

the ways in which they interact with society. The field note below is an example of the men's adherence to their religious code:

*The men had to eat before next prayer and it may have been causing them some anxiety that they needed time to do this. Food for these men is an important part of their day and grabbing a quick sandwich on the way to prayer is not something they would do. Eating appears to be a shared activity and takes place at (name given), the male only restaurant, which is where we all went after the talk. The men are happy to welcome me into their restaurant (FN9: p1).*

### 6.3.2 Identity by divided loyalty

The Somali men interviewed in this research migrated to the UK because of civil war in Somalia. This process of migration appears to have left the men with a feeling of abandonment of their country as they fled from war:

*In Somaliland ... when civil war broke down ... have got no choice but to bring us over here and we come here in 1990 as a family and we lived here since then (participant 015 IT: p1).*

This process of migration seems to have developed a sense of an identity split between two countries. Participant 015 talked about this when he talked about his identity,

*Black British...I am one of the lucky ones who got two countries to go to so I love my country, Somaliland (participant 015 IT: p1).*

It could be that this divided loyalty to countries created uncertainty in the way these men viewed their permanence in the UK. The men talked about returning to Somalia when they are older and did not appear to be stateless. Participant 018 talked about his father who had recently had an operation: "operation of prostate cancer (participant 018 IT: p2)" and who then went "back home [Somalia] ... he loves the area (participant 018 IT: p3)". Similarly, participant 015 was conflicted when he



talked about where he will live, although he was certain he would return to Somaliland when he is older:

*You know I go there or I stay here so I see myself as staying in Somaliland when I grow older  
(Participant 015 IT: p2).*

This talk of the desire to go home when the men are older, and the conflict one man expressed when talking about his country of origin, generated thinking about where loyalties lie for these men and whether this affects their construction of the reality of health and illness. The following memo was made during data analysis on the concept of health and illness in relation to divided loyalty between two countries:

*Divided loyalty has largely come from my interviews with Somali men ... older Somali are less imbedded in the community as they spent their adult years working at sea and during the time they spent on land they largely lived in boarding houses with indigenous families. Divided loyalty aims to capture feelings the men have when they are talking about their place in the community and where they feel they belong in terms of their future and healthcare... Participant 015 is of Somali origin and he moved to the UK because of civil war. He is divided in his loyalty to the UK and his desire to go back to Somali. This means the Somali men studied in this research have immersed themselves in the Somali community. They want to be part of the culture they were torn away from and this adds another layer of complexity when thinking about their health beliefs. Their health beliefs stem from the beliefs of the Somali community and are not extended to the beliefs of the wider society.  
(Extract from memo writing January and May 2015)*

Participant 017 migrated as an older man, when compared to participants 015 and 018, and he had strong views about the influence of the West on people's health.

This man appeared to believe that people are healthier in Somalia and that being in the West causes problems for health:

*SF: Okay, so you were... that you think people come here and they eat lots of sugar and they make themselves.*

*P: Here is where there is always the change, so they becomes worse.*

*SF: What's worse?*

*P: Worse, the (unclear)*

*SF: Okay so that weather's worse.*

*P: Not helping the people who are sick all the time.  
(Participant 017 IT: p1-2)*

In section 7.4.2.2 there is discussion about this man's beliefs in traditional medicine, but also that he had experienced western medicine and now appeared to feel imprisoned by his body because this medicine restricted him from returning to Somalia. Participant 017 also seemed conflicted in his behaviour towards his health in the same way that participant 015 was conflicted about where he calls home. It is possible these men try to avoid interaction with healthcare professionals so that those men who can, return to Somalia. The importance of this for this research is how this affects the perceptions these men have about their risk for illness, adding an additional layer of complexity for the Somali men.

### **6.3.3 Identity by language**

The Somali men who took part in this research migrated during the civil war and some of these men, who were at school age at the time of migration, appeared to have poor English literacy. Participant 015 was the most competent at speaking English and it came as a surprise when he could not write or understand written English. Below is an extract of a field note made during the time we spent together:

*He did not receive an education when he arrived here and he cannot read or write. He is happy to look at documents but when we did some form filling together he asked me to complete the forms on his behalf...we talked about my work and how he might help me. He allowed me to interview him for my research and I read him the consent form so he could*

*consent to the study. He has a good understanding of spoken English... this man feels Somaliland is his home...I can't help but wonder how disruptive it must be to a person's identity when his country of origin is destabilised by civil war... his inability to read and write ... will cause him some obvious problems with engagement with healthcare services but maybe his perceived difficulties with identity (British or Somalia) also stop him from engaging beyond the Somali community (FN 9: p3)*

The conflict that his man may feel is also evident from the interviews with participant 018. On page 162 participant 018 talked about his father having an operation for prostate cancer. As the interview progressed it later transpired that his father may not have had prostate cancer. Participant 018 said he had an operation for “*some stones, yeah, some stones (participant 018 IT: p3)*”, and that the doctors, “*didn't tell us really, cancer (participant 018 IT: p4)*”. He talked about going into the consultation with his father when his father's diagnosis was discussed:

*SF: So did you go with him to the hospital?*

*P: Yes I did*

*SF: And did you see the doctors together?*

*P: Yes, because a long time ago, more than five years ago, six years ago but yeah he went, he was in (place name) hospital”  
(Participant 018 IT: p3)*

This man appeared to have received health information from a health professional with his father, therefore there was not a miscommunication in the explanation given by his father to the participant, rather it seems there was a poor level of understanding at the time of the consultation and this apparent confusion could isolate this man from a full understanding of health. He did not appear concerned about not having a full understanding of his father's health complaint and it is believed that this is linked to the Somali men viewing their bodies as not belonging

to themselves, as discussed in chapter 7, section 7.4.1 The medical body. The communication barrier that has been created by poor English literacy amongst these men may contribute to the views of their bodies not being their own.

Participant 017, who was older than participant 015 and 018 at the time of his migration, was very clear about the language he identifies with. When he was offered information about prostate cancer written in Somali he said:

*SF: That's information in Somali about the blood test.*

*P: Everything, lovely.*

*SF: And*

*P: That's what we want.  
(Participant 017 IT: p.6)*

This man appeared confident that he identified himself as Somali through his language. He was perhaps not part of the generation who migrated during his educational years and he appeared more rooted, compared to the other Somali men, in his identity as Somali.

### **6.3. Summary**

The Somali men do not identify themselves as black, unlike the African Caribbean men; they identify themselves by their country of origin, their religion and their language. The analysis has been informed by the social structures identified through the age at migration and the influence this may have had in the men's need to identify themselves by language use. The men also talked about their social structure and where they felt home is. Participant 017 was the most open about his

feelings when he left his homeland and the most negative about the influences of a western environment on health. The other men were more positive about their lives in the UK, but still feel drawn to their country of origin and identified themselves as Somali. The social influence of religion has also been discussed as implicit and from the time spent with the community.

Religion, language use and the influence of migration have created an identity for these men, which includes the values of their country of origin and it is thought that this contributes to their views of health risks because of the conflicts they experience when accepting western health care whilst wanting to return to Somalia.

## 6.4 White Working Class men

### 6.4.1 Identity by similarity

The White Working Class men in this study talked about illness as an everyday part of their lives. The men appeared comfortable talking about their health problems and talked about sharing their experiences with men with similar health concerns.

Participant 013 talked about going to a support group for people with diabetes:

*Well, I'm diabetic and I go to, I've just finished a six week course on understanding diabetes and that was good, I've had it about 15 years ... and it was really good ... there were 15 of us went (Participant 013 IT: p4).*

In this interview extract, participant 013 identified himself as diabetic and appeared to have enjoyed being part of a group of people with the same health complaint. He appeared to have found a similarity with this group of people. Participant 035 also found this similarity when he talked about sharing health information with people at the allotment:

*I mean down the allotment... there's one or two down there with bowel problems and we talk about it and I've told them I've got an enlarged prostate, you know (Participant 035 IT: p16).*

Participant 035 talked about sharing his health experiences with other men who identified themselves as having on-going health concerns, and he seemed to have used this similarity to make conversation. Participant 022 also found an identity through health and his body, and this was related to increased health risks associated with age:

*I was expecting a big operation [appendectomy]... they also had a look at my prostate and they said it was a bit bigger than normal but that's not unusual for my age group (Participant 022 IT: p6)*

This man appeared to be identifying himself as belonging to an age group that has an increased risk for health problems and accepted this as normal and similar to those around him. Participant 034 also found similarity by age when he talked about attending age-specific groups:

*West End Club...over 50s night once a fortnight, we have entertainment there, it's good and that's it really (participant 034 IT: p1)*

Unlike participant 022, who identified his age in relation to his body, this man identified himself by age in a social context. He made the decision to put himself in an age-restricted group and it appears that this has now become an important part of his identity.

### 6.4.2 Summary

The White Working Class men in this research talked about similarities across age groups, related to their risks for illness and social encounters. Some of the men talked about sharing their health experiences with other men during social exchanges. Chapter 9 provides an account of these social exchanges during the focus group discussion with White Working Class men. The men didn't talk about being White Working Class as a way of comparing themselves with other men, and it is possible this is because the colour of their skin is the same as the majority in their population. The men also didn't talk about themselves as coming from a particular area.

### 6.4.3 Chapter summary

The references the African Caribbean men made to being black seem to embody the social identities of these men. The men talked about being seen as different at the time of their migration to the UK and they appear to have developed ways of coping with the discrimination they faced. The Somali men talked less about being black and more about their identity as from Somalia. They didn't talk about a struggle with racism when they first came to the UK or having to find ways to manage discrimination. Identity for these men is embodied in religious beliefs and loyalty to their country of origin. The men have created their own community based on their identities and may have limited their interactions with the wider society by not becoming literate in the English language, perhaps because of their desire to return to Somalia

The White Working Class men did not talk about differences. These men talked about the similarities they have with other men of the same age, or with people with the same health condition. These men have lived in a country in which the colour of their skin is indigenous in the majority of the population. It may be that having not experienced living in a minority, the White Working Class men have not created an identity based on a minority population. The class structure in the United Kingdom means that these men are identified as working class (in this study based on the area they are living and their level of educational achievement). Their status as working class did not come out in the talk of these men in the way they identify themselves. The African and Caribbean and Somali men identified themselves by their minority status without prompting, and this could be because this is an importance part of their cultural heritage.

The African Caribbean men and the Somali men have experienced living in a minority. This was articulated by the Somali men in their preference for Somali language and their desire to return home, and by the African Caribbean men when talking about their experiences as black children and young men. The Somali men didn't seem to talk about this in a negative voice, but it appeared that their identity in the UK was influenced by their enduring relationship with their country of origin. In chapter 11 the experience of living in a minority is considered in relation to the men's views of their bodies and how their relationships with the wider society may have shaped these views.

See Figure 4 for a diagrammatic representation of theories developed for this category.



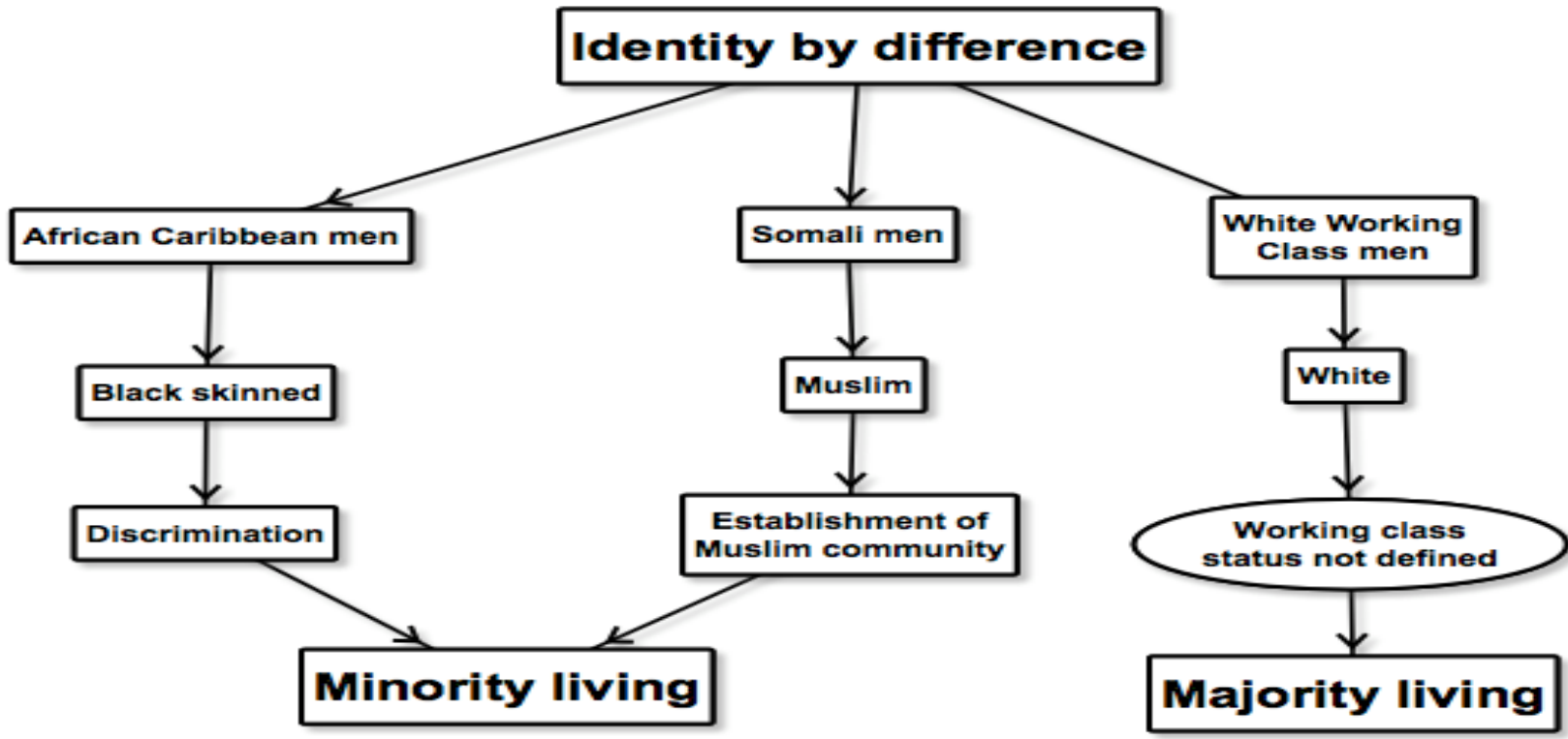


Figure 4 Development of category Individual Difference

## 7.0 Category 2 – Views of the body

### 7.1 Introduction

The following chapter examines the way men talk about the body in relationship to health and illness. There were differences found between the White Working Class men, the African Caribbean men and the Somali men in the way they talked about the body with reference to body image, health and illness and knowledge of the body.

The men were not asked directly how they thought about their bodies. Instead the men talked about their bodies in relation to their experiences of illness, their concerns about health risks and the importance of body image in positioning themselves in society. The categories presented relate to how the views of the body differed between the White Working Class Men, the African Caribbean men and the Somali men.

### 7.2 White Working Class men

#### 7.2.1 Images of the unwell body

The White Working Class men talked about experiencing their relative's bodies declining through illness as they became older. Participant 034 recalled visiting a cousin, who had been diagnosed with breast cancer and the vivid images of decline he had:

*I've had a cousin-in-law, she had cancer...I went to see her...she was in the bed her arms were just bone and muscle, terrible*

*(Participant 034 IT: p3)*

Participant 036 had similar memories of visiting his uncle, who came back from the Second World War with leukaemia:

*They said if you want to see your Uncle (name given) you'd better go and see him, he's, and I went into see him and well he was just rolling in pain and of course next time I see him up in the funeral (Participant 036 IT: p7)*

These experiences seemed to have left memories of frailty, decline and pain that the men talked about with clarity. They talked about how cancer diagnoses were kept away from family members when they were younger, so the images of cancer that they experienced appeared to have been negative and shocking in their unexpectedness, creating lasting perceptions of the declining cancerous body:

*I didn't even know he had cancer... I wasn't aware of it, cancer, and he kept it a bit close inside  
(Participant 014 IT: p1)*

Most of the men talked about the body looking thin after a diagnosis of cancer and they appeared to believe that this is one of the main signs that a person may have cancer. This may be related to their experiences of witnessing bodies in the later stages of a cancer diagnosis when weight loss is more common. The men used these images to assess their own bodies for cancer risk:

*She'd lost a hell of a lot of weight [wife's cousin] and that's why perhaps, I mean I got this trouble with my bladder and I've got a catheter in ... I've got all that trouble but it might be, the only thing that sort of relieve me is the fact that I can't lose blinking weight, that's all, I thought if I had cancer I'd lose weight (Participant 034 IT: p3)*

The men who were more involved in the care of someone with cancer talked about the images as being difficult to tolerate. Participant 035 had a niece who was dying

from a brain tumour at the time of the interview. He visited her every day and found sadness in her distressed image:

*Just sit there with her sometimes, she just doesn't want to talk, you know. But that's the worst thing is you can see it in her face you know  
(Participant 035 IT: p4)*

### 7.2.2 Social acceptance

Despite being exposed to distressing images of illness, the men talked easily about health, illness and dying. Most of the men appeared to think that talking about their own bodies in relation to illness was accepted by society and created friendship groups by sharing experiences about which they could openly talk. This is also evident in chapter 6 when considering the similarities men found with each other through discussions about health and illness. During his interview participant 034 called talking about health 'out-illing'. He used this term to describe the talk of older people when the focus of their conversation was about health:

*Elderly people when they get on they tell you all their problems...no matter what you've got wrong with you there's always someone who will out-ill you  
(participant 034 IT: p13)*

The term 'out-ill' encapsulates the way the White Working Class men talked about their ageing bodies. The men appeared to accept that their bodies will inevitably age, and therefore, the body that is unwell as a process of ageing was normal within this group of men. Illness talk is socially acceptable for the White Working Class men and seemed to relate these men in their everyday lives. Chapter 9 examines the way men talk to each other about health and the ease at which the men talked about the topic during the focus group. The following notes were made immediately

after the focus group with White Working Class men and provide an insight into thinking about the White Working Class men and the social acceptance of illness:

*The white men appeared to talk as individuals, telling me about their health problems. They were not concerned about talking in front of each other but they did not talk to each other. It appeared that their engagement in talking about health, during a focus group, was to talk about their own health experiences as a linear process, rather than as a conversation about each other's health. The environment was safe for them to talk and they said they enjoyed the opportunity to talk. Two of the participants admitted to having chronic health conditions at the start of the group and preferred to speak about their own health problems and experiences, than stay on the topic of the focus group discussion. (Focus group observation White Working Class men.)*

### **7.2.3 The body at risk**

#### **7.2.3.1 The older body**

Participant 027 made the relationship between age and health risk clear. He was the youngest participant (age 40 years) in this research and lived in one of the most deprived areas targeted for recruitment for this study. His mother was diagnosed with kidney cancer three years before his interview, which was treated with curative surgery. His father also had investigations into symptoms that may have been related to bowel cancer, which transpired to be non-cancerous, and when participant 027 was asked if these experiences had influenced his own views of illness, he said:

*Not really, I don't see myself as, generally I see it [cancer] as a middle aged onwards, I'm quite fit and healthy in my work and physically I feel fine (Participant 027 IT: p3)*

Participant 027 provided a timeline that he believed concerns about the body start to occupy a man's mind. In the trajectory of ageing, and thinking about the body and illness, participant 036 put the occupation of these thoughts at later than middle age;

*Well I'm 78 now, I thought, you know keep your eye on it [prostate cancer symptoms], 78, 80 you know  
(Participant 036 IT: p8)*

This man viewed his risk for prostate cancer as increasing with age, and participant 022 also considered health risks associated with the ageing trajectory. This man was in his mid-60s at the time of his interview, and he comforted himself when he talked about his own cancer risk by recalling experiences of older men dying from cancer:

*His own father [friend] died of cancer but he was pretty old, in fact he was in his 80s  
(participant 022 IT: p5)*

#### **7.2.3.2 The ageing and familial body at risk**

The men talked about risk in the context of age and also family history. Family history was commonly referred to when talking about risk for cancer and other chronic conditions. Participant 022 was concerned about his health and familial risks for illness. He talked about his father living with arthritis and he believed he had increased risk for this chronic condition:

*I've been expecting to get arthritis since [father's death]...you know there's no sign of it quite frankly  
(participant 022 IT: p12)*

Family history of illness was also a feature of health risk perceptions for participant 035. This man had a history of prostate cancer in his family and he was concerned that this increased his risk for prostate cancer: *"I suppose my risk must be above average because we have got it in the family"* (participant 035 IT: p8). He managed his concerns about prostate cancer risk by asking his GP for a regular PSA blood test - a process of screening that is not normally available for men concerned about their

bodies risk for prostate cancer. As discussed in chapter 2, the discussion of a PSA blood test was assumed to be unusual amongst men from socially deprived areas, and participant 022 was the only man who talked about speaking to his GP about this.

Participant 014 also talked about his concerns about prostate cancer because of a history of prostate cancer in his family. His father died of prostate cancer not long before his interview and he recalled being concerned about symptoms that he thought were related to prostate cancer:

*P: Yes, if you want that it's my own doctors, you know, it's very rare I'll go. There was one time I was a little bit worried so I had various blood tests.*

*SF: Okay, what were you worried about?*

*P: Cancer*

*SF: Specifically?*

*P: Prostate cancer.*

*SF: Okay*

*P: I thought it was hereditary.  
(Participant 014 IT: p4-5)*

During the interview with participant 014, it transpired that he was worried about, “a bit of blood in my back passage (participant 014 IT: p5)”. This is a misconception about the symptoms of prostate cancer that is discussed in section 7.2.3.5.

### 7.2.3.3 Managing perceived risk

Participant 022 was the most active and health conscious of the White Working Class men. He was aware of prostate cancer but did not feel this was his main health concern:

*I mean I would suggest that probably prostate cancer is not the biggest thing I'm afraid of, probably heart disease is probably higher up the list... because it kills a lot, bigger proportion of people than prostate cancer (Participant 022 IT: p8)*

This man based his perception of risk on statistics and led a healthy lifestyle to reduce his risk for heart disease, by cycling regularly and maintaining a healthy diet. However, this did not ease this man's concerns about risks to his body. Using the language: "prostate cancer is not the biggest thing I'm afraid of" (participant 022 IT: p8), suggested that for this man health risks were a source of anxiety, although his healthy behaviours to reduce his risk of heart disease did not seem to alleviate his concerns.

Managing risk by maintaining a healthy lifestyle was mentioned by most of the White Working Class men taking part in this research. However, apart from the man discussed above, few talked about practising a healthy lifestyle. Participant 013, who had recently been to education sessions on how to manage his diabetes, appeared defensive when asked if he would change his lifestyle to reduce his risk of complications related to his diabetes:

*SF: And are you going to make changes?*

*P: Oh well I have, yeah.*



*SF: Good, what have you done as a result of it?*

*P: Well I changed my eating habits a bit, it's not going to make a lot of difference with losing weight because it's the insulin I'm on makes you put weight on (Participant 13 IT: p4)*

Participant 014 was also reluctant to change his lifestyle despite thinking he has an increased risk for prostate cancer, because of his father's death from this cancer.

Unlike participant 013, this man recognised that there was more he could do to help reduce his risk and blamed himself for his risky health behaviour:

*I think it's quite high [risk for cancer], I mean I'm a smoker so I haven't done anything to tackle that...my father never smoked in his life you know...my father didn't and I thought if somebody is super fit, there was Lance Armstrong as well wasn't there, I think if you're super fit you think oh no they're invincible (Participant 014 IT: 12)*

It appeared that to try and understand this apparent dissonance in beliefs and behaviour, this man referred to physically fit people being diagnosed with cancer.

He appeared to be giving himself a reason for not taking responsibility for his own health risk, and participant 013 also conveyed this attitude:

*I don't know, with lung cancer... smoking is a big help; maybe with alcohol ... something triggers it. But I knew someone...he was a non-smoker, non-drinker, and he got it ... (Participant 013 IT: p3)*

Participant 013 further talked about health not being his responsibility when he said, "you've got to have it before they tell you how not to get it like" (Participant 013 IT; p3). It appeared he was passing the responsibility of his body to healthcare professionals; he was not talking in a proactive way about reducing his risk for illness, he saw this as someone else's responsibility.

#### 7.2.3.4 The private body

When discussing prostate cancer, the White Working Class men recognised a barrier to seeking health information as the area of the body that is affected. Participant 014 talked about conversations regarding health between men and identified that some cancer talk would be acceptable, but that talk about prostate cancer may not happen because of the area of the body involved:

*Because it's not to do with any genitalia or anything like that [lung cancer], you know, that's all. I think you can talk about that but anything else [prostate cancer], no (Participant 014 IT: p7)*

Participant 022 also recognised that this area of the body is private to men and he talked about this being related to concerns about the masculine body:

*The men don't tend to, it's a bit sort of macho, it's not so much something men want to talk about so much [prostate cancer] (Participant 022 IT: p9)*

However, the men in the focus group were happy to talk about health and illness and recognised the private body. They were happy to talk to each other about the functioning of their bodies with reference to urinary function, but when considering the rectal exam they agreed that some areas of the body should to be kept private:

*P04: I think most men are reserved on the sexual side of their body, it seems to be part of that category and they won't talk about it.*

*SF: Okay, so it's to do with where it is in the body, do you agree with that, because of the area it has some embarrassment, what do you think?*

*P01: Mmm, I had two mates who were too shy to go to the doctors and they didn't last long, a couple of weeks.*

*P05: I lost two friends through it in that respect, that was up our allotment.*

*(White men focus group transcript: p11)*

The men talked about embarrassment when talking about this private area of the body. However, when asked how they would feel about having a digital rectal examination to examine for possible prostate cancer, all the men agreed that they would have this examination if a doctor recommended it:

*Well if the doctor recommends it [rectal exam] then I'd say yes go ahead  
(participant 022 IT: p14)*

*If I was at that stage in proceedings then I'd be fully compliant... I know  
that I wouldn't object to that [rectal exam]  
(participant 027 IT: p7)*

Therefore, it seems that the public talk of embarrassment would not prevent these men from having a rectal examination if it were felt necessary. The men in the focus group also agreed that they would have the examination if it was necessary, and they appeared happy to talk about this in public:

*P03: I've had it done quite a few times [laughter].*

*P06: You sort of tense up don't you.*

*[...]*

*P05: I think if you're going in and you really feel that there is a problem, I think most of us probably would say, if that's the person you've got to see, then that's the one you've got to see whether it's a man or a woman.*

*SF: So you would go for it and*

*P05: If you really thought you had to go for you know, you needed it  
(White men focus group transcript: p8)*

There seems to be some contradiction in the way the men talked about the rectal examination and the perceived embarrassment associated with this. Perhaps these men felt they needed to provide a social image of non-acceptance, which may form part of their social construction of the male body.

#### 7.2.3.5 Misconceptions

When the White Working Class men talked about how they might become aware that they were experiencing symptoms of prostate cancer, they said that the main symptom is rectal bleeding. Rectal bleeding is not actually a common symptom of prostate cancer.

It is possible that because of the apparent association of prostate cancer with the rectal exam the men appeared to link this to the area of the body that is at risk.

When asked what type of symptom would be related to prostate cancer participant 027 answered:

*The onset [of prostate cancer] might be noticing blood in your stools maybe, maybe that's all I'd, you know if I spotted something like that then I'd get that flagged up  
(participant 027 IT: p7)*

This misunderstanding was shared by most of the White Working Class men.

Participant 034 said he has read about the symptoms of prostate cancer and the association with blood in the stool:

*No, well the symptoms, well the symptoms that I read in the toilet on the stools  
(participant 034 IT: p7)*

These misconceptions were initially supported when the men in the focus group were asked to discuss the most common symptoms of prostate cancer. However, participant 05 remembered that when his father had prostate problems he had difficulty passing water;

*P03: I would say the one who's passing blood [in the stool].*

*P05: Passing water more often, my dad had prostate problems about three or four times and I always thought a lot of problems with prostate is actually restriction of your water flow rather than an increase in your water flow.*

*(White male focus group transcript: p3)*

Participant 05 used his experience of prostate cancer to talk about his understanding of symptoms, but this was not evident in all the men with experience. Participant 014 talked about his father dying from prostate cancer but was still concerned about rectal bleeding:

*I had a bit of blood in my back passage so I think that give me a little bit of a wakeup call (Participant 014 IT: p5)*

#### **7.2.4 Summary**

The White Working Class men talked about their bodies ageing and how they associated this process with illness and decline. They had witnessed the declining body through their relatives' illnesses and so associated ageing with this process. They had also associated this with cancer, and they talked about their experiences of seeing a thin and declining body as influencing their perceptions of their own risk for cancer. This seemed to influence their perception of risk for cancer by associating concerns for cancer with weight loss and decline. The White Working Class men talked about the image of a body with cancer as one that is thin, and for some men, not being able to lose weight seemed to appease them that they were not

at risk for cancer. This contextual view is based on the knowledge and experiences of the men at the time of the research.

The White Working Class men appeared to find talking about their health a normal part of social conversation, during the focus group their talk was littered with references to their own health (see chapter 9). The social acceptance of ill health and its place in social conversation was vocalised by participant 034 as 'out-illing'. It appeared that these men used talk about their bodies as part of their everyday conversations and this talk became competitive.

The men believed that their risk for cancer increased with age and the youngest participant did not give any thought to his risk for cancer or how he could lower his risk, apart from maintaining a healthy diet and lifestyle. The men were also aware of the contribution of family history to their risk for cancer and only one man who had a history of cancer in the family monitored his health with more scrutiny. They talked about certain behaviours (smoking) increasing the likelihood of a cancer diagnosis, but they also used examples of men who had maintained a healthy lifestyle and had still had cancer. Those men who were the least engaged with their bodies, in relation to health and illness, appeared to use these examples to justify their risk-related behaviour or their lack of motivation to find out how to look after their bodies.

For the White Working Class men in this research, the social acceptance of illness and its apparent place in the everyday lives of these men seemed to keep the unwell body at the centre of their social experiences. It seems that for the White Working

Class men, illness was a socially acceptable part of growing older and therefore, the unwell body had a place in society for these men. For some men, talk of illness provided access to social groups and this was evidenced by the way they describe their openness of health talk in social situations. Although some of the men talked about not wanting to discuss health concerns, it will be seen in chapter 9 that discussing illness is part of these men's opportunities to socialise and maintain status within a social group.

The men also talked about areas of their bodies as being private, in terms of the area of the body involved with a prostate cancer diagnosis. The men talked of friends and work colleagues who have delayed seeing a doctor because of problems related to their genitalia. One participant related this to 'being macho' but most of the men didn't mention being masculine, rather the difficulty of discussing an area that they viewed as private. Despite this, all the men in this research said they would agree to have a digital rectal examination if their doctor thought this was necessary. The men appeared to be accepting of openly talking about their health, and in the focus group did not place restrictions on the areas of the body they included in their social talk.

Most of the White Working Class men appeared to believe there is a relationship between rectal bleeding and prostate cancer. It is thought that this is related to their understanding of prostate cancer examinations involving a digital rectal exam as this knowledge was openly discussed amongst the men, increasing their awareness of this procedure.

## 7.3 African Caribbean men

### 7.3.1 Body image

The African and Caribbean men talked about their close involvement in caring for their elderly relatives during the final months of their lives, in a way that the White Working Class and Somali men did not. Participant 016 talked about his involvement in the care of his mother who was diagnosed with cervical cancer. He did not choose to talk about the image of her body during this time, but made it clear that the family chose to be involved in her care through the constant involvement of her children:

*She has six children so apparently she was happy, I took time off to go to stay with her for a week and we keep alternating  
(Participant 016 IT: p6)*

Participant 030 was also involved in the care of his mother and talked with more intimacy about the image of her dying body. He seemed to find this experience disturbing and he talked with clarity about the memory of this:

*In the end she was like well I would put her on the toilet and put my finger underneath her and she was just bones you know. It was just awful; you wouldn't let animals live in those conditions you know  
(participant 030 IT: p5)*

This man was disturbed by the image of his mother with cancer and comparable to this is the experience of participant 010 recalling the image of his girlfriend, who died from cervical cancer. He remembered the effect cancer had on her body and recollected seeing the changes to her body;

*In my girlfriend's case when her stomach started to swelling like she was nine months pregnant I seen it with my own eyes and I sat there and I seen her stomach  
(Participant 010 IT: p6)*



These experiences have provided the men with exposure to the unwell body and appeared to have created disturbing images and perceptions of cancer. This may have led these men to consider illness as something that can disfigure their bodies and as a group of men who appeared conscious of their body image this may have caused difficulties with accepting illness.

Having a fit-looking body was important to these men, as voiced by participant 024, *“Muscle size has always been important to me and shape has always been important to me”* (participant 024 IT: p17). Of all the African Caribbean men interviewed, participant 024 was the most conscious of his body image and he talked about people’s concerns over the image of illness. He believed people would choose to keep symptoms of illness hidden if there was a risk of changes to their body image:

*Image thing is a funny thing [image of illness], yeah, because that’s hard to take. You know if some people can keep it hidden and let it stay hidden although it might cost them their lives (Participant 024 IT: p26)*

The importance of body image appeared complex for the African Caribbean men. As discussed in chapter 6 these men have lived their lives in the United Kingdom on a background of racism, which seemed to have generated feelings of pride amongst these men, exhibited in their talk of being black, fit and strong. The acceptance or non-acceptance of the unwell body was part of this complexity of body image. The impact of these images had an emotional effect on these men that ranged from being scared, *“I’ve seen the build-up [to Invictus Games] where they’ve shown the before and after and it’s always scared me”* (participant 024 IT: p28), to feeling disgusted, *“when they say this happened and that happened and it makes me ill, makes me feel sick like, physically”* (participant 019 IT: p9). Related to the importance of a physically fit and

healthy body image, the African and Caribbean men talked about health literature relating to prostate cancer as not being relevant to them as the men appeared too healthy to be portraying illness:

*It doesn't come across as if it's a problem, to me, you know and the guy himself he looks alright to me, he looks like he's getting paid to do it (Participant 024 IT: p27)*

During the debate between the men in the focus group, one man talked about the impact of watching television programmes about disfiguring health complaints. He appeared shocked by the images he had seen and another man in the group was particularly concerned about seeing this type of image. It appeared that the image of an unwell body was salient to these men:

*P03: I mean I watched this programme Embarrassing bodies and I seen them when they're looking from what you call it, call it piles, and you see people turn around and some of them you can see their haemorrhoids way down.*

*SF: Hanging yeah*

*[...]*

*P01: I would never watch, I could never watch something like that. (African Caribbean focus group transcript: p16-17)*

During the interview with participant 019, when discussing how he thought awareness of prostate cancer should be raised amongst black men, he said the best way would be to “*shock them sort of thing*” (participant 019 IT: p24), and although he did not make specific reference to an image of the unwell body he saw the value in striking health messages. For these men, the image of the unwell body was salient, whether they chose to look at these images or not, there seemed to be impact and clear recollection.

### 7.3.2 The body at risk

#### 7.3.2.1 The ageing body and familial risk

The African and Caribbean men recognised that, as their bodies start to age, there would be changes and possibly illness. They were aware that their bodies didn't function as they did when they were younger, and that this meant they needed to be aware of possible health problems. For some men, this was a cause for concern because of changes to their body image:

*I was in such good shape that I believe this is a specimen to help science and stuff, that's how it felt. I never realised that the older I got things were breaking down, you know. I still keep myself relatively fit; I still do the gym (participant 024 IT: p4)*

Because participant 024 had such a high regard for his physical fitness he was trying to counteract changes relating to age by exercising regularly. In the extract above this man was talking about maintaining a healthy body image through exercise rather than reducing his risk for illness, which is dissimilar to the talk of the White Working Class men. Participant 024 is not unusual amongst the African Caribbean men interviewed for this research, participant 030 also placed regard on his physical fitness and was keen to talk about his exercise experience during his interview:

*Every night and I'm playing table tennis or football...did sports you know, best part of my life and martial arts for seven years (Participant 030 IT: p14-15).*

However, other African Caribbean men in this research appeared more concerned about the physiological changes to their bodies as they aged, as opposed to fitness and image. These men talked about areas of their bodies changing and needing to

be aware of risks as they get older. Participant 010 talked about his toilet habits changing as he aged and he accepted this as a normal change in his body:

*I've always slept through it but now I find myself now starting to wake up hence I'm thinking well is the bladder getting weaker because I'm getting older*

*(Participant 010 IT: p7)*

Participant 032, who was the most informed about prostate cancer, also talked about needing to be aware of changes to the body as he aged:

*As I say as you get older there are a certain things that you need to be mindful of so but yeah (Participant 032 IT: p10)*

The African Caribbean men in the focus group also talked about how their views of lifestyle and risk have changed as they've become older, when they reflected on the health behaviour of younger men. The men talked about temporal risk when discussing changes in attitude over time:

*P01: Well we're at the ripe age where we can say look, you know, we should have done that when we were kids, you know what I mean?*

*SF: And is that what everyone thinks, what do you think?*

*P03: But when you are younger it's okay, and now it's different.*

*P02: He was a kid and now it's too different.*

*(African Caribbean men focus group transcript: p8)*

The African Caribbean men were aware that their bodies were at increased risk for health complaints if there was a history in the family. Some of the men understood that a history of chronic health conditions in their families could increase their own health risk:

*It's hereditary apparently, everything seems to be hereditary, you know, it seems to be a pattern. I never knew nothing about diabetes yet my father had diabetes, my sister has diabetes and a niece now has diabetes (participant 024 IT: p4)*

Participant 032 talked about hereditary risk but balanced this with lifestyle choices changing the balance of risk of a cancer developing. He talked about his uncle who died from lung cancer. He was aware that his uncle's lifestyle may have increased his risk for cancer by saying his uncle was a "good liver" (participant 032 IT: p6).

Participant 019 also recognised that lifestyle can put a person at risk from cancer when he talked about a man dying of cancer, "so I said well Lord he's like a, he drinks Lord, likes women and all that sort of stuff" (participant 019 IT: p13).

### **7.3.2.2 Risk and being black**

Whilst in the community centre in an area used to recruit the African Caribbean men, I engaged in conversation with an African Caribbean man who told me that all the men in his area were aware of health risks because of their ethnic origin:

*He tells me that the African Caribbean men in this area are aware that they have a higher risk for prostate cancer, just as they know they have an increased risk for diabetes and high blood pressure. He is not sure how the men use this information to find out about their increased risk but he knows that he does not go and see his GP or look for information himself (FN 7: p1)*

The views of this man were confirmed during the interviews when the African Caribbean men talked about being black as giving them an increased risk for certain health complaints, "Yeah because they're [black men] the ones at risk" (participant 019 IT: p22). This man made a distinction between black and white skin as an indicator of absence or presence of risk, "I thought it was only white people that had it [melanoma], but cancer it can happen to anybody can't it?" (Participant 019 IT:

p21). Participant 032 was the most informed about health and he was well informed about the specific risk for prostate cancer in black men. His attitude was not to worry about the risks to his body because he has equipped himself with the knowledge to manage these risks:

*I'm aware of the risk to African Caribbean men [for prostate cancer] but I'm also aware of the symptoms, or the likely symptoms and I don't want it to become a worry as well ... it's not a life sentence being African Caribbean  
(participant 032 IT: p12)*

Participant 030 was conscious that some people were at greater risk for certain health complaints because of their ethnicity but he was not aware of his particular risk for prostate cancer. This man talked more than any other participant about the community; he talked at community level rather than about his own health. When he was asked about his awareness of health risks specific to being black, he said:

*R: If you know that because of your race you need to be having certain things looked at at a certain period then in time...(Participant 030 IT: p17)*

Here, participant 030 seemed to be referring to people wanting a screening programme to motivate them to see their doctor and consider their specific risk. This view was not uncommon amongst the African Caribbean men in this research, and this is considered below.

### **7.3.2.3 The screened body**

Participant 030 believed that people in his community needed encouragement to think about their bodies as at risk from disease:

*Most people in these communities...diseases and death is abstract to their life, that's out there, that's nothing to do with me, you know (Participant 030 IT: p8)*

This man appeared to believe that people are not engaged with their bodies and health, but he went on to say he would be interested in any information about lowering his risk for illness through regular check-ups, and thought the community would also be interested in this. His belief was that people would be more proactive in protecting their bodies if they were invited to regular screening:

*I need to take the following steps and have the check-ups or whatever it is, you know, in that context people would be interested yes (Participant 030 IT: p9)*

Participant 016 also talked about the value of screening. This man believed that regular screening told him that his body was healthy, and based his decision-making about health risks on this screening process:

*P: I put my name down for screening. So apparently I'm going to be screened but I have on a yearly basis, my GP is here.*

*SF: Oh just in (place name)*

*P: Yes, I have screening from them you know, so I don't have any medical issues.  
(Participant 016 IT: p4)*

This man appeared to feel safe with the screening process and reducing his body's risk for illness. His comments mirrored the thoughts that participant 030 had of the health behaviour of individuals in his community. He appeared unaware that prostate cancer cannot be screened for; he talked about a friend who was diagnosed and eventually died from prostate cancer and believed that his friend's cancer was diagnosed from a general screening process:

*So apparently after seven days, when he went for his result they told him that look gentleman it seems you have a problem... it's from that screening that they discover he has cancer (Participant 016 IT: p2)*

The men in the focus group also talked about screening when discussing concerning health symptoms. One of the men started to talk about the bowel-screening programme that is now available for all people between the ages of 60 and 74 years. Participant 03 in the focus group was open about the fact that he had taken part in this screening and that his results had been clear:

*P03: They send some test strips through the post on what you have to do so I done that. I think I done it twice now.  
(African Caribbean men focus group transcript: p8)*

The men's involvement in bowel screening programmes was very positive and the ease at which they talked about intimate examinations was surprising. This was also seen amongst the White Working Class men, and this comfortable nature of conversation will be considered in more detail in chapter 9.

### **7.3.3 The private body**

During an examination to check for prostate cancer, the men may have a digital rectal examination. The African Caribbean men in this research were asked if they had any concerns about having this type of examination. Participant 024 was the most explicit when he considered why he found the procedure disturbing. When discussing the examination, he said: *"there's many things about a man and another man and I find it extremely disgusting"* (participant 024 IT: p18). This man seemed to be making reference to homophobia and there were other African Caribbean men in this research who talked about concerns relating to homophobia. The men in the



focus group debated the acceptance of the digital rectal examination during task four (appendix VIII). They referred to the beliefs of men in the Caribbean;

*P03: I had the different thing by going to the toilet and put it on the swab and everything so this [the rectal examination] will be strange to me because I never had it done. But I know in the West Indies a lot of people don't like this.*

*P01: They don't have that.*

*P03: Just a minute (name given)...they don't want this because they're thinking anti man and man putting something up there.  
(African Caribbean men focus group transcript: p14)*

Participant 032 also made reference to sexual acts between men, and the relationship of this to specific concerns for black men and why they might find this examination disturbing;

*I think part of it [fear of rectal exam] may be down to, I'll say latent homophobia with a connection to anal sex and things and gay sex, do you see what I mean... going back to the latent homophobia, I know there's a huge intolerance to homosexuals in the Caribbean and to the point of persecution (Participant 032 IT: p16-17)*

For some of the men in this research, who migrated to the UK as young men, they appeared to have gone through a process of acculturation and now accepted that a medical procedure, which involves a digital rectal examination, is not akin to a sexual act. They seemed to have been able to accept the views of the dominant culture, that homosexuality is accepted as part of the wider society. The men in the focus group talked about men in the Caribbean as being different to them, in terms of their acceptance of a rectal examination. Participant 03 said; *they don't want this because they're thinking anti man (African Caribbean men focus group transcript: P14)*; this man seemed to be making a distinction between himself and men from his

country of origin. As a consequence, the African Caribbean men in this research appeared to talk openly about having had a rectal exam, as this participant in the focus groups explained:

*P04: I've had it done just over a week and I never had this done to me I was sore for bloody days, but I knew why it was done and I understand so (African Caribbean men focus group: p14)*

For other men, who have not had the experience of a rectal examination they also appeared accepting of why the examination would need to be done. Participant 030 was informed during his interview that he would have a rectal examination as part of testing for prostate cancer, and accepted that it might be required: *"it's just something odd isn't it, just get on with it...I don't think I want to die"* (participant 030 IT: p16). Participant 019 also recognised that having the examination would be uncomfortable but he acknowledged that he would have the procedure if it were required:

*I think I would do whatever I got to...what's got to be done has got to be done, I mean if somebody said look it's life threatening you need to do this, well you know really you should let them do what they've got to do if you've got any sense (Participant 019 IT: p19)*

This view was also mirrored by participant 032 who realised that if this was a potentially lifesaving procedure he would consent to the examination being carried out:

*It's [the rectal exam] not the reason I wouldn't go [to the doctors], no. Not that it fills me with a lot of joy but (laughs) but I think on balance you do have to bring it into context don't you, do you see what I mean and potentially it's a life saver so you do have to put it into context don't you (participant 032 IT: p13)*

These men appeared happy to overlook their concerns about a rectal examination as their drive to maintain their health appeared greater than risking a potentially life-threatening diagnosis such as prostate cancer. Two of the African Caribbean men interviewed had experienced a rectal examination at the time of their interviews and for one of these men the experience was particularly traumatic.

Participant 024 was the most explicit about how this made him feel. He recalled feeling violated by the experience and found it hard to forget what had happened to him:

*That was the first time that I had a doctor put his finger, no man has ever touched me in that way ... you know and he did it, I felt violated, I really felt violated. That affected me ... it stayed in my mind for a long time because I felt that the back passage in there was being enlarged, I could feel it opened wider, it went on for weeks (Participant 024 IT: p17)*

This man displayed the most pride when he talked about taking care of his body and the importance of physical male body image, and it is possible that his reaction to the rectal examination was related to concerns about homophobia and the uninvited invasion of his body. For this man, it seemed that the image of possessing a masculine body, based on the preconceptions of the black heterosexual body, was salient and this made the uninvited invasion of his body difficult to cope with.

However, despite the experience described by participant 024 he talked about reconciling himself to the fact that he would need to have the examination again, and has had a rectal examination for a second time. His concern for finding out if

anything was wrong with his prostate outweighed his concerns about homosexuality and the rectal exam:

*But I had no alternative because I wanted something to find out what was going on. Fair do's, I appreciate that (Participant 024 IT: p17)*

#### 7.3.4 Misconceptions

When asked what the men know about prostate cancer, all the African Caribbean men, with the exception of participant 032, mistook prostate cancer for testicular cancer. They talked about being able to feel for a lump themselves and one man told me about boys at school being educated about their prostate and running out of school to 'have a feel'. The field note below is an extract from a conversation with this man:

*SK told me a story after the run that the boys in secondary school had a talk about prostate cancer. They were taught how to examine themselves and left school rushing off to 'have a feel'. He is confusing this with testicular cancer, and this misconception seems common in this community (FN 18: p3)*

It seems that for this man 'having a feel' is an amusing term and it appears that he puts this remark in the context of something the boys will enjoy doing, like participant 016. Participant 016 also talked with humour and with secrecy when he was asked what he knows about examinations for prostate cancer:

*So most of the time when I'm sleeping I wake up in the morning and I try to examine myself (laughter). When she [wife] goes to the bathroom I do whatever I want to check myself (Participant 016 IT: p5)*

This man was talking about examining himself as a private act and something that his wife should not know about. He appeared entertained by this apparent secrecy

and through his misconception possibly linked an examination for prostate cancer to a secret and possibly sexual act.

Participant 010 also made a misconception when he talked about his acceptance of having a rectal examination and his experience of this:

*I thought it was something to do with the testicles and stuff until like I said we went to see my doctor and he put his finger up my rear (laughter)  
(Participant 010 IT: p3)*

It is possible the men made this misconception because they received media messages about testicular cancer. Participant 016 and 019 both referred to hearing about what they needed to do if they, “*feel any pain, any lump within scrotums, your testicle*” (participant 016 IT: p5). It is also possible that this misconception is related to the views these men have about their bodies. The men appear to want to maintain an image of health and masculinity based on the pride they feel about being black, which seems to have been developed from their experiences and the social context of the body. It may be that the men are aware that prostate cancer is a uniquely male complaint and they have made a connection to one of the most salient of male genitalia, their testicles.

### 7.3.5 Summary

The men talked about how they had been closely involved in the care of relatives with cancer and they recalled with clarity the images of their ill bodies. This experience had left fear of the images of illness in these men, which appeared to be involved in the importance of reinforcing the value of a healthy image for these men.

For these men, the image of a healthy body was also talked about as a physically fit body and they placed emphasis on maintaining this image, even as they grow older. The importance of the image of fitness was complex for these men, and was bound in the need for a healthy image and the fear of illness, as well as the background of racism they may have experienced. It seemed that these men were maintaining a positive identity, in spite of being black.

It is thought that because of their exposure to unwell bodies, these men needed to see images of other unwell bodies in health literature before they felt it was relevant to them. They needed to draw on their memories of unwell bodies to find the information salient. Conversely, the men also talked about hiding symptoms of illness because of concerns about body image. The talk was conflicted and this needs to be explored further.

The men talked about risk in relation to ageing and the effect this had on their bodies. They already knew their bodies changed as they got older and that they would be at increased risk for certain conditions. Some of the men combatted this by talking about keeping fit but this had relevance to their body image and not simply prevention of illness. The men were also aware there was some risk associated to familial health and that being black put their bodies at higher risk for certain conditions. Their actions in relation to this knowledge was unclear, and one man explained how most people in his community found illness abstract to their bodies.

The benefits of the screened body were talked about by most of the men. Some men believed that the community would be more active in protecting their health if screening was available. One man believed that he was screened for all health complaints through attending regular screening clinics at his GP surgery. This reliance on screening handed over any concerns the men had about their bodies to the medical profession. The men talked about taking up screening to protect their bodies but they talked relatively little about actions they were taking to maintain their own protection from risk, outside of the screening process.

One requirement in the process of obtaining a prostate cancer diagnosis for these men was having a digital rectal examination, which most of the men accepted as being necessary. They had concerns about this as a process of screening or diagnosis because of the background of intolerance of homosexuality in their countries of origin. This had created fear of the examination in some men, but they also seemed to realise the importance of the examination and accepted it. The men seemed to have been through a process of acculturation, so the link between the examination and homosexuality may have lessened.

It is possible that because of the views of their bodies in relation to physical fitness, masculinity and performance, these men were more likely to focus on cancer affecting the organs that make them uniquely male, the testicles. It seemed they were concerned about their male image and problems testicular cancer may cause to this image, and so testicular cancer may have become more salient to them. The men's desire for screening was met by information given to them about testicular self-examination, which enabled them to monitor this area of their bodies. The

misconception between prostate and testicular cancer was the embodiment of the views of their bodies as male, and the greatest risk to their health.

## 7.4 Somali men

### 7.4.1 The medical body

When talking about illness the Somali men constructed their bodies as not really belonging to themselves. They had so much faith in doctors that they appeared to hand over all responsibility for the unwell body to this profession. The Somali men appeared to do this completely and without question. This may be linked to the non-questioning approach of the Somali men because of their limited use of the English language, as discussed in chapter 6. Participant 017, who was the oldest of the Somali men interviewed for this research, was unquestioning about who he would talk to about his body:

*P: If you are ill you see a doctor, (unclear)*

*SF: And would you ever talk to your friends if you felt unwell, the men out there, if you felt ill or something was wrong with you, would you talk to your friends before you went to the doctor?*

*P: Why I told them, I am sick? I have to look my solution.*

*SF: It's the doctor.*

*P: Not somebody else.*

*SF: Okay*

*P: Go there straightaway.  
(Participant 017 IT: p3)*



Because of this apparent faith they placed in doctors the Somali men were very open about allowing doctors to do anything that was required to examine their bodies and those of their families;

*For example somebody I wouldn't go to anybody to touch my wife or my mum's body but when I talk to the doctors, doctors do (Participant 015 IT: p8)*

These men also didn't seem to believe that they should know the symptoms of prostate cancer, because they were not trained to know about their bodies.

Participant 017 was asked what he knew about prostate cancer and his simple response was, *"I am not a doctor"* (Participant 017 IT: p3). He did not seem to understand why he should know his own body and this was also evident in the focus group. During the task 1 (appendix VIII) in the focus group, the men were asked which symptoms might indicate a problem with their prostate; the men answered: *"We're not doctors, we don't know"* (Somali men focus group transcript: p4).

These men also talked about their bodies as belonging to doctors when they were asked about having a digital rectal exam; the men were immediately accepting of the exam. Participant 015 seemed puzzled about why going to talk to a doctor about a problem with his genital area, and possibly having to have a rectal exam, would be a concern:

*I think health is health, I mean if you're a doctor and a female and I come and see you, you're a doctor you know, and I wouldn't be embarrassed to check everywhere for me (participant 015 IT: p8)*

This man did not talk about the relationship of the rectal exam and his feelings about the experience, as the White Working Class and African Caribbean men did.

Participant 017 had the same view as participant 015. At the time of the interview this man was complaining about going to the toilet too often at night. He asked what would happen when he went to the doctor with his concerns; when the digital rectal exam was explained he said: *“I will ask him [for the examination] myself”* (Participant 017 IT: p5).

Participant 018 had no concerns about having the rectal exam but he did appear to have concerns about who did the examination. He said he would not want a woman to do it but would only want a “straight” man:

*P: Yeah, sometimes we won't let a (laughing), I don't want to go to a girl yeah.*

*SF: So you'd have to get a male doctor in to do it.*

*P: Yeah, straight man yeah.*

*SF: Okay*

*P: Straight man, yeah, it's okay yeah. No straight man, no.*  
(Participant 018 IT: p7-8)

This man made a link between the rectal examination and his own views of homosexuality, in the same way that some of the African Caribbean men did. He did not talk about this in the wider context of the Somali community or the beliefs of his country of origin. When the relationship between the rectal exam and homosexuality was explored further with this man, he said:

*When somebody got those kind of feelings you know you don't want to get involved...I know someone who works there in the corner you know, it's no harm for me, I don't care what they do with their lives (Participant 018 IT: p9)*

This man appeared to think about his body as being sexual and linked the digital rectal examination to a sexual act, which the other Somali men did not. He talked about the examination by a homosexual man saying it would be: *“not intimate, it’d be abuse”* (participant 018 IT: p9). Compared to the other Somali men, this man appeared more engaged with his male body and how the body was viewed in the context of others behaviour. Despite this he did say that he would allow a doctor to conduct a digital rectal examination: *“If I trusted by the doctor yeah”* (Participant 018 IT: p7). Although limited in number, the Somali men appeared to be accepting of the rectal examination, despite the reluctance of participant 018. This topic was discussed further with the Somali men in the focus group and their acceptance of the topic as social talk is discussed in chapter 9.

## 7.4.2 The body at risk

### 7.4.2.1 Protecting the body through shared knowledge

For these men not having knowledge defined the body at risk. Despite these men passing on responsibility for their bodies to doctors, the men were also concerned that they didn’t know enough about how to protect their bodies from risk. The men demonstrated a sense of responsibility for preventing illness but they did not seem to feel responsible for the management of illness. The Somali men were motivated to find out about health problems, which might affect them specifically:

*More than anybody I want to know how do you prevent those cancers and how do you get treatment and how do you not try your best to get those kinds of cancers*  
(participant 015 IT: p10)

The men in the focus group also talked about the importance of having information to protect their bodies. They recognised that they could work together to find out about risk; in these conversations, the body extended beyond the individual to encompass the community. The responsibility for education to lower potential health risks was shared amongst the men in these communities:

*P06: What's good for you is good for others.*

*SF: Okay*

*P06: It will help with others.*

*P01: Like if you get information, health information, because if it happens to you, or about your body, you can advise your brother, cousins, brother-in-law, father, do you know?*

*SF: So you've got this community feeling of helping each other.*

*P01: Exactly  
(Somali men focus group transcript: p11)*

The experience of protecting the body as a shared approach was witnessed at a community event organised by a third sector organisation, to inform the men about prostate cancer. The community were motivated to find out about protecting their bodies together, they took a shared approach to managing risk. During a visit to the study area, and whilst the third sector organisation were visiting the area with information about prostate cancer, a field note was made about the men's shared approach to this activity:

*I arrived at the van [travelling van with information about prostate cancer], which was parked on (place name), at 11am ... it transpired that the van had actually been there from 7am ... MY had been at prayer at 07.18 and had told his community about the event that was happening that day. The staff on the van had seen 14 men from the Somali community by 11am...they told me that MY had encouraged these men to attend after prayer. The staff also told me that white men approach the*

*van individually, rather than as a group as seen with the Somali men.  
(FN29: p 1)*

This shared approach to the body appeared have been developed from the community understating of the body. The men seemed to share responsibility for health and their bodies, the body seemed to be perceived as a community concern.

#### **7.4.2.2 The cultural body**

Some of the Somali men talked about treating their own bodies for illness. Although these men put all their trust in doctors, they were still keen to maintain traditional remedies for health complaints. During the interview with participant 017 he talked about a current health problem relating to itchy skin and being too hot. He had been treating himself for this with traditional remedies:

*P: It's very cheap what they use, garlic or something like that, ginger.*

*SF: Ginger yes, garlic*

*P: Lemon, I used to myself.*

*SF: So you make yourself?*

*P: I get better then*

*SF: Something to make yourself better.*

*P: Sometimes I, lemon, with my own skin or when I see something  
(Participant 017 IT: p6)*

This man migrated in the 1980s and he had kept his traditional views of how to treat his body. He was given medication by his GP for unknown health problems and he now appeared to feel trapped in the UK by his body. He couldn't access the

drugs he needed in Somalia and his body did not allow him to go back to where he would like to be [Somalia] as an older man:

*SF: You don't go now because you need to have your medication?*

*P: Yes, I can't leave here.*

*SF: Do you miss Somalia?*

*P: I miss everything, I miss everything.  
(Participant 017 IT: p7)*

During a talk given to the Somali men about prostate cancer, by the same third sector organisation that took their van to the community, a man from the community attended the talk who had recently experienced prostate cancer. He had been experiencing a similar conflict to participant 017 in receiving Western treatment for his cancer, whilst trying to maintain a traditional approach. He was very pleased to talk about his traditional approach and wanting to prove his body had recovered by using his traditional treatments. The following field note details this conversation:

*He told me he had been diagnosed with prostate cancer whilst living in South Wales and had been treated by a well-known Professor at the local hospital. He did not know if he had received curative treatment but he did know that his prostate cancer was better because of an herbal drug he had found in Somalia. He laughed at the traditional western treatments we offer... his comment was "I have cured my cancer; I will tell you sometime how I did it. Not with your medicine", with a menacing smile on his lips as he told me (FN29:p4)*

Both men appeared conflicted about treatments for their bodies. They had accepted Western treatment but were keen to maintain their views of traditional remedies, based on their experiences in their country of origin. It appeared they knew that they were safe in the hands of Western medicine, but felt trapped by their acceptance of these treatments and therefore keen to share experiences of the

healing effects of their own remedies, perhaps in order to maintain their cultural roots.

### 7.4.3 Misconceptions

When these men were interviewed for this research, it was clear from early in the interview process that they had limited knowledge of their bodies. They did not make any obvious misconceptions because they had little or no knowledge on which to base them. During the interviews, they were given information about prostate cancer, written in Somali, which some of them read. After briefly looking at this they made interesting connections to their experiences of illness and the symptoms of prostate cancer.

After looking at the literature, participant 017 focused on the fact that problems with the prostate were related to difficulties passing urine. This man had experience of difficulty passing urine, as he explained during his interview: *"I go to toilet for this too much"* (participant 017 IT: p4). When asked about his knowledge of prostate cancer and the relationship this might have to his problems passing urine frequently, he drew on his experiences whilst living in Africa to try and understand the problem:

*P: The water in Africa...is not too much, so the water make something when you drink happen, something like stones.*

*SF: Stones?*

*P: So this come down where the bladder area.*

*SF: So you can cause a blockage.*

*P: So this is maybe a blockage somewhere, so if it takes long there maybe infection there.  
(Participant 017 IT: p4)*

This man made a connection to the urinary system, apparently based on his experience of problems with the water in Africa. It was, of course, difficult to make this link with certainty because of this man's limited English use. He was interviewed with a translator and so the intricacies of the questions he was being asked may have been lost during the interview. However, the younger Somali men, who had spent less time living in Africa, used experiences from their time in the UK to decide about the symptoms of prostate cancer. Participant 015 talked about his father-in-law who has recently been diagnosed with cancer:

*P: Yes he's passing a lot of blood, a lot, yeah, that's what happened to him.*

*SF: You don't tend to get blood in your urine [with prostate cancer].*

*P: He don't have it in his urine, it's coming from his bum.*

*SF: Okay, so that's bowel. So that's slightly different.*

*P: Oh is it?*

*(Participant 015 IT: p11)*

Participant 018 did not make a direct misconception about the symptoms of prostate cancer. When he was asked if he knew what the symptoms of prostate cancer were, he said that he did know, but that people in the community would use the Internet to find out:

*SF: So you know if you had a problem what the symptoms would be?*

*P: I would yeah, if you got a problem they look, they ask the doctor on Google.*

*(Participant 018 IT: p5)*



This man appeared vague in his answer, although earlier in the interview when he talked about his father's urinary problems (see p.162), he was asked if he knew anyone who had had prostate cancer. He talked about men in the mosque needing to go to the toilet too often, so it could be assumed that he had a certain level of knowledge:

*P: [...] I know a lot of Somali, all men they got yeah*

*SF: They've got problems with their prostate yeah?*

*P: You see at the mosque here they keep having*

*SF: Oh that's interesting, so they're going out?*

*P: Yeah, (unclear)  
(participant 018 IT: p5)*

#### **7.4.4 Summary**

The Somali men had little knowledge about their bodies and the difficulties they may face through illness. The men demonstrated some level of knowledge, such as knowing that not drinking enough can cause renal stones, but they did not appear to have taken on new learning since their migration to the UK. This was perhaps because they seemed to place their trust in doctors, completely and without question. The men seemed very comfortable with letting doctors touch their bodies and did not question having a rectal examination. There were some concerns from participant 018, who appeared to be the most engaged with his body, about the homosexual link with having a rectal examination but he was unusual amongst these men.

Despite their faith in doctors, these men were not averse to receiving information about how to prevent prostate cancer and felt it was their responsibility to know more. They talked about this as knowledge belonging to the community and talked about sharing health information. It is possible that for these men the representation of their bodies overlapped with representations of other men's bodies; embodiment in a social context. It was as if for these men their bodies were supported by the community and not just viewed as an individual concern. These men were open and willing to talk about prostate cancer and they wanted to establish their knowledge together.

Some of the men seemed to feel trapped in their bodies. They talked about being unable to go back to Somalia because of reliance on Western medicine and described their bodies as falling between the traditions of two countries they called home (UK and Somalia). It is conceivable that this was due to their lack of knowledge about their bodies and how to make decisions outside of the direction of medicine. This lack of knowledge also meant that they did not seem to make the same misconceptions about prostate cancer as the White Working Class and African Caribbean men did. Instead they used their experience of illnesses to make a judgement about prostate cancer symptoms and causes, and for these men, this seemed to differ according to the length of time they had lived in Africa before migration to the UK.

## **7.5 Chapter summary**

The images of the unwell body had a lasting effect on the men in this research, with the exception of the Somali men. These men didn't talk about experiences of seeing

unwell relatives or friends experiencing illness. The White Working Class men also didn't talk about being involved in the care of relatives but they had been exposed to dying bodies and this left them with images of pain and frailty, which were also described by the African Caribbean men. The African Caribbean men appeared to be the most affected by seeing images of unwell and dying bodies. These men talked about being involved in the care of their unwell relatives and witnessing the deterioration of their relatives' bodies. This exposure seemed to have made the acceptance of the unwell body difficult for these men, and it appeared they talked about people ignoring health problems because of this difficulty.

As with all the findings discussed in this research, difficulties with the acceptance of the unwell body are relevant within the context of this research and the men involved. It would be interesting to explore this finding further to have a better understanding of whether acceptance of the unwell body is driven by gender or culture, or both. For the men in this research, the African Caribbean men articulated the most concerns about images of the unwell body, when compared to the White Working Class and Somali men.

The avoidance of the unwell body by African Caribbean men meant that an image of healthy looking men on health literature had little impact. Although these men talked about not wanting to look unwell, in this case not physically fit, they said they needed images of illness to capture their attention. There was talk about the benefits of watching health-related programmes and seeing disturbing images, for the purpose of education. The White Working Class and Somali men didn't talk about requiring these sorts of images to capture their attention.

The White Working Class men were the most at ease when talking about their bodies in relation to health and illness. The social acceptance of illness through the process of 'out-illing' meant talk about their bodies was a normal part of everyday life for these men. A number of the African Caribbean men talked of their fit bodies and involvement in sport and exercise, which for them seemed to be more acceptable than talking about illness. Talk of illness was not part of everyday life for the African Caribbean or Somali men. The Somali men were happy to talk about experiences of being in an unwell body if this would help other men in their community, and they didn't talk about their bodies on an individual level, as the White Working Class men did.

The White Working Class men and the African Caribbean men both talked about the effects of ageing and familial risk for cancer in the same way. They recognised that their bodies would start to change and there would be things they would need to monitor. The African Caribbean men also talked about the risks to them because they were black, but they didn't see this as a death sentence, just something they knew they needed to be aware of. Despite this, it was not clear what specific actions the African Caribbean men took to manage risks related to their bodies. The reasons for this appear complex; the men were concerned about being seen as healthy through the image of their bodies and were also reluctant to accept the unwell body, possibly because of their experiences of caring for relatives and the association of this to death. This could also be related to feelings of pride discussed in chapter 6.

The Somali men didn't talk about risk in relation to ageing and family. They appeared to be unaware that these were specific risk factors and this is likely to be due to lack of knowledge amongst the men interviewed for this research. The Somali men didn't talk about their bodies as being black in the same way as the African Caribbean men. This may be because they don't see themselves as being black; they talk of themselves as being from Somalia or Somaliland. Their bodies were an extension of their country of origin and this was where the views of their bodies were formed.

The African and Caribbean men had confidence in the process of health screening. These men talked about feeling protected by the screening process and that men in their community would take more interest in their bodies and prostate cancer if a screening process was available. The White Working Class men did not mention blanket screening, although compared to the African Caribbean men, the White Working Class men were proactive in asking their GPs about screening for prostate cancer. The Somali men also did not talk about screening and this appeared to be because of the trust they placed in the medical profession. This seemed contrary to their desire to protect themselves from illness, and it is possible this has been underexplored with these men because of linguistic difficulties. The men didn't use the term screening but they did talk about seeing their doctors, and it could only be assumed that as they aged they would be invited to regular screening following national guidelines. It is not known from this research if screening was accepted.

What was more evident in the talk of the Somali men was that the knowledge they had about their bodies was limited, and maybe this was because of the trust they

placed in doctors, to do the right thing for their bodies. This meant the men didn't make any obvious misconceptions about prostate cancer; they used their experiences of illness to make links to the likely symptoms of prostate cancer. Conversely, the African and Caribbean men made a very clear misconception about prostate cancer. These men appeared to believe that the prostate relates to the testicles and that they could do their own examination for prostate cancer. It is thought this was related to their views of the body in relation to being male and the salience of their male genitalia in this relationship. The White Working Class men made the misconception that symptoms of prostate cancer were the same as those for bowel cancer. It is thought this was because the white men in this research were the most focused of all the men on their unwell bodies. They were aware of, and most of them had experienced, the digital rectal examination or knew someone who had. The relevance of this to the self-monitoring of their unwell bodies had possibly caused the men to make a connection of the examination to problems with their bowel.

In summary, the body was in different ways evident in the talk of all these men. For the Somali men, the body was talked about in the context of the wider community in which they lived, and information or experiences they acquired with their bodies were shared with other men. The African Caribbean men also talked about the community and knowledge of the body amongst people in their community.

The White Working Class men only talked about their bodies as individuals, and only as part of a wider community when discussing their health conditions. They

saw this talk as socially acceptable and used the seemingly competitive process of 'out-illing' each other to find status amongst friends and acquaintances.

See Figure 5 for a diagrammatic representation of theories developed for this category.

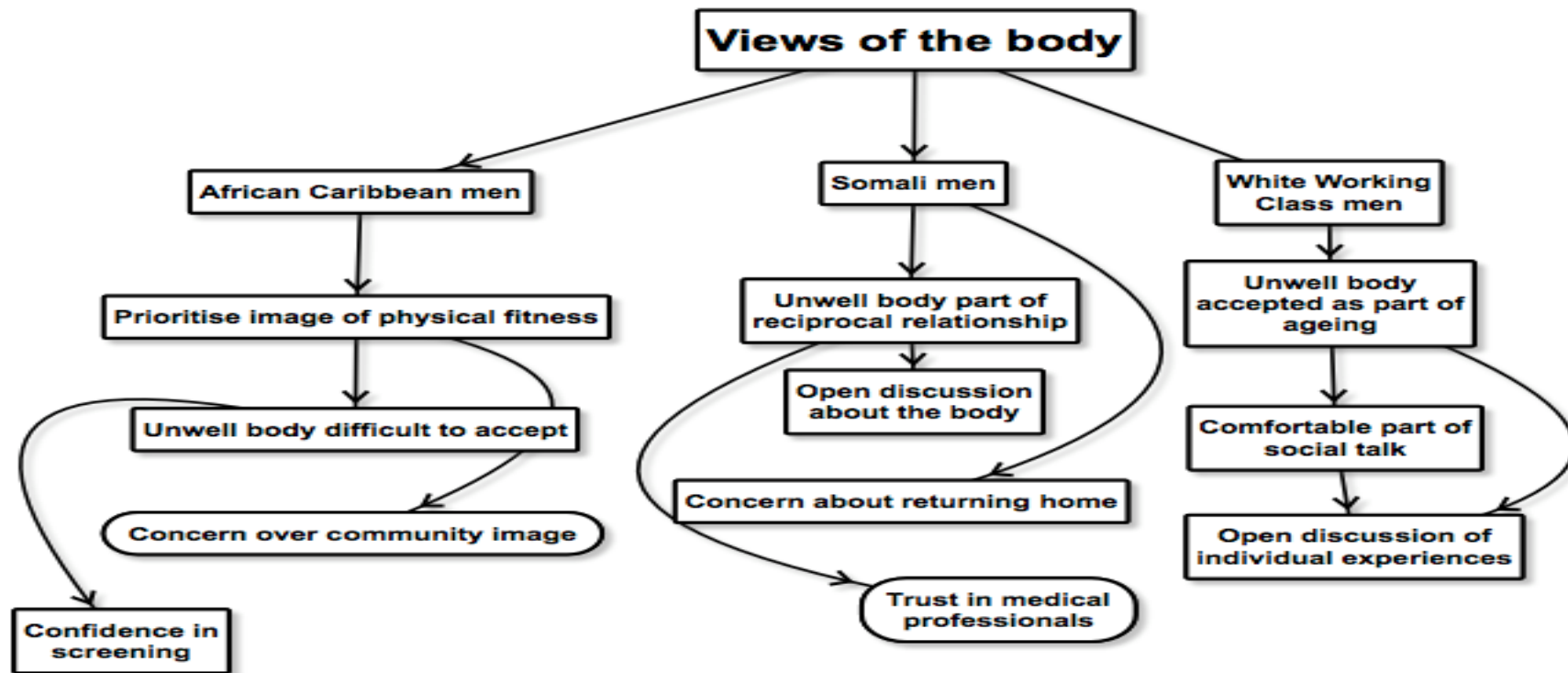


Figure 5 Diagrammatic representation of category Views of the Body



## 8.0 Category 3 – The everyday body

### 8.1 Introduction

The category Everyday Body is generated from analysis of the men's talk about their everyday lives and their views of health risks and prostate cancer education. For this research, everyday lives are discussed in the context of the social patterns of the men's lives, as generated from cultural norms and expectations, and the constructions of their body and health within their lives. There were differences between the groups in the way the men talked about their everyday lives in relation to health. For example, the White Working Class men were the least likely to talk about health in the context of their lived environment. The following memo explores the thinking during data analysis and generation of this category:

*White men talk about their health as individuals and learning about their health risks through individual media, such as leaflets, social media, and newspaper. The white men talk about belonging to groups, with which they identify, and some of the men talk about learning about cancer through the experiences of their friends in these groups. They don't identify themselves as the group; membership of social groups do not form part of these men's everyday identity. The black men live their lives through the community. The community in which the black men belong is part of their identity and their everyday life. For the black men identity as part of a community has a boundary by the colour of their skin. African Caribbean men talk about being black and this separates them from the indigenous white population, and for the Somali men this separation is created by a desire to go home and by their religious identity. This is explored in the category Identity by Difference, but it is likely to overlap the sense of the everyday body by creating a community bound by these differences. In this context, community is about how men learn and share information with each other, to influence their perception of risk. It is about how men identify where they come from and what they belong to. Sometimes this is implicit in the data, it is about the men making references to the people in their community and how they learn and talk about health. For white men, the category is developed from groups that they belong to and how these provide access to people to help identify risk. This is coded as a group because it appears that this does not relate to the*

*men's heritage in relation to how they identify their body through health and risk for illness.*

**Memo writing September 2015**

## **8.2 White Working Class men**

### **8.2.1 Sharing health in a group**

Most of the white men made reference to belonging to a group. In the context of this research, a group is an activity during which the men talk about doing something together, even when the boundaries of the group are loosely defined. For example, participant 033 talked about belonging to an allotment, but he talked about this in his everyday life as a means of keeping himself busy and it seemed to prevent him from worrying about his health:

*I have so many other things going on in my life, I can't do that [worry about health risks]. I belong to an allotment and in April we're going to sell the seeds that have grown into plants, to those that wish to have them and all the proceeds, believe it or not, goes to cancer  
(Participant 033 IT: P10)*

Going to the allotment was important in this man's life and he talked about this activity in terms of working with others to create a purpose for himself. Conversely, participant 035 talked about belonging to an allotment as an everyday social activity and talked about developing friendships and sharing health information:

*I mean down the allotment I've got some good friends down there we talk about all sorts down there...there's one or two down there with bowel problems and we talk about it and I've told them I've got an enlarged prostate  
(Participant 035 IT: P16)*

It appears that participant 035 found membership of this group provided a comfortable place to share health information. This was reflected in the way he talked about the overt sharing of health concerns, which seemed to have become

part of the everyday talk at the allotment. This was in contrast to participant 022 who referred to covert sharing of health information with the group of men he worked with in a voluntary organisation:

*I do hear of, I mean some of my colleagues, the people at (place name), they have got prostate problems and they are being monitored put it this way and they just get on with their lives, we don't talk about it (Participant 022 IT: p10)*

It appears that this man was conflicted when he talked about the sharing of health information in this group. He was aware that there were men who had prostate problems, despite saying that they didn't talk about it. When he was asked how he came to know of these men with prostate problems he said: *"tend to be through word of mouth, someone else will tell you something like that"* (Participant 022 IT: p10). It is possible that for participant 022 membership of this group did not provide him with the opportunity for everyday talk about health; rather talk was based on the sharing of health information through rumour.

These White Working Class men identified themselves as belonging to a group and talked about sharing health information, either deliberately or through group rumour. However, some of the men thought very differently about the group and how individuals interact in the modern social environment.

### **8.2.2 The broken group**

Participant 014 talked about not being involved in his social environment because he associated himself with a group of people at work. This man was 50 years at the time of his interview, one of the youngest White Working Class men involved in this

research, and therefore young enough to still be in work. He made a connection with the men at his work but it was clear that he didn't talk to them about health:

*I mean I would talk about it [illness] if it was to come up, no problems with it but the group that I associate with are people in work, we don't talk about things like that  
(Participant 014 IT: p4)*

This man viewed the group at work as different to a group that he might belong to in a wider social context. For him this group would have been in a pub or social club rather than the groups the other White Working Class men talked about, which were bound by an activity requiring a commitment to allow the activity to prosper, such as an allotment. Participant 014 believed the banning of cigarettes in public places had dismantled his preferred social group:

*I think years ago when people worked maybe in pubs and clubs and whatever, you're in conversation and you light up a cigarette whereas you don't see so much now  
(Participant 014 IT: p14)*

It appears participant 014 was referring to the death of the pub culture, related to the smoking ban, and for this man the availability of a social conversation had gone. Because of his preference for smoking he had not been able to replace it. However, he did find the structure of his work provided access to health information and this will be discussed in section 9.2.3. Participant 027, who was also in work, was another White Working Class man who felt he had no access to a social group. He based this on the area he lived, which he said was: "*pretty rough, yeah. It can be pretty frontline after dark sometimes*" (Participant 027 IT: p19). Like all the men in this research he lived in an area of social deprivation and, unlike the black men, did not relate his identity through his social surroundings.

Spending time in the social environments of the Black and White men in this research, created an understanding of how the atmosphere and surroundings differed in relation to being conducive to community cohesion and group membership. The following is an extract of a field note made after spending time in one of the areas where the White Working Class men were recruited:

*The area is traditionally white working class and is dominated by a large council estate that spills down the side of a hill as I approach the venue for today's talk. The taxi driver who took me to the venue lives in town A and explains that things are "better, like, at the top of the hill but go downhill after that." The housing gets smaller and less cared about further down the hill but there are a fair number of cars that seem well looked after. In the inner-city areas where I have spent time the community is more multicultural, people seem to worry less about their possessions and the image they are creating, and I wonder if this is because the population in these areas places more emphasis on their community rather than individual possessions. Here, in town A, on the street there are less people walking around than there are in the inner city. The community in this suburb has less of a centralised feel. There is a row of shops but there is no one standing outside chatting, as you would find in the largely black populated areas I have experienced. The community feels closed behind doors.  
(FN 4: p2).*

The area described in this field note is a location that people were moved to during demolition and reconstruction of the inner-city areas that these people used to live in. Participant 027 talked about how he felt people in these new areas thought about the community around them:

*I don't think people care about other people in their neighbourhood or care about themselves to be honest  
(Participant 027 IT: p18)*

This may help explain why these men appeared to think about themselves as a member of a group, rather than a community. As will be discussed in section 8.3, the talk from the Black men, about the environment in which they live, is very

different. For some of the White Working Class men, changes to their geographical areas, brought about by political influences on health (such as the smoking ban), appeared to have constructed an approach to communicating about health and illness that was embodied by political approaches to health that, for these men, had created isolation in health talk. The opportunities for health talk, and the type of talk used by the White Working Class men, is discussed in more detail in chapter 9.

### **8.2.3 Individual knowledge**

The White Working Class men in this research have talked about sharing health gossip and have also provided examples of groups that are conducive to having these conversations. For these men, their everyday talk appeared to be regulated by the social space they occupied. Talk of the body between friends was restricted to specific activities or environments, and sometimes restricted by political concerns relating to health. Finding suitable environments for the men to discuss health and risks for illness is going to be an important factor in educating men about their risks for prostate cancer.

The men were asked to consider how they thought prostate cancer awareness could be increased. The men did not talk directly about constructing their knowledge of prostate cancer through group learning opportunities. This is contradictory to the men talking about learning through rumour and it may be that for these men less formal education, such as chatting to friends at the allotment, provided a better resource for health education.

None of the men specifically said they would not enjoy a group learning situation, but when asked to think about how to inform people about prostate cancer, they gave examples of individual behaviour, such as collecting leaflets from their GP's surgery or using the internet. Participant 027 talked about accessing the Internet for health information and the benefit of seeing information about cancer risk in public places:

*R: For me I don't watch a lot of television but I can understand how it would, that would get into a lot of people's homes through television, an advert or something. I don't know a bus shelter advertising maybe or an advert on the telly or internet advert (Participant 027 IT: p15)*

Participant 033 also thought he would make a connection to advertising in public places accessed by men in their everyday individual lives:

*I: Bus stops, when you're waiting at the bus stop, especially a covered one because you've got lots of room there (Participant 033 IT:p13)*

Participant 013 took value from information at his GP's surgery and said that if there were information in his GP's surgery about prostate cancer he would read it:

*To start off with if there was some information in the doctors, there'll be information on all sorts of stuff, they have loads of leaflets...I don't remember seeing anything on cancer (Participant 013 IT: p8)*

#### **8.2.4 Summary**

Most of the White Working Class men interviewed for this research were retired and they talked about the everyday structure of their lives in terms of groups they belonged to, which for some men brought with it talk about health. The men described this as rumour rather than taking advice about health from each other, and this type of talk will be explored further in chapter 9 when considering the preferred resource of health information. The men didn't seem to realise that by

listening to accounts of other people's health concerns they also appeared to be learning about health problems that may affect them. This covert sharing of health information should be considered as a way of increasing awareness in this group of men. Strategies for doing this could include providing prostate cancer information resources at places known to generate talk amongst these men, such as a Men's Shed. Men's Sheds are used as an area for men to meet and work on individual projects, such as those involving carpentry or bike maintenance (UK Men's Sheds Association 2017). It is possible that the presence of information about prostate cancer could generate conversation amongst these men. The White Working Class men have identified this type of social space, such as an allotment, as somewhere they would share health talk and using this type of social space for raising prostate cancer awareness could be explored.

There was one man who didn't talk about health matters as part of a group. Participant 014 was still in work and he talked about not having the type of relationship with his work colleague where health was talked about. Participant 027, who was also in work, worked alone and so also did not relate work with a place to talk about health. This contributed to thinking about these men finding a safe environment to access health information. It appears that it was acceptable for the men to talk about other people's health in a group situation but they may not have brought up concerns about their own health. This is seen in the interview transcripts in table 6, which were focused on raising awareness in the wider society where the men could remain anonymous. The men appeared to talk about finding out about personal health-related matters as individuals, rather than in a group.



## 8.3 African Caribbean men

### 8.3.1 Health as a community concern

It seemed that for the African Caribbean men the community was part of their everyday lives and they talked about the community as if it were part of their identity. Participant 016 talked about the time he spent in the community as a place he came back to after work:

*Yeah because let me tell you, when I was doing, when I was (place name) I used to leave my house at 7 o'clock and I wouldn't be back to this community until 1 o'clock in the night (Participant 016 IT: p7)*

This man now found he enjoyed having more time to spend in his community and he also enjoyed the availability of social opportunities at his local community centre:

*I get more time to spend in the community because they run a lot of programmes here (Participant 016 IT: p8).*

An activity that appeared to be important to the men in this community was dominoes. As discussed in chapter 4 recruitment to this research involved spending time with the African Caribbean men and it quickly became apparent that a regular activity for these men was playing dominoes and attending domino tournaments.

Below is an extract of a field note made after time spent at the weekly dominos club:

*The domino club meets at a local community centre every Sunday and Thursday evening. The domino club is open to anyone but is largely populated by African Caribbean men who have a long tradition of playing dominoes in their community...dominoes seems to be a male only activity. There were women at the club and when talking to them they told me they were the wives of the players but that they did not take part in playing dominoes. They seemed surprised when I went to play dominoes with the men, although the men were keen for me to take part (FN 29: p1).*

Participant 019 talked about dominoes being a part of the everyday lives of African Caribbean men based on the areas from which they migrated. He recognised that domino clubs in the UK were associated with areas that were highly populated by the African Caribbean community and that this created a community through which education could be passed on:

*Get hold of some of the black community centres like the docks and stuff...when I was in London we used to go to these domino matches...you know and you'd get together and say look we're going to have an awareness day  
(Participant 019 IT: p17)*

Participant 019 was identifying a way to educate the African Caribbean men, and it appeared he thought it was acceptable to promote cancer awareness at an event that was normally a social, rather than educational, event. This may have been because it seemed that Dominoes was a part of the everyday lives of these men, therefore they didn't see the club as somewhere restricted to a social event. It appeared that Dominoes was a rich part of these men's heritage and so it seemed that this was an activity embedded in the everyday identity of these men. This is different to the White Working Class men in this research who did not talk about the influence of their heritage on their social activities.

Participant 024 talked about the importance of community and identity with the community, when he talked about a famous African Caribbean man living in his area who stayed with his family when he had the opportunity to leave:

*There's someone famous...its (name given) and he's a young man that has always loved his family and his community, otherwise he'd have shot off like everybody else to make more money (Participant 024 IT: p29)*

This man was talking about community as more than an area or a neighbourhood. By describing love for the community, he appeared to be describing something that for the young man formed part of his everyday identity, such as family providing the background to ideas of the self. The men in the focus group also talked about the importance of the community when considering changes in how the community worked for each other. The men compared the sharing of health information as younger men in the Caribbean, compared to the empowerment of the modern community through new knowledge:

*P03: We didn't have the thing, now they have this television link so you could have an operation, the surgeon could be in (place name), and he's directing what to do. We didn't have that kind of knowledge before.*

*P01: Well in them years okay, it was like what I learnt okay, for you to know it you've got to pay me to get it. Whereas they found out now that is not the way to go forward, whatever you've learnt, pass it on because it helps the community, it helps people along and then somebody else will come and improve on that see, that's what's going on.  
(African Caribbean men focus group transcript: p11)*

These men talked about helping the community by seeing their health knowledge and experiences of their bodies as beneficial to the wider community, through the sharing of health information. The men also recognised progression in health knowledge and more openness in sharing of health information in the modern community.

### **8.3.2 Community as a barrier**

Some of the African and Caribbean men agreed that knowledge was important but were sceptical about how people in their community would react to having information made available to them. Instead of talking at an individual level, as

seen amongst the White Working Class men, participant 030 talked about what he felt was the approach of the community:

*Most people in these communities...diseases and death is abstract to their life...that's nothing to do with me  
(Participant 030 IT: p8)*

He went on to say that people in his community didn't view their bodies as potentially becoming unwell in the future. They preferred to wait until they had a health problem before they acted:

*SF: So, you think that people are more likely in this community to just get on with their lives and just not worry about it?*

*R: Yeah, until it hits them and then.*

*(Participant 030 IT: p9)*

It appeared that part of the everyday lives of people in the African Caribbean community was to share information when someone had a health concern, but they chose to remain detached from health knowledge until it became a concern. This was similar to the Somali men in the way the men talked about their bodies and avoiding a health diagnosis.

This detachment from health was discussed on page 194 when participant 024 talked about the nature of the image of illness as being uncomfortable for people to accept. The influence of the community, on keeping the image of illness discrete, is also talked about by participant 030 on page 202 and by the men in the focus group. The men in the focus group recalled a learning event and the actions of the men after this event:

*P03: Some people would because I know in the old centre there used to be learning programmes and some people I know, they wouldn't come to the centre.*

*P01: That day*

*P03: No not the day, they wouldn't come to the centre for that kind of lessons but yet they will go over (place name).*

*SF: Because it's more*

*P04: It's out of area*

*SF: Right okay*

*P03: They will go to (place name) but they won't come here.*

*(African Caribbean men focus group transcript: p13)*

These men were saying that the familiarity between people in this community, and possibly the relationship of their bodies to the community, prevented them from attending learning opportunities where they might have been seen by someone they knew. Participant 030 also talked about the community being a place where people were unable to keep their health concerns discreet because of the close relationships of the people to their community. He felt that attending an appointment at a doctors' surgery was a barrier in his community, and that putting a doctor in a non-medical space would increase access for some people:

*It's a simple concept, you know, we took the health, taking the doctor out of the surgery and putting them in the community and my argument is based around my knowledge of this local community (Participant 030 IT: p10)*

This man was talking about creating a safe place for sharing health information, which appeared to be particularly important for the African Caribbean men. It could be the case that community concerns about being seen accessing healthcare related to the perceived negative image of being unwell, as articulated by the African Caribbean men in this research. This may be related to the pride these men talked about in being black, which seemed to be related to their masculine body

image. It could be that having an unwell body was not seen as masculine amongst the African Caribbean men in this research.

Despite the men referring to GPs' surgeries as a barrier to accessing health information in their community, one man in the focus group talked about how valuable he found his visits to the doctor's surgery for regular blood tests, which provided an environment for sharing health related experiences:

*I go for INR blood test, I mean you go for your blood test, how many people you meet there that you know...and then before you know it, you're sitting talking to them and you're talking, they say how long they've had it and they pass on information and it's only because you've gone there... you see somebody else is talking, you're surprised how much.  
(African Caribbean men focus group transcript: p14)*

It appeared that for this man a doctor's surgery could be a safe place to talk to other people about health, once men had accepted that they had a condition which needed regular monitoring and which was common in their community. It is also possible that in this context the men identified themselves as patients. This seemed to give the men permission to talk, and may have broken a barrier in the social construction of health-related talk. For this man, his experience of illness had become part of his everyday life because he had a routine of regular blood tests, and part of this everydayness of the blood tests was talking to other people in the same situation.

### **8.3.3 Community as enabler**

For some of the African Caribbean men their identity as part of a community was talked about as enabling them to access health information. When these men were asked how they thought prostate cancer awareness could be increased, they talked about educating the community, rather than being educated as individuals.

Participant 016 appeared to enjoy being part of a community and when he was asked about educating the community about prostate cancer he said:

*Yeah, yeah, I will encourage you if you can organise a talk...that will come and then talk and everything, so what you need to do is you advertise it, you can advertise it in the community living there, in the shops, yeah, you can get to know the Chairman of this place  
(Participant 016 IT: p10)*

Like this man, participant 019 also talked about educating the community. On page 247 he talked about accessing dominoes clubs to encourage men to find out about illness specific to the black community, and he went on to say:

*You'd get together and say look we're going to have an awareness day and get someone in the community... and say look this is important, get as many men to come and listen to this important talk and people need to know... you speak to somebody who's like a well-known in the community... you ask him to find out when they're having some event or something like that can you talk before or when they go to an event can you announce the meeting and it's important that the people come, very important for their health and stuff like that. That's what I would do  
(Participant 019 IT: p17)*

This man was highlighting the importance of having someone known to the community to help access black men. Participant 016 also identified this when he talked about involving the Chairman of the Community Centre as a way of raising awareness to educate the men about their specific risk for prostate cancer. It appeared that for these men the social structure of their community involved a hierarchy of people who were respected for their status, although it was not clear from this research how these people became respected and took on this status in the community.

The men also talked about the social space occupied by the younger generation in their community. They believed that children having knowledge could be used as a facilitator for the older generation to access health information. They talked specifically about giving children and youths information about prostate cancer.

Participant 019 talked about inviting men to a talk about prostate cancer and made a distinction between the actions of children if they were also invited:

*Invite them but I would invite the young ones too because the children are the ones who'll make, especially now, they'll make the parents go, make them go, that would be the best way yeah (Participant 019 IT: p17)*

This man believed that children would: *"make them go"* (participant 019: p17), and that boys and girls should be invited because; *girls and that would be worried, maybe more about their dads you know, than the guys* (participant 019: p17). Participant 030 also shared this view. He felt that teaching the younger generation would lead to children telling their fathers about prostate cancer:

*R: The answer, getting to young people at a young age and getting them to understand how important it is so they can talk to their parents about it.*

*SF: Okay that's interesting.*

*R: Anything about prostate cancer he'd be you know, because saying you can get prostate cancer then he'd be interested and then you say this is how we know and these are things that would happen to him and they would relate it to themselves as well (Participant 030 IT: p16-17)*

Participant 030 was talking about fathers relating children's knowledge about prostate cancer to themselves, and he felt this was driven by the place of the family in the community:

*There's a fierce protection of your family and your children and your brother or something, they're more inclined to move on with their self oh*



*that could happen to me...it's all men but particularly in this community,  
yes  
(Participant 030 IT: p17)*

The African Caribbean men in the focus group also discussed educating children at school when completing task 4 (appendix VIII). After some debate the men agreed that educating children would help raise awareness through conversations at home:

*P01: And also, if you tell the kids*

*[...]*

*P01: When the kids go home, like you know, they're aware as well, if they hear it and their elderly grandparents are going back and fore to the toilet they're more watchful of it in the sense of hey what's wrong, you know you're going to the toilet quite often. They can just say well you know, go home and tell their mam or,*

*P04: If the kids are aware they're communicating with (overlapping speech)*

*P03: Sometimes they go home and they've got nothing to talk about, you know, didn't want to talk about their school lessons and there's certain things they don't want to communicate.*

*P04: They won't go home and talk about sex but they would talk about something like this [prostate cancer] with their parents and they could explain something.*

*SF: And do you think that would help raise awareness in older men who haven't had that, do you agree with that, do you think that?*

*All: Yes*

*SF: Yeah*

*P03: I mean they could say well if he could say it, we should be telling him instead of he telling us, you know, so I think it could open doors.  
(African Caribbean men focus group transcript: p.120)*

For these men, it seemed that after school conversations with their children had been part of their everyday talk. It appeared that listening to their children talking

about health made their position as a father salient so that they acted on health-related risks, such as prostate cancer. When the White Working Class and Somali men were asked to complete task 4 in the focus group, they had differing opinions about the benefits of educating children about prostate cancer. The White Working Class men didn't talk about educating children although one of the men interviewed for this research referred to educating children about prostate cancer as a way of providing information that might not otherwise be shared:

*Well I think so because it's there in their mind then isn't it, it's not something down the road, but they might not even know about it because like you said men might not talk about it and they won't talk about it (participant 035 IT: p13)*

However, this man was sceptical about discussions within the family, because of possible problems with father/son communication. He identified that educating boys would only work: "If they talk to their fathers" (Participant 035 IT: p8), which for this man had been difficult: "I found it very difficult to talk to my father... you just didn't get many conversations out of him" (participant 035 IT: p8). The Somali men were against the idea of educating children about prostate cancer:

*P05: The GP where everyone is going*

*P06: To tell the young people is not a good idea. I do not think the young person will tell his father. (Somali men focus group transcript: p8)*

#### **8.3.4 Summary**

It appeared that for the African Caribbean men the community was part of their identity and it is suggested in chapter 8 that this is because of the men's fight for status, living in a country in which the colour of their skin has placed them in a

minority. The men have taken some of the rich history of their country of origin, such as playing dominoes, and created a community that felt safe. For these men, it seemed that the community was a place that kept people together and part of this was the sharing of health information.

The men also talked about the importance of hierarchy within the community and it is proposed that this reflects their cultural past. The importance of hierarchy is seen in this research when the men talked about finding a community leader to help access African Caribbean men in the community to talk about health. Some of the men suggested speaking to the community leader about putting on an event to share knowledge about prostate cancer; it appeared that this was an accepted way of directly accessing the men most at risk. From the way the men talked about these events it seemed that arranging a talk without discussing this with the community leader would jeopardise the number of men who would attend. The community leader could give the event importance and the men then recognised this was something significant for their community's health.

The men also talked about targeting male-only areas, as well as targeting the younger generation. It appeared that the importance of protecting the family, by being aware of personal health risks, was a way to educate African Caribbean men about prostate cancer. The men felt that children were best placed to educate men in this way because after school talk with their children would make their individual risks salient, related to feelings of protection of the family in the African Caribbean community. The men didn't talk directly about their position as a man in the family,

but it is conceivable that this provided status, which mirrored the hierarchy within the community.

## 8.4 Somali men

### 8.4.1 Health as a community concern

In similarity with the African Caribbean men, the Somali men talked about health belonging to the community. The difference for these men was that their view of the community was structured through the lens of their religion, and this changed their everyday health-related talk. Unlike other men in this research, one Somali man talked about the community response to a cancer diagnosis:

*In the male community, if I talk to the male community, the cancer whether it's serious or not the guys they, fairly bad illness as a country, if somebody said oh they've got cancer, they think that's it (Participant 015 IT: p6)*

Here participant 015 was expressing cancer fatalism, which has not been talked about by other men in this research. He believed that all men in his community would be afraid that cancer would lead to death. Participant 015 also believed that his community was motivated to find out how to prevent cancer, possibly because he believed they had fatalistic beliefs, and that they should reduce their risks by seeking health information:

*So and I think most of the communities need to do, need to find out those kind of questions (Participant 015 IT: p6)*

Participant 015 was talking about what he felt was lacking in the community; he did not refer to being educated as an individual. He made a distinction in his talk of the community by referring to the everyday talk of the Somali men, and not the wider Somali community. It is presumed that this was because of religious codes

that divided social communication between Muslim men and women, which was experienced during a visit to the male- only restaurant/community centre:

*All men in the (restaurant name) are Muslim and women are not allowed in the restaurant. When I walked in they were surprised by my appearance (white female) but they did not ask me to leave. It felt that there was more interest in what I was doing, as a healthcare professional, than anxiety about a female being in a male only environment. I'm sure if I were a Somali woman my reception would have been very different. During the visit, I sat at a table and drank coffee. An elderly man sitting near me, but not on the same table, moved away. He was eating after prayer at lunchtime and I felt as though I had intruded on his space whilst he was eating. He simply moved and continued eating. The younger men, who may be more integrated with Western culture probably through school, seem more accepting and don't appear worried by my presence (FN 19: p1).*

It is accepted that this field note was made at a particular moment in time for this community and that the field notes have not been through an analytic process.

However, observations of the community showed a clear divide in the communication strategies in public places and this is thought to influence the structure of communication in the wider Somali community.

The Somali men interviewed for this research talked about their relationships with other men in the community, and like participant 015, they talked about everyday conversations involving men. The men in the focus group agreed that they would talk to men in their community about health, especially if this talk could help the community:

*P06: I mean when you pick up a leaflet in the surgery, I pick it up if it's of benefit for me or someone else.*

*SF: So you'd also help each other.*

*P01: Yes, an uncle, a brother or a friend, if it is good for them.*

*P06: What's good for you is good for others.*

*SF: Okay*

*P06: It will help with others.*

*P01: Like if you get information, health information, because if it happens to you, or about your body, you can advise your brother, cousins, brother-in-law, father, do you know?*

*SF: So you've got this community feeling of helping each other.*

*P01: Exactly*

*(Somali men focus group transcript: p11)*

During his interview, participant 018 also referred to sharing health talk in the community when he said:

*When we first got the problem, you would talk to men and say oh, that's what happened to me you know*

*(Participant 018 IT: p1)*

This man was referring to sharing health experiences with other men before going to seek medical advice. He later said that he would prefer to be educated at an individual level because: *we can talk even more (participant 018 IT: p11)*. He based this on his view that some people in the community didn't want to share their health information:

*A lot of people in the area still feel shame ... some people they don't want to know Some people they don't want to know, maybe they, (unclear) ... he's older than me [friend] but he always telling me his problems, he wouldn't go telling everybody (Participant 018 IT: p11)*

This man did not make it clear why the men felt shame and whether this was before or after a diagnosis of illness. He was asked to elaborate on this but this was difficult to explore further due to communication through a translator. This man's contradictory talk about shame and the openness of older men in his community is complex and difficult to explain. Conversely, participant 015 was clear in his opinion that the men in the community wanted to know about their health, regardless of the area of the body involved:

*Normal stuff about health yes, about that because of course they're adults, we're all adults we talk about health so it's not a shame I think, it's not a problem personally to talk about what problems this is and what kind of cancer is this you know (Participant 015 IT: p12)*

Here participant 015 was being very open about what he felt were the views of the community. Participant 017 also talked openly about his health concerns and preference for traditional treatment, as discussed on page 221. He did not talk about learning events regarding health, or offer his views on how he would prefer to receive new knowledge. Participant 017 did not appear engaged with his health in this way, and this could be because of his feelings of being trapped in the UK because of his unwell body. It appeared the men had differing feelings about sharing health talk in the community. For some men education involving the community was a valuable resource to prevent restricting illness. This is explored further in chapter 9 when the style of talk between the Somali men is examined from analysis of the focus group discussion.

#### **8.4.2 Educating the community**

Like the African Caribbean men, some of the Somali men talked about educating the community rather than being educated as individuals. As discussed in chapter 8 a community education event took place whilst engaging with the community for this research. The event was attended by 25 men, (FN 29 Feb 2015), who appeared interested in learning. However, these men conducted themselves as external to the talk in the way they moved during the talk, and the impression was not that the men were being rude but that this was how they normally conduct themselves in a community learning experience:

*The group of twenty-five men themselves stayed for the talk with a little bit of moving around. Some went out to get their friends or have a chat with someone they had seen outside and then came back in again, some got up to go to the toilet or just have a walk around  
(FN 29: p4)*

It is proposed that this freedom of movement during learning events was reflective of the feeling of community, which the men talked about in the focus groups and interviews. This was supported by their desire to share their health experiences and be taught as a community.

### **8.4.3 Summary**

There was a sense that the Somali men wanted to help each other when learning about health risks, by finding information and sharing this with men in the community. Participant 015 believed men in his community thought that death would follow a diagnosis of cancer, but other Somali men did not talk about this. Participant 015 was also the most motivated when talking about the community needing education to prevent cancer risk. It appeared that his belief that death followed a cancer diagnosis did not, in his view, create a passive community, rather it motivated the men to find out more about their health. On the contrary, it seemed that participant 017 was not engaged with the process of education about his health, and this may be because he was concerned about continuing to be trapped in the UK by his unwell body. For these men, it appeared that illness was a potential barrier for their return to Somalia as it was for older men.

There was a sense that these men differed in their approaches to health education. Participant 018 said he would prefer to be educated as an individual because he



would have the opportunity to talk about his concerns openly. However, this man also talked about talking with other men about health concerns as a normal part of his everyday talk with the community. For him it may have been acceptable to talk about a health concern before a diagnosis had been made, but that once there had been a diagnosis of illness, this type of talk should not happen, and he related this to shame. It seemed, in this context that shame was spoken about at the level of the individual and not at community level. It is possible that for these Somali men once they became unwell, the individual was concerned about being viewed differently by the community. From these limited data, it is not clear what the relationship of illness was to only the male community and if illness was also related to their bodies being imprisoned in the UK, hindering their ability to travel back to Somalia. This could be an important point at which these men disengaged with the medical process, and produced a barrier to the benefit of health education and provision of health services.

The men talked about sharing their everyday talk with the male community, and did not talk about sharing this talk with women in the social context; this appeared to only apply to Somali women as described in the field note extract on page 262. These men were happy to talk to a white woman, and it appeared this was particularly true if this woman had information to give them about their health. The relationship was reciprocal. The men were very comfortable about coming together for an event about prostate cancer and their relationship with the community encompassed their everyday behaviour during this learning event.

## 8.5 Chapter summary

This chapter has explored the men's everyday lives and their relationship of this to their perception of health and the acquisition of health information. In the context of this research, everyday lives are the cultural patterns seen in these men's day-to-day activities and the influence of these on their attitudes to health and illness. The cultural patterns are implied by these men when they referred to their interactions with the wider society; in the case of the White Working Class men this is referred to as their membership of groups in which they share an interest in the group activity, and for the Black men from their interactions as part of a community with which they identify, which appeared to infiltrate their thinking about their own identity.

For the White Working Class men, membership of a group was used to keep the retired men occupied or form friendships. The men talked about the group differently depending on the reason for the membership of the group; some men found that the group could provide a way of covertly finding out about health risks by discussing the health of other members of the group. The White Working Class men who were still working identified work as a social arena that they would not use to talk about health, and for these men access to health talk was more difficult. These men seemed to feel that the traditional White Working Class community had been lost due to political interference and a ban on smoking in social spaces, as well as a lack of care for the White Working Class neighbourhoods.

It is proposed that this lack of interaction is linked to the way the White Working Class men talked about belonging to groups, rather than being part of a community. Their domestic lives happened behind closed doors and this individual life encouraged the men to look for health information as individuals. Unlike the Black men, these men did not talk about finding health information to help the community. For the White Working Class men, the purpose of understanding their risk for illness, in this case prostate cancer, was to protect themselves as individuals.

The Black men talked differently about their everyday lives. For these men, the community in which they lived was part of their identity. For both the Somali men and the African Caribbean men, the community was talked about as a place they went to find health information and to talk about health with each other. The African Caribbean men talked about the community as a safe place, and a place that shared health beliefs. The men talked about sharing health knowledge to help the community and relate advances in healthcare as beneficial to the community, rather than to themselves as individuals. However, there was some scepticism amongst the African Caribbean men about how the members of the community would use health information, with one man believing members of his community would wait until they became unwell before they thought about illness. This man believed illness was abstract to the lives of the people in his community.

The Somali men talked about their health and the community in a similar and different way to the African Caribbean men. One man felt that the men in his community would be fatalistic if they received a diagnosis of cancer. However, the Somali men appeared open to being educated about health risks and it is proposed

that this openness to education was in response to concerns about probable death after a diagnosis of cancer, rather than adopting a passive response if death was thought to be certain, as is purported in the theory of cancer fatalism.

The African Caribbean men talked about the importance of the community in the recognition of the self and their identity. One man referred to the community in the same context as family, and this was not unusual amongst these men. However, some men felt that this proximity to the community could also be a barrier to accessing health information, due to sharing of talk in the community. To overcome this, one man had been involved in placing a doctor in a community centre which he believed hid the identity of people accessing a healthcare professional, and he felt this had increased community access to medical help. Placing a healthcare professional in a community centre could be a way of accessing these men to provide information about prostate cancer.

Unlike the views of the African Caribbean men, the Somali men were not concerned about attending a community event in relation to prostate cancer, despite this being in their local area, and they treated this as an education resource to be shared with each other. The African Caribbean men also talked about educating younger members of their community, to pass information to parents. They felt that because of the importance of family in their community, this social unit could be used for sharing information. The African Caribbean men seemed to believe children were a valuable resource for this, in relation to prostate cancer, because of a father's strong desire to protect the family.

The White Working Class men and Somali men did not talk about the protection of the family in the same way. One White man refers to children being educated but did not feel that the information would be shared with the father, and Somali men agreed that this type of conversation would not happen in a Somali household. It seems that the place of the family has differing status amongst these groups of men. This requires further exploration.

Unlike the White Working Class men, the African Caribbean and Somali men talked about a hierarchy within the community. This was most obvious in the talk of the African Caribbean men when they were asked to think about how they would like to be educated about prostate cancer. The men referred to using a community leader to promote a prostate cancer awareness event. For these men education could be done through the community but it seemed they would only consider the education as relevant if a community leader had helped to raise awareness of an education event. From field notes made during the education event attended with the Somali community, it was clear one man had helped organise the event and encouraged the men to attend (see page 167). However, this leadership role within the Somali community seemed to be less well defined and this Somali man seemed to be an organiser rather than a community leader.

This chapter has addressed the differences men face when considering their identity and how they prefer to be educated about health. It became clear that for the Black men, health was a community concern, but that the community could also create a barrier in accessing healthcare for the African Caribbean men. It was as if the closeness of the community to their identity exposed them in a way that

left their privacy vulnerable. Table 6 provides an illustrative example of the differences of identity with health and the community between these men, through their views on approaches to education about risk.

White men	African Caribbean men	Somali men
Individual approach to acquiring knowledge of risk	Community approach to acquiring knowledge of risk	Mixed approach to acquiring knowledge of risk
Extract from transcript	Extract from transcript	Extract from transcript
To start off with if there was some information in the doctors...they have loads of leaflets but you don't see, I don't remember seeing anything on cancer (Participant 013 IT: p.8)	Have an open day isn't it...the local radio station would advertise...not a lot of people might tune into that so I think the best way to do it would be to do flyers, especially in this area (Participant 010 IT: page 6)	You could do [give a community talk], if you tell the systems when whoever call that cancer, as you say go to the toilet and things like that, just tell them in a way professionally what it's going to cost them and how they get treatment and things like that ... ( Participant 015 IT : page 12)
I think if you got in touch with for example, football clubs, rugby clubs you know...just for the players to get the message across (Participant 014 IT: p.17)	That will come and then talk and everything, so what you need to do is you advertise it, you can advertise it in the community living there, in the shops, yeah, you can get to know the Chairman of this place, they have radio (Participant 016: page 10)	If I suffering (unclear) or think about you know, information about it, have the testing (Participant 017 IT: p5)
The sort of traditional methods that the government use to get any sort of health message across is about the most effective method. You know a lot of advertising (Participant 022 IT: p.13)	You ask him to find out when they're having some event or something like that can you talk...or when they go to an event can you announce the meeting and it's important that the people come, very important for their health and stuff like that. That's what I would do (Participant 019 IT: page 17)	Last time we had a talk about public health, they bring some kind of, some mousses and sandwich and the people stayed there about an hour, you know, and water, so sometimes (Participant 018 IT: p12)
I don't know a bus shelter advertising maybe or an advert on the telly or internet advert (Participant 027 IT: p.15)	Now when I go into a man's toilets right, there's never any information in there other than a condom machine, and I'm thinking what a wonderful place to tell a guy, it's about you mate, you know (Participant 024 IT: page 21)	For example what they say if you learn something about today in here, you can go back home and tell your friends, oh I've seen something going on in that centre, in the cafe, you know and then you know (Participant 01 Somali men focus group transcript: p11)
Pieces of paper that slip through the letter boxes or in the butchers, there's a piece of paper in the butchers and they go to buy meat and they glance down and see because they go to the butchers (Participant 033 IT: p.11)	I think schemes like be healthy...are really the answer, getting to young people ... to understand how important it is so they can talk to their parents about it Because if ... anything about prostate cancer he'd be you know, because saying you can get prostate cancer then he'd be interested ... (Participant 030 IT: page 16-17)	P01: Basically we all agree, the best place to be is in the centre, the health centres, GP's, everybody can get, your wife can get information (overlapping speech) not very often she can check that kind of thing for breast cancer. So or you can tell your friend. Only asking, I go to the toilet very often. Can go to the GP for information if you're concerned about that (Participant 01 Somali men focus group transcript: p9)
Just look at some articles...just look at articles and read up about it and see what they're saying the symptoms were if you like (Participant 035 IT: p.11)	I mean obviously you've been to events ... to the Black History thing...you can give out leaflets and give people a talk...say a Domino's club for example, you could even go then and give out leaflets (Participant 032 IT: page 14)	P05: A poster, it may be something, you can put it on a poster if you like, also the best thing is if you want it attached to the GP or surgery community, you go to the surgery you look at the board (Participant 05 Somlai men focus group transcript: p9)

**Table 6: Extracts from interview and focus group transcripts demonstrating individual and community strategies for raising awareness of prostate cancer**

## 9.0 Category 4 – Social talk

### 9.1. Introduction

During analysis of the interview transcripts it became apparent that knowledge about risk for prostate cancer is generated differently between the groups of men. This seems to be dependent on their relationship with the community and how they identify themselves based on the social construction of the male body. The following memo describes thinking during data analysis and the decision to conduct focus groups:

*All men have poor knowledge about prostate cancer and all agree they would take part in prostate cancer screening if it was available. The black men are more likely to talk to each other about their health because they live in a closer community, and although they don't have informed knowledge they don't worry about offering support to each other. Men in the black community take support from each other because their lives are more obviously divided into male and female roles. The men and women don't socialise with each other as much as in the white community, and in the Somali community men and women are entirely separate in a social situation. In the white community men and women socialise together, but the men talk about speaking to other men, in a group setting, about their health experiences. Conducting focus groups would help gain insight into how men talk to each other about health. This will be analysed alongside interview data to interpret how these interactions may influence men's perception of risk for prostate cancer. Risk perception, in this research, is being studied as a social construct that is generated through multiple sources: experience, knowledge, social interactions, belief systems, weight of importance.*

**Memo writing September 2016**

In order to achieve data saturation relating to the theory being generated from this study, it was felt important to have an understanding of how the men talked to each other in their social environment, and how this could influence their social constructions of the male body and their response to the threat of illness.



Therefore, focus groups were conducted using the tasks outlined in Chapter 4 (see appendix VIII), to generate discussion between the men. These data have been used to inform the categories discussed in chapters 6-9 and to provide an insight into how the men verbalised illness to each other.

These data are presented as theoretical codes generated for each group of men, using constant comparison to provide examples of similarities and differences between these distinct cultural groups.

## 9.2 White Working Class men

The focus group with the White Working Class men was conducted in a community centre in area A. The men frequented this centre for general interest talks and to access the library, which was in the same building. The men were known to each other through their access to the groups run at the community centre. The notes from the observer of the focus group document that the group was made up of some men with chronic health conditions and one man who had worked as a paramedic, who quickly took control of the group. The following is an extract from notes made by the observer:

*Two of the participants admitted to having chronic health at the start of the group and preferred to speak about their own health problems and experience than stay on the topic of the focus group discussion. The group was not particularly democratic, preferring to defer to the man with the most healthcare experience. The conversation felt excluding of some men. One man particularly wanted to talk about his own health and seemed excluded by other men in the group, who stopped talking and looked at the floor. None of the men seemed uncomfortable to talk about health and their experiences with each other.*

*(Extract from focus group observer notes White Working Class men: p2)*

These notes indicate the social processes that formed the dialogue of the focus group, and it is proposed that these are based on the norms of social interactions between these men. The following categories have been raised to theoretical codes that are most representative of the type of talk between the White Working Class men.

### 9.2.1 Out-illing and telling

On page 177 participant 034 used the term 'out-illing' when he talked about his experience of social conversations with people of his age. In this research, the term has come to mean that the White Working Class men appeared to be happy talking openly about their health, and this seemed to be the style of talk between the White Working Class men during their focus group.

The White Working Class men did not appear to have close friendships with each other. There was little banter or conversation between these men, instead they gave individual opinions when discussing the tasks and these opinions were based on their own health experiences. The men appeared to take part in an exercise of out-illing each other when they completed task 1 to identify possible symptoms of prostate cancer:

*P02: I go to the toilet just before I go to bed, like last night I went to the toilet before I went to bed and I woke up at four o'clock this morning and went to the toilet and then I got up at half past eight and went to the toilet then.*

*P03: I have good nights sometimes.*

*P06: I used to be able to do a little job and think I'll go to the toilet now, now I've got to hurry.*

*[Unclear and overlapping speech]*

*SF: So that's another change?*

*P06: Yes, I hardly make it sometimes I've got to squeeze the end of my penis to stop it.*

*(White men focus group transcript: p4-5)*

These men appeared very open when talking about their health; it was as if these men were more focused on out-illing each other than being concerned about the intimacy of their talk. This type of talk could also be viewed as supportive through sharing, although the dialogue was competitive and this was also evidenced in an exchange between participant 04 and 06:

*P04: I'm diabetic as well.*

*P06: I am too, I take 15 tablets a day so.*

*(White men focus group transcript: p3)*

The individual out-illing of each other was also evident in debate the men had during the focus group. The men talked about how easy it was to access a doctor, if they have a health concern, and two of the men got into a debate about who had the most knowledge of making an appointment at the health centre:

*P03: ... I'd try and get an appointment with the doctor. I say try because it's a nightmare.*

*P02: If you do it at half past ten Friday*

*P03: You see a nurse*

*P02: No you will see a doctor*

*P01: It all depends which practice you're in*

*P03: Down here you see a nurse.*

*P02: Down here I go.*

*(White men focus group transcript: p1-2)*

It seemed here that the men were identifying themselves as being the most knowledgeable about accessing health services and it seemed important to them that they were correct. There was no agreement reached about this because participant 05 stopped the flow of the conversation by saying; *“that’s the same for most of us I think”* (participant 05: p2). This man had the most experience of health, having worked as a healthcare professional (paramedic) and he quickly took on the role of leader of the group. The men appeared happy with his position because: *“he knows an awful lot”* (participant 04: p14). As a result, this man was not challenged and this allowed participant 05 to dominate the focus group.

The talk of the focus group did not involve conversation; instead the men gave individual accounts of their experience. The men overwhelmingly used the pronouns ‘I’ and ‘me’ during talk about their individual experiences of healthcare:

*P04: ... I’ve been going to see (name given) for ten years and I see her four times a year to have my blood checked and all that and I went down to get my last one done and have the blood test and I asked for the appointment and she said oh no you can’t see (name given), so I said but I always see (name given) and she said no I can’t give you an appointment...*

*SF: Okay, yeah.*

*P04: So you know I don’t know where we’re going.  
[...]*

*P06: I go with this new practice in (name given) and you know it’s a month now before I can get an appointment and the only nurse I saw really did everything for me...  
(White men focus group transcript: p17)*

This style of talk supported the finding that these men seemed to talk about their health as individuals, rather than through the wider context of their social identity.

### 9.2.2 Using humour

The men did not challenge what each other said and talked as individuals, apart from during task 4 when they considered the image from the 'Don't Fear the Finger' campaign. The men agreed that they didn't understand the underlying message of the campaign, and found they could laugh together about the image of the erect finger (appendix VIII):

*P01: I've got one of them on the back of the car.*

*P05: yeah, to other drivers.*

*P02: It should be that finger [gesticulates].*

*Overlapping speech.*

*P03: It should be a middle finger [name given].*

*[Laughter].*

*(White men focus group transcript: p7)*

It seemed that the men found humour whilst discussing a topic that could be seen as intimate. The men didn't directly talk about being embarrassed by the image, but their joking style of talk seemed to make the topic easier to discuss. This seemed different to their individual talk. In the interviews, the men were more reserved in their talk about the rectal examination. They were happy to talk about it but seemed to prefer to move quickly away from the topic. In a group setting it seemed the men used each other to direct the conversation away from the message of the

campaign, that they may require a digital rectal examination if they went to their doctor's surgery with concerns relating to prostate cancer.

### 9.2.3 Summary

The style of the dialogue between the White Working Class men in a focus group setting supported the findings generated from the interview data. The data suggested that the White Working Class men preferred to find out about health information as individuals, and the retired men functioned in their social worlds as individual members of a group, rather than as part of a community. The men in the focus group appeared to be in competition with each other when they talked about their health, and communicate through the process of out-illing. The flow of their talk was often disrupted by individuals talking about a specific health complaint, or by the man with the most health knowledge dominating the focus group. The men did not counteract or interrupt this man and agreed that he had the most health knowledge, and therefore should be allowed to talk for the group.

It appeared that the White Working Class men preferred to talk about their individual health complaints but realised that when in the company of someone who is knowledgeable they should allow them take the lead. It is possible this could stop the men challenging information given to them about health, in the context of their own body, and it is postulated here that this could be related to their socioeconomic status and the known interaction between deprivation, educational achievement and health awareness. Perhaps the men didn't feel well enough informed to

challenge someone they felt was more knowledgeable. This could have implications when discussing the use of the PSA blood test with a healthcare professional.

The use of conversation amongst these men was evident on two occasions. On one occasion, they disagreed about how easy it was to access a doctor's surgery for an appointment, and on a second occasion they used humour to diffuse a topic that could have been difficult to discuss. Otherwise, the style of talk was direct speaking with limited listening to develop conversation.

### 9.3 Somali men

The focus group with the Somali men was conducted in the male-only restaurant that was used to interview the men in this research. The observer of the focus group noted that the men discussed the tasks in a dyad before opening discussion to the wider group, and that a mixture of Somali and English was used for these discussions. The observer also noted that once the dyads had completed discussing the tasks, there was general feedback to an older member of the group:

*Two participants sat towards the middle of the group read out a list in Somali to the rest. The group then began to discuss between themselves, mostly with the person directly next to them ... an older gentleman (in the corner) speaks first.*  
(Extract from focus group observer notes P.1)

No one took control of the group, but the oldest man was given the most respect, and after each task provided a summary of the thoughts of the group after some deliberation. All the opinions of the men in the group were valued. The men used deliberation to communicate and there was little disagreement or democratic talk.

### 9.3.1 Including and deliberating

These men talked about their community when they were considering answers to the questions in each task. When deliberating task 3, participant 06 said;

*We have to think the way we think. We will put information where they put for themselves  
(Somali men focus group transcript: p9).*

The men use the pronouns 'we' and 'us', instead of 'I' and 'me' when they consider their responses to the tasks, and they did not consider their responses based on their own experiences. The following extract is taken from the talk of the men when considering what the symptoms of prostate cancer might be:

*P01: If you know someone who knows about the symptoms you have, but it is not your doctor, will you speak to him?*

*P07: Yes, yes, that's mostly what we do.*

*SF: Mostly what you do.*

*P07: Mostly with the Somalis do is they come to ask someone, about their health before they would go anywhere.*

*SF: Ah, okay*

*P07: We do that*

*Overlapping speech Somali speech (translation):  
Yes, yes. Somalis do. We tell each other. We talk to friends. Culturally we speak to friends.*

*(Somali men focus group transcript: p6)*

In this extract, the men appeared to identify the way communication was driven by their cultural norms. They talked about the community as an embodiment of themselves as Somali men, and they identified with this in their conversation. The



men also said that they would talk to each other before taking medical advice and they were specific about how this commutation would take place, between friends. This is contrary to the interview with participant 017, who talked about who he would talk to first if he had concerns about health. The reasons for this are not clear as the sharing of health information with friends seemed to be culturally important for the Somali men in the focus group.

As well as talking with inclusivity, the men listened to each other when they talked, and deliberated over the answers to the tasks in dyads, creating conversation by exchanging thoughts. An example of this was between participants 05 and 06 when they considered what the symptoms of prostate cancer might be:

*P05: In my opinion leave the one about the stomach pain.*

*P06: The 65 year old who is passing too much water.*

*P05: They use tissues not water.*

*P05: That one is a surprise.*

*P06: Yes, it is swollen not enlarged.*

*P05: Those three are the symptoms.*

*(Somali men focus group transcript: p4)*

The flow of the talk was not interrupted by individual opinion; rather the men used their deliberations to reach an agreement as a group. There was respect for each other and agreement between these men, and sometimes this style of conversation meant the men changed their minds. When the men discussed where the best place would be to find information about prostate cancer, the men were certain they

would prefer the information to be in the public toilets. The men then started to talk about the cultural appropriateness of having information in the toilet:

*P01: The man, public toilets*

*SF: And you agree with that?*

*P05: Yes I agree with that.*

*SF: You'd look*

*P07: The toilets, yes*

*P01: Public man's toilet.*

*SF: Good place for you?*

*P07: Yes good place*

*[...]*

*P06: Somalis do not even look information in the toilets.*

*P05: A poster in GP surgery*

*SF: Good place to have information.*

*P06: Overlapping speech: Then we will not put in ours. Look at me. We have to think the way we think. We will put information where they put for themselves. Why you have to put in toilets?*

*[...]*

*P07: That is good. (Unclear, overlapping speech) why they cannot put in theirs, no. We have to say no. Toilet is for cleaning. Not a food place. (Somali men focus group transcript: p8 -9)*

In this extract participant 07 seemed to change his mind, after some deliberation with the other men. The men again reached an agreement about their community and what would be culturally appropriate, based on their experiences and their own perceptions of cultural norms.

### 9.3.2 Using humour

Like the White Working Class men, the Somali men used humour when they were shown the 'Don't Fear the Finger' picture (see appendix VIII). In this situation, the dominant language used was Somali and the men shared their humour about the picture in a relaxed manner:

*P07: I do not like that. It is not valuable. It is not good. It is a doctor. No, it's up to the doctor. If the doctor wants to do it then it is fine, but what if this picture is used as a board? It will make people run (laughter)*

*[...]*

*SF: What's he saying?*

*P01: You see this finger it's going up your. You run away (laughter).*

*SF: So this makes you fearful?*

*P06: It doesn't make sense.*

*Overlapping speech (laughter).*

*SF: What's he saying?*

*Laughter*

*P01: He said it's too long (laughter).  
(Somali men focus group transcript: p12-13)*

The men appeared to be enjoying this opportunity to laugh in each other's company. The humour sounded like it was being used by these men to bond and affiliate with one another; it seemed that, for these men, humour was being used to affirm the similarities between these men. The following memo was made during the analysis of this focus group:

*These men use humour in their conversations because they know each other. They are comfortable sharing jokes. The men laugh openly and*

*without restraint; the laughter is contagious when listening to the focus group. They don't use humour as banter in the same way that the African Caribbean men do. Banter is not part of their normal speech (Focus group memo writing: p1)*

### **9.3.3 Summary**

The Somali men were respectful of each other and used deliberation and agreement to find answers to the tasks. There was little disagreement and little democratic talk; a leader of the group did not emerge amongst the men and the men appeared happy to share their talk as equals. Some men talked about cultural norms, and these appeared to have an influence on the decisions they reached in their conversations. Some of the participants changed their minds during the focus group and this appeared to relate back to what the group believed was the most culturally appropriate response for their community. When discussing the tasks, the men talked about other men in their community, they didn't answer as individuals and they used the pronouns 'we' and 'us', instead of 'I' and 'me'. These men did not seem to consider deliberating answers to the tasks from an individual perspective.

The men possibly used humour to discuss something that made them feel uncomfortable but it also appeared that they used humour to affiliate with each other. The style of the men's talk created an environment of openness, in which the men felt safe to share their thoughts because they were communicating at the level of their community.

### **9.4 African Caribbean men**

The focus group with the African Caribbean men took place in a community centre within the community with which the men identified themselves. The focus group

was held in the evening, before the men attended the local dominoes club at the same venue. There was an observer present who noted that the talk was democratic with discussion and disagreement between all the participants:

*This group appeared a lot more democratic [compared to the white and Somali men focus groups] with significantly more discussion and disagreement between participants before a decision is reached (and sometimes not even then).*

*(Extract from focus group observer notes P.4)*

There was also a predominant use of banter, particularly when the men started to disagree. Banter in this situation is defined as the putting down of another person with humour, which appeared to be accepted by these men and seemed a normal part of the discourse.

There was no clear leader of this focus group and this was reflected in the democratic talk of these men. The following memo was written during data analysis about leadership of the group:

*This focus group was democratic. There was no clear leader of the discussion but two of the men tried to be. Although participant 03 was talkative and trying to get his point across he had less need to try and control the group... participant's 01 and 04 were jostling for position throughout most of the focus group. Participant 04 talked as though he should be in control of the group because he has had experience, whereas participant 01 just wanted to be heard and be seen as a joker in the group. It is difficult to distinguish the effect of emotional security of individuals in the focus group, and the effect this may have had on their responses to conversations within the group has been attended to.*

**Focus group memo writing p: 2.**

#### 9.4.1 Democratic talk and sharing experience

The men shared disagreements before reaching an agreement for each task, and sometimes they conceded that they would need to: “*agree to disagree*” (*African Caribbean men focus group transcript: p3 P01*). This type of talk appeared normal amongst these men, and although this could sound aggressive the men seemed to enjoy the opportunity to share their differing opinions. The following extract demonstrates this when the men talked about whom they would talk to first if concerned about their health:

*P03: I would say his partner*

*P02: Yeah, he would say his wife first.*

*P03: Yeah well that's his partner.*

*P01: Hey, how do you know the man's got a, how do you know he's a typical bloke (laughter). He's got a woman.*

*P03: No, no, that's why I said partner.*

*P01: Okay my friend, yes (laughter)  
(African Caribbean men focus group transcript: p1)*

The talk amongst the men was also democratic when they considered the ‘Don’t Fear the Finger’ image. The image amused the men less than the Somali and the White Working Class men. The African Caribbean men recognised that this was a procedure that needed to be done, and that they should receive education about the purpose of the digital rectal examination. The men disagreed about whether they would be happy to have the procedure, and related this to their experiences of living in the Caribbean:

*P04: What I'm trying to say is this was years ago, a lot of education has gone back there now since we left home, we left, I left home in 61. When did you leave, '64?*

*P03: I left in '65 but you must remember I came from the West Indies in March, I was there I just came back in March.*

*P04: But I'm saying (overlapping speech).*

*P03: Just a minute, the education part of it there still, right, but the actual doing, people don't want to do it.*

*P04: People just don't, if they don't want to do it then they just going to have to die then isn't it.*

*[...]*

*P01: No (name given), also,*

*P03: I'm telling you (overlapping speech)*

*[...]*

*P04: If you're talking about black people.*

*P01: What I'm trying to say is if we don't want this*

*P04: No that's what you're talking about. We're not talking about men in general, we're just talking about black people, there's a difference. (African Caribbean men focus group transcript: p17)*

This extract may also be related to the men's experiences of being black in the UK. The men in the interviews talked about experiencing racism when they were younger men and this seemed to have led to a sense of pride and recognition that the men were seen as different to White Working Class men, through the creation of community. In the focus group extract above, participant 04 articulated this when he said: *"We're not talking about men in general, we're just talking about black people, there's a difference"* (African Caribbean men focus group transcript: p17).

Here it seemed this man had recognised that black men understood their health risks differently to other men because of their relationship to being black.

The above extract also provides an example of the democratic talk amongst these men. This type of talk seemed to become particularly evident when the men talked about a topic that divided them and perhaps questioned their acceptance of a procedure, which was seen by some as unacceptable. Participant 04, in the extract on page 296, also recognised that their conversation was about black men. He made a reference to black men thinking differently about the 'Don't Fear the Finger' image, and participant 01 talked about this in the context of the heritage he identified with:

*Look (name given), if we got one person over here in this country that takes that attitude, okay, you can just imagine how many people back home would take that attitude  
(African Caribbean men focus group transcript: P15 p03.)*

This man used the pronoun 'we' to talk about his concerns for men of the same heritage. This man was thinking beyond himself with regards to health awareness when he referred to: "*people back home*" (*African Caribbean men focus group transcript: p03*), perhaps reflecting the feelings of the community, who may see home as their place of heritage. This was considered in chapter 6 when the identity of the body in the social context was discussed. The men later used this type of talk when they considered their access to education as younger men:

*P04: But when we were young we were back in the West Indies.*

*P03: That's what I'm saying*

*P04: And they didn't have that information on health*

*P01: Education is key  
(African Caribbean men focus group transcript: p9)*



The men made a connection in their talk by relating to their country of origin and the opportunities they did not have at the time. This appeared to be providing these men with a reason for not fully understanding their risk for certain health problems, such as prostate cancer, and they together acknowledged this knowledge deficit.

#### 9.4.2 Using humour and sharing experience

The African Caribbean men did not use humour in the same way as the Somali men and White Working Class men. During the talk about the 'Don't Fear the Finger' image, the men became animated and talk was at the most democratic. This is perhaps because they were talking about a procedure that could affect the social identity of their bodies. Participant 01, who seemed to find the conversation about the body and illness threatening, used the most banter during the focus group. For example, during the discussion about which symptom would be most concerning as a symptom of prostate cancer (task 2), participant 04 started the discussion by telling the men that he had experienced symptoms that he found concerning and participant 01 uses this as an opportunity to make a joke:

*P04: Oh I've been through that so I should be.*

*P01: Man in a white suit there.*

*P03: We could leave you with them (name given).*

*P04: Sometimes it's time to be serious, you're silly.*

*P01: (laughter).*

*(African Caribbean men focus group: p6)*

It appeared that participant 01 was making light of participant 04's knowledge and experience, and this prompted a return of banter in the form of a put-down: "*you're silly*" (*African Caribbean men focus group transcript: p6*). This did not come across as an aggressive exchange and the conversation moved on. During task 4 the men discussed the "Don't Fear the Finger" image, and although they didn't use humour during the initial discussions, participant 01 started to use humour related to his interpretation of the sexual content of the picture:

*P03: You'd just walk past, you don't, it looks like a chimney (laughter).*

*SF: That's interesting, okay.*

*P02: Saying what it is on there, and then you'll stop and you'll think about what it signifies, you'll look at it in a better, in a better light.*

*[...]*

*P01: I've got a new one for that.*

*P03: What*

*P01: Don't die a virgin*

*P04: That's what I'm talking about, you know. People wouldn't see it as something educational, they'll see it as like this dickhead sees it. (African Caribbean men focus group transcript: p20-21)*

There was disagreement in this extract and it seemed not all the men enjoyed the humour. Humour appeared to be regarded by participant 04 as something other men would use if confronted by an image that may appear to threaten their identity as a black man.

Relating this to illness and body image, participant 04, who seemed to have the experience and knowledge of the unwell body, did not dominate the discussion by

talking about his own health experiences and concerns. This was unlike the style of talk of the White Working Class men. The African Caribbean men were very happy to share their experiences with each other and talked about this as a way of exchanging knowledge:

*P01: Is that in the night then (name given)?*

*P04: Night and day, mostly night but, so when I went to the hospital they had me to, every time I go to make a note of it and it turned out I went 24 times in 24 hours.*

*P01: How much was you drinking though, fluid?*

*P03: Doesn't matter*

*P01: Doesn't matter, does it?*

*P01: Doesn't matter, you just feel like, you have the urge, you may not pass a lot.*

*P04: No, that's it, I wasn't passing a lot.*

*P03: Well you just have the urge*

*P01: Because I drink a lot, I like drinking water.  
(African Caribbean men focus group transcript: p6)*

### **9.4.3 Summary**

The discussion between the African Caribbean men moved between democratic talk, in the form of agreement and disagreement, information sharing and banter.

Despite the incidences of disagreement, the men were respectful of each other's opinions and this was demonstrated using banter to diffuse situations where the discussion could have become confrontational. It appeared that the men were used to communicating with each other in this way. This may have been a reflection of the pride that was talked about in the research interviews, related to their identity

of being black. It is possible the men were articulating pride through their democratic talk and banter.

This comes across most strongly in the style of talk that uses the pronouns “we” and “us”. The men referred to themselves as people who have migrated to the UK as adults, and so had received a Caribbean education as children. The men talked in a manner that was inclusive of the Black man’s experience and how this affected accessibility and understanding of health-related information.

### 9.5 Chapter summary

The African Caribbean men and the Somali men talked as a group of friends. They had respect for each other, shown through banter and allowing time for each other’s comments. The White Working Class men spoke as individuals and seemed less respectful of each other in their conversational style. They showed respect to the man they felt was the clear leader, but not always to other men in the group. There was no clear leader in the focus group with the African Caribbean men, although they jostled for this position through democratic talk, and the Somali men had silent respect for the eldest man in the group.

The use of humour was the same for the White Working Class men and Somali men during task 4. They used humour unconsciously, and this may have been an instinct to cover up discomfort the men felt at seeing the picture in task 4. All the men talked about the significance of the picture but frequently came back to humour during this task. It seemed that these men did not want to be in a position where an intimate examination was discussed with each other. This is different to the

responses of the men in the interview discourse who were open and willing to talk about the digital rectal examination. It appeared that for these men this was a conversation for a private space and would not form part of their social discourse. This relates to thinking about finding the right space to share prostate cancer education.

The reaction to task 4 was different in the African Caribbean focus group. The men were quick to understand the significance of the poster and openly talked about having the examination. The men related the examination to the views of men in the West Indies, in an attempt to try and understand why there might be resistance to the image. The men talked about belonging to the African Caribbean community in the way they shared their understanding of the cultural views of the country from which they had migrated. Only participant 01 used humour during task 4 and this seemed to be because he was the most concerned about the image of the unwell body. This humour led to banter involving participant 04.

The Somali men and the African Caribbean men appeared to discuss their answers to the task using their social identity. They talked about the answers to the tasks from the perspective of other men in their communities, who they identified with as Somali or as Black. The White Working Class men did not talk about other white men, they talked as individuals. It is proposed that this is because they have not lived in a minority and so have not had to find their position in the wider society in which they live. The talk of the White Working Class men could also reflect the nature of their social identity, as belonging to a group rather than a community, which appeared to have driven their health talk as they negotiated their space and

place for health talk through the influence of political health initiatives, such as the 50+ Club.

The use of the focus groups has added to the semi-structured interviews by providing insights into the way men talk to each other. The focus groups have also added clarity to the concept of the differences between these men and the body in everyday life. Understanding of the social construction of the body, in relation to health and illness, has been enhanced by the inclusion of these data that provide an insight into the everyday talk of the men in this research.

The use of the pronouns 'we' and 'us' by the African Caribbean and Somali men supports the theory that the Black men are part of an established community, possibly brought about by their migration to the United Kingdom. The White Working Class men used the pronouns 'I' and 'me', supporting the theory that they live as individuals because of their firmly established Welsh identity. These men also had a disjointed conversation about health, providing individual statements about solutions to the tasks, brought together by a self-imposed leader given respect because of his medical background. This also appears to be related to the process of out-illing, discussed in chapter 7.

See Figure 6 for a diagrammatic representation of theories developed for this category.

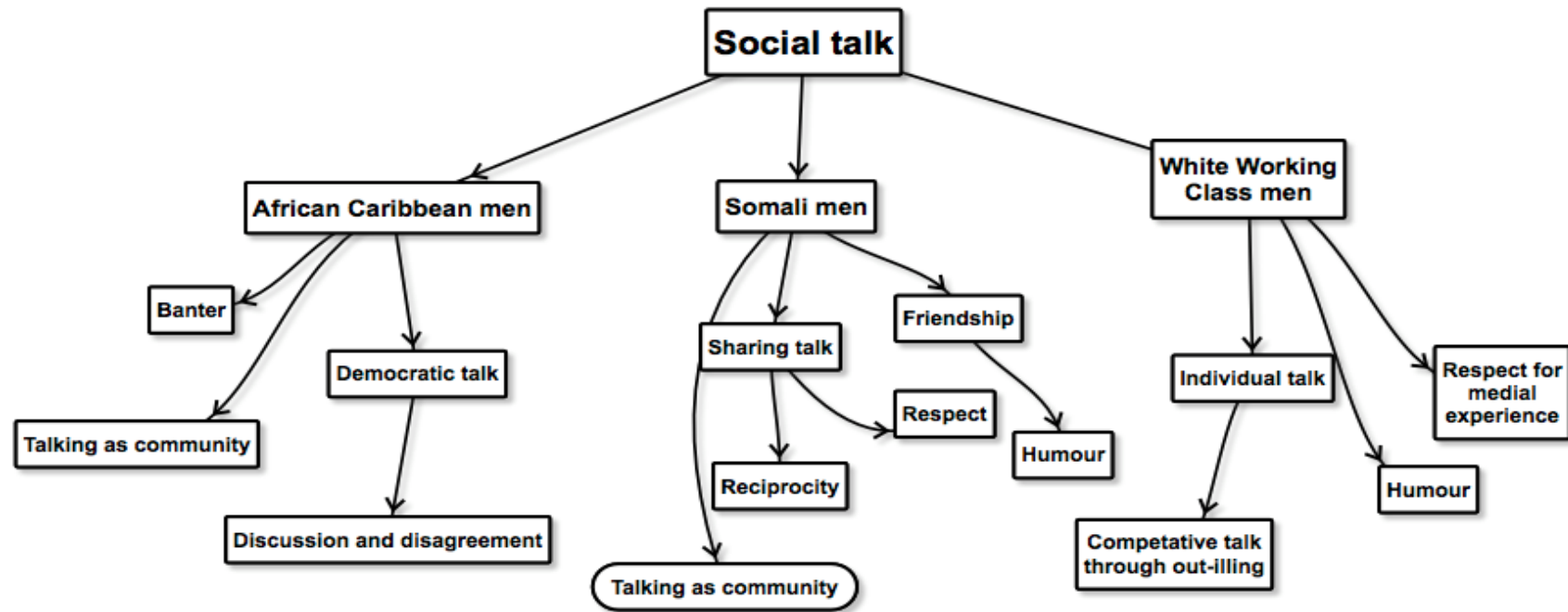


Figure 6 Diagrammatic representation of Social Talk

## 10.0 A grounded theory of social constructions of the body and perceptions of prostate cancer risk

*To understand is first to understand the field with which and against which one has been formed*  
(Bourdieu 2004, p.4 Sketch for Self-Analysis)

At the analytic core of the categories created from theoretical analysis of these data, are the embodied experiences of the African Caribbean, Somali and White Working Class men. It is proposed that these experiences have created socially constructed perceptions of the men's bodies and understandings of their bodies' risk for prostate cancer. To understand the differences in how Somali, African Caribbean and White Working Class men perceive their risk for prostate cancer, we must first understand the influences of the men's life journeys and accept the impact of these on perceptions of the body and the acceptance of illness.

Box 1 presents the proposed grounded theory, generated from this study, which suggests that a man's perception of the body is influenced by the place of the body in society. The social worth of the well or unwell body is thought to influence the men's understanding of their risk of prostate cancer.

The social construction of the body is important in helping men understand their body in society, which mediates the way in which men are socialised to understand and accept their risk for prostate cancer.

**Box 1 Proposed grounded theory of reasons for cultural differences in men's perceptions of prostate cancer risk**



The social construction of the body is presented in this thesis as the way in which the men differently perceive their risks for prostate cancer and how they might respond to prostate cancer awareness-raising campaigns. Differences of the experience of the male body in social space, rather than the boundaries of the physical body, mediate the way in which the men understand their bodies and accept their risk for prostate cancer.

Prostate cancer is a uniquely male concern (Kelly 2009), and associated with it is an understanding of risks to a uniquely male area of the body. It is proposed that cultural influences on social construction of the body mean that Black and White Working Class men consider prostate cancer through the lens of being similar or different to the majority. These experiences of being similar or different position the body as more important or less important to maintaining the normalisation of the body in society. It is proposed this mediates the way in which the men respond to the threat of illness; in the case of this research to the threat of prostate cancer. Figure 7 is a diagrammatic representation of the grounded theory, demonstrating the concepts of the proposed grounded theory in understanding the differences in the men's perceptions of prostate cancer risk. The diagram shows how the body is sociologically constructed for the three groups of men and the ways in which social construction of the body this mediates the way the men understand their risk for prostate cancer.

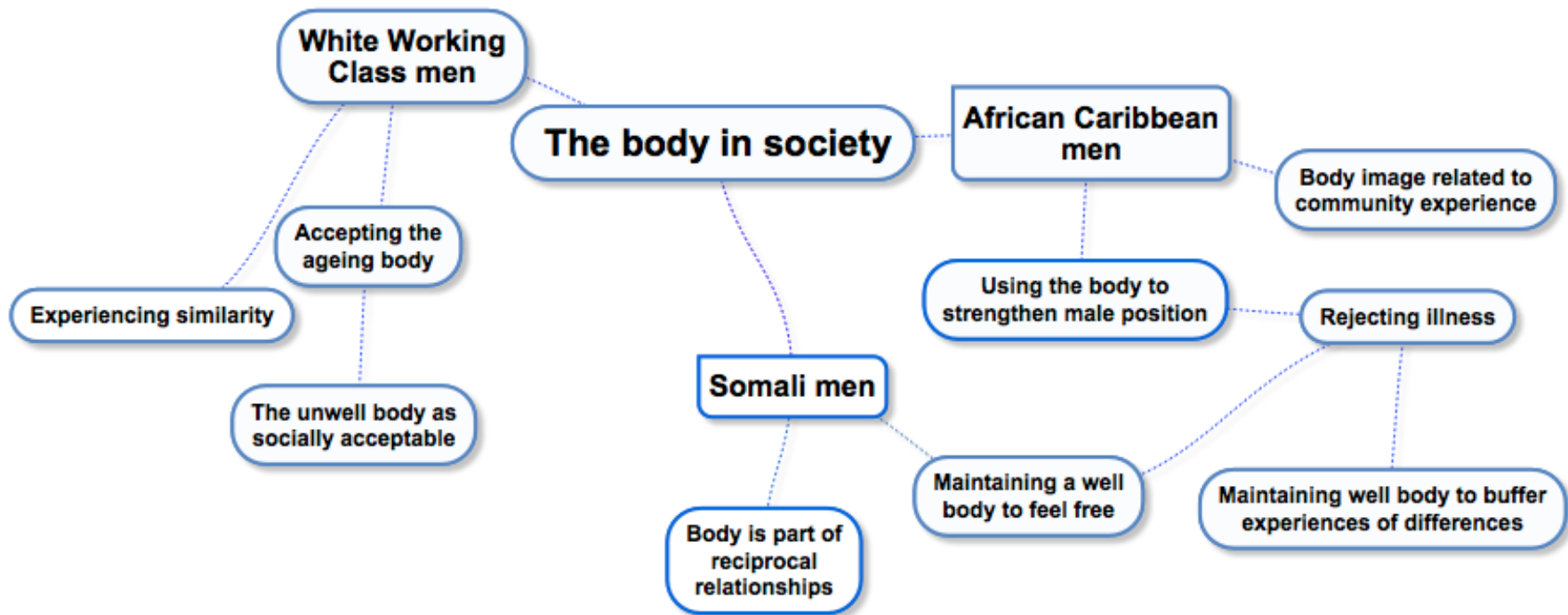


Figure 7: Illustrative example of generating grounded theory

## **11.0 Discussion**

### **11.1 Introduction**

The preceding findings chapters have presented the final analysis of data collected from interviews and focus groups with White Working Class, African Caribbean and Somali men, living in areas of deprivation in South Wales. The findings have been presented as separate theoretical categories: Identity by Difference, Views of the Body, The Everyday Body and Social Talk. The categories have been separated and discussed for each group of men involved in this research, and similarities and differences have been found between and within the groups using the method of constant comparison. Constant comparison has also allowed the researcher to make analytical distinctions at every level of analysis (Glaser and Strauss 1967), and allowed the researcher's observations to form part of the overall findings by comparing these observations to the analytical categories generated from the data (Charmaz 2014). As in the preceding chapters, the discussion of the Somali and African Caribbean men in this chapter will be referred to as Black men when the groups are discussed together, and their individual group names, Somali or African Caribbean, will be used when discussing similarities or differences between these men.

In keeping with constructivism, the interview and focus group data have been analysed through the lens of the social construction of knowledge, relating to the men's perceptions of prostate cancer risk and how these perceptions are influenced

by the everyday experiences of the men. From the start of this research, the premise was that reasons for the low attendance of Black men in prostate cancer clinics in South Wales was unknown, and that the differences in their understandings of prostate cancer risk when compared to White Working Class men was also unknown. It was the intention of this research to find out how men from differing cultural backgrounds without a diagnosis of prostate cancer understood their risks for this male health concern.

During the initial literature review, to form the basis of the research question, the evidence suggested that black men were less knowledgeable than white men about prostate cancer and would prefer education campaigns targeted at their social environment (Odedina et al. 2004); and this continues to be the case (Santos et al. 2017). However, the literature did not provide evidence of how the everyday lives of these men affected their readiness for accepting their risk for prostate cancer and their use of related prostate cancer information. Using a constructivist grounded theory approach, this study has found it is the everyday lives of the culturally distinct groups of men that affects and influences their understanding of risks for prostate cancer. Of specific interest to these research findings is how the cultural lives of the men influence their potential engagement with prostate information, rather than focusing on what the men say about their preferred methods for education and their current level of prostate cancer knowledge (Odedina et al. 2004; Odedina et al. 2011; Martins et al. 2015; Santos et al. 2017).

The categories that have emerged from this research have provided evidence of differences between the groups of men in how their social constructions of the

unwell body have influenced their acceptance of risk. The findings also suggest that the influence of sociocultural background have created a subjective view of the body, based on experiences of being similar or different to the majority population. In the case of this research, the majority population is seen as the White Working Class men. However, their position as belonging to a neighbourhood regarded as an area of deprivation should also be considered in the context of marginalisation.

The African Caribbean men were the most explicit in their talk about being different and how this had affected their social interactions. For the African Caribbean men the experiences of enduring racism appeared to be part of their construction of the body, influenced by a feeling of pride and the well body being a symbol of their masculinity. There has been a long history of rejection of the black male in predominantly white areas, indeed fear in the early years of the transatlantic slave trade (Marriott 2000), and this may have generated feelings of inferiority amongst Black men (Edwards 2006). The relevance of this to the research findings in this thesis will be discussed in section 11.4.

The Somali men involved in this research did not talk as much as the African Caribbean men about 'being Black' and the difficulties this has caused them living in a predominantly white country. This may be because the Somali men involved in this research migrated later than the African Caribbean men and because of their reason for migration (fleeing civil war), which appeared to have left the men with the hope that they would return home (back to Somalia) rather than seeing the UK as their permanent home. The Somali men's constructions of the masculine body also appeared to be influenced by the importance of their religious beliefs on their

everyday lives. In the following discussion of the literature, this will be discussed in relation to the constructions of masculinity and the positioning of Somali men within their social group.

The talk of the Somali men about the desire to return home appeared to have created distance between themselves and their bodies. More than any other men in this research the Somali men talked about their bodies in relationship with their community, valuing the usefulness of their experiences of the unwell body on the knowledge of the male community. These men saw their bodies as a vessel of knowledge for other men, but also passed the responsibility of understating their bodies to healthcare professionals. The Somali men talked about being trapped in the UK by the unwell body and by accepting Western medicine. This may have mediated their willingness to become involved in better understanding their bodies. A caveat to this is the very small number of Somali men involved in this research, but in the context of this study their views of the bodies in relation to health and illness are thought to contribute to the grounded theory by adding to comparisons between the groups of men.

In contrast to the findings for the Black men, the White Working Class men were very accepting of illness and talked about the process of ageing and illness as related and being used as part of social talk. One of the participants used the term out-illing and it is proposed here that this is a new concept in understanding White Working Class men living in areas of deprivation, and their relationship with health and illness. Out-illing is seen as a way of gaining social recognition through the process of diagnosis and treatment, which was discussed openly between these men. The

men in the focus group were very open about their health concerns and it could be that the men felt the focus group format was as an acceptable place to talk about the body in relation to health and illness.

In their interviews, the White Working Class men also talked about accepted spaces to talk about health such as the allotment, and the UK scheme Men's Sheds (UK Men's Sheds Association 2017) has been suggested as a potential space for discussing the body in relation to prostate health. For the White Working Class men, health and illness talk was articulated as something that happened to them as individuals or through gossip during a group activity, in contrast to the Black men who talked about health and health knowledge as a community concern.

The findings of this research suggest that the White Working Class men embody what is already understood about health education strategies in relation to men's health. Current layperson prostate cancer literature focuses on the man as an individual. For example, the most recent prostate cancer information from Prostate Cancer UK states:

*If you notice any of the changes we talk about in this booklet or you're worried about your risk of prostate cancer, visit your GP ...* (Prostate Cancer UK 2015a)

The information provided for Black men on their specific risk for prostate cancer uses the same terminology (Prostate Cancer UK 2015b), and it is suggested that this may not reach Black men, who in this study talked about their bodies and illness as inclusive of the community. The proposed grounded theory, that social

constructions of the body mediate acceptance of prostate cancer risk, would suggest that the prostate cancer risk should be written using inclusive terminology such as 'men in your community are at risk from prostate cancer'.

What follows is a comprehensive review of the literature in relation to these research findings, discussed through the lens of the men's social constructions of what it is to be male and potentially affected by a uniquely male illness. The grounded theory is positioned within the overall theoretical framework of embodiment. In embodiment theory the body is seen as the subject of culture, forming the basis in which a person feels they can act as a free agent based on their understanding of the body within their culture (Csordas 1990).

In this study, the theoretical framework of embodiment has been applied to the discussion of the grounded theory, based on the importance of the cultural understanding of the body and acceptance of the unwell body, on the way in which the men have been socialised to understand their risk for prostate cancer.

In this work, the theoretical framework of embodiment is seen as influenced by the field and habitus theories of French philosopher Pierre Bourdieu, drawing on preconceptions of the self, based on the conditions in which a person has developed. This included gender order in society manifested through hegemonic masculinity (Connell 1995). The following discussion will present an argument, based on the research findings, which positions the men's readiness to accept and understand their risk for prostate cancer in the social construction of the everyday lives of the men in this research.



## **11.2 Habitus, field, embodiment and hegemonic masculinity**

The following section will discuss the theoretical underpinnings of the grounded theory. In this work, the social embodiment framework is used to capture the social construction of the body in its social and historical context. It is thought that in relation to these research findings, embodiment is applied with understandings of the position of the male in society, masculinity as socially constructed, preconceptions of the body by the distinct cultural groups (habitus), and the influence of cultural experiences relating to the body on the men's readiness to accept risk (field).

### **11.2.1 Habitus and field**

For Bourdieu (2007) habitus is the study of a subject (person) within their own lived experience. Bourdieu rejected the notion that a person could be understood without first understanding a person's current situation and the habitual state of the body, based on the predispositions and inclinations of that person (Maton 2014). To fully appreciate the concept of habitus, we must also understand the work of Bourdieu in relation to field theory (Maton 2014). In the context of habitus the field becomes a place in which a person's identity is structured by their interactions with others, and the boundaries placed on a person by others or institutions (Thomson 2014). The conditions faced by a person in the field place limitations on what can be achieved by influencing the predispositions or habitus of that person (Thomson 2014).

An example of this was discussed in chapter 2, page 17, when social deprivation and the work of The Marmot Review (2010) was considered in relation to the lives of people living in deprived areas. The Marmot Review (2010) concluded that socially affluent areas create favoured people who will live longer than those in more deprived areas, and as such poverty and health are inextricably linked. Drawing on the work of Bourdieu, we can conclude that social status within a person's social field can affect habitus and shape interactions and experiences with positive or negative health outcomes. Bourdieu (2007) calls this the effect of economic capital on a person's social space, although he acknowledges that for people living in areas of deprivation their cultural capital (worth) can be higher than those with greater economic capital, dependant on their subjective experience of life (Crossley 2014).

Habitus and field theory are of relevance to this study because the men all lived in areas of social deprivation and it is proposed that the men found ways to increase their cultural capital through access to group activities, for the White Working Class men, and for the Black men through the creation of a community of similar people. It is suggested that these structures influenced the ways in which the men perceived the world and their actions within it. Habitus has previously been used as a framework to study health, and in particular gender differences in health behaviour with an emphasis in recent years on men's health (Watson 2000; Gill et al. 2005; Robertson 2006; Dolan 2011). Related to this are the concept of embodiment and the relationship of masculine embodiment to men's health practices, which have also received considerable attention (Robertson 2006; Kelly 2009).

### 11.2.2 Embodiment

In a seminal text examining embodiment, Csordas (1990) discussed embodiment as a collapsing of mind and body and subject and order. People are the embodiment of themselves as a whole being and not merely as affected by the environment or a physical and psychological product of the processes through which they have travelled (Csordas 1990). The body is manifested through a cultural pattern of behaviour; it is embodied by the experiences of the cultural background and it is against this background that the embodied person emerges (Csordas 1990). Here, it is easy to see the link of embodiment to the work of Bourdieu in relation to habitus and field theory. A person is an embodiment of their experiences, preconceptions and the limitations or freedoms of the field in which they live. This is of particular relevance to this research; the body is considered against the social background of the men in this research, and it theorised that habitus and field theory shape the differences between the men in this study.

Criticisms of embodiment and field theory have focused on lack of specificity in research about which field is being examined, in relation to embodiment (Thomson 2014). For example, field is seen as having multiple layers of capital, for example economic, cultural and social capital, all of which could form the focus of research. The use of a constructivist grounded theory approach in this study has alleviated the researcher of this problem. The decision to focus discussions of the grounded theory on the social and cultural field through the framework of embodiment also includes thinking about the social value of the male in society. In this context, social

field, cultural capital and socially constructed masculinity provide a focus for discussion of the differences in the men's perceptions of prostate cancer risk.

The constructivist approach to reality relates to this view by attempting to make sense of a person's understanding of the body (Charmaz 2014). Connell (2005) agrees that the constructivist approach has been successful in removing the body from examination under purely biological terms, by considering the influence of society on the way in which the functioning of the body is accepted. An example of this would be the social construction of gender (Connell 2005).

Social embodiment and men's health has received recent attention in sociology literature after a period of time when research focused on the physicality of the male without considering the effects of their experiences on understandings of their bodies (Watson 2000). Watson (2000) was one of the first researchers to address this gap with a study of men's health, using a grounded theory approach. Watson (2000) was interested in the effect of the everyday lives of men on their understanding of the body and health. His research took place in Scotland, in an area built to accommodate the Scottish oil industry, which Watson describes as an area inhabited by young families with some local authority housing stock. The area Watson (2000) describes appears similar to the areas chosen for this study; the areas were traditionally built on the sea trade with housing built for local workers and local council housing in the 1950s to fill a gap in social housing need.

During his research, Watson (2000) studied the everyday lives of men aged between 30 and 40 years, to try and unpick their understanding of the body through their

everyday lives. Like the current research, Watson (2000) was interested in, “everyday ordinary, unexceptional bodies embedded in the detritus of daily living rather than bodies excavated by the drama, for example illness” (Watson 2000, p8). For Watson, the body and embodiment were categories that emerged during data analysis and his application of a grounded theory approach meant that he was free to explore the theory of embodiment in everyday lives (Watson 2000). His work generated theorising about a male body-schema related to four types of embodiment: normative, visceral, pragmatic and experiential, which Watson discusses as being interdependent, each acting on everyday understandings of the male body (Watson 2000).

The work of Watson (2000) is of interest to this study because of the similarities in his methodological approach and study area, and his findings relating to the body in everyday life. Pragmatic embodiment, which focuses on the way the men talk about the social order of being male, is particularly important to the research findings from this work. In this study, embodiment is thought about as a cultural concept, in which culture is defined as the values and beliefs that define the men as different from each other. It is these differences that are seen as influencing the way the men construct their reality of the masculine body. It is also recognised that in this context cultural embodiment is influenced by gender expectations in society, and these expectations have influenced the way the men have experienced their bodies.

In this study, the African Caribbean men appeared to experience the masculine body through their relationship with the community and the importance of physical strength to maintain their position in the community. Conversely, the White

Working Class men seemed to find value in illness to strengthen their position amongst other men. Although the Somali men seemed to resist the acceptance of the unwell body, as this brought with it restrictions of travel to Somalia, the men also found social value in illness to fulfil their reciprocal relationship with other men. These social ideas about masculinity also form part of the theoretical positioning of this research.

### **11.2.3 Hegemonic masculinity**

The concept of hegemonic masculinity is constructed from the ways in which gender roles have been created by society (Connell (2005). The concept of hegemonic masculinity can be used in different ways, as a theoretical concept, but has been mostly understood as a pattern of behaviour, developed in social psychology as a reaction to feminism and the study of patriarchy in which men hold the power (Connell and Messerschmidt 2005). In this study, hegemonic masculinity is used to form an explanation of the thesis, and the concept has been used in other research studying the everyday lives of men and their understanding of the body (Watson 2000; Robertson 2006). Hegemonic masculinity has also been used in understanding men in marginalised groups (Connell 2005) as well as in trying to unpick the burden of poor health in black males living in towns and cities (Staples 1995).

There has been a focus on hegemonic masculinity and the experiences of men with prostate cancer (Kelly 2009). Using an ethnographic approach, Kelly (2009) studied masculinity in the context of prostate cancer and found that men reorganise their

understanding of masculinity, after a diagnosis of prostate cancer, in an attempt to restore their former selves. These findings are important to this study because Kelly (2009) postulates that masculinity is not static, rather is influenced by the reality facing men as illness changes their social construction of reality. Kelly (2009) writes that masculinity occurs from concerns of self-identity, locating masculinity in a social context bound by social expectations of the male role. Writing about the influence of social processes on the construction of masculinity, Wedgwood (2009) recognises that for Connell the body is not a symbol of a person; the body is open to change from the influence of social constructions of the body. This fits with constructivism and understanding reality. In constructivism, reality changes depending on the individual's experience and the construction of themselves they must draw on at a particular time and place (Berger and Luckman 1966).

Criticisms of the concept of hegemonic masculinity have included concerns about the apparent rigid position of comparing male and female (femininity and masculinity) as heteronormative, therefore missing the fluid movement of bodies through gender and ignoring differences within gender categories (Whitehead 2002, cited in Connell and Messerschmitt 2005; Kelly et al. (2012) In a summary of hegemonic masculinity and the use of the concept in research, Connell and Messerschmitt (2005) remind us that although the body and its lack of fluidity in terms of sexual categorisation, is central to the concept of hegemonic masculinity (by making a distinction between male and female), the relationship of the body and the social context in which it occurs is also an essential element of the theory. In

other words, masculine embodiment is important in establishing the extent to which others also perceive the effects of hegemonic masculinity.

The interplay between the social context of masculinity and perceptions of the body are important to this research because of the differences in the way masculinity is embodied within cultural groups. Wedgwood (2009) reminds the reader that Connell's approach to studying men grew from concerns about determinism of gender order, and challenged the simplicity of this approach to publish works of the complexity of masculine construction in the social form.

This construction of the male form and hegemonic masculinity are important to this study in theorising about the subordination of Black men by White men. None of the White Working Class men in this research talked specifically about their feelings towards Black men<sup>3</sup>, but experiences of racism on the perception of the African Caribbean body, by other Black men, is seen as influenced by the social embodiment of hegemonic masculinity for the African Caribbean men in this research. Connell (2005) refers to this when he discusses marginalisation interacting with hegemonic masculinity through the subordination of Black men by White men as they try to construct their social position based on social constructions of gender.

Staples (1995) writes about the social construction of masculinity in his discussion of the masculine mystique and Black men's health, in which he draws our attention to high levels of risk taking among Black men as they find their masculine self in a

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<sup>3</sup> The men were not asked about their opinions towards Black men. The research was about perceptions of prostate cancer risk and the concept of racism and the effect on views of the body came from this research and the interviews with the Black men.



social context. Staples (1995) contends that the embodiment of the black male, as fulfilling the strong male image, can lead to black men ignoring illness until it becomes disabling for fear of losing their socially constructed male status. This thinking is evident in the current study when the African Caribbean men talked about ignoring illness until it became too late, and seeking healthcare outside of their local community for fear of being seen accessing medical help.

As discussed on page 328 the role of masculinity in this study is based on the ways in which the Somali and African Caribbean men have found to be a valued part of society, in spite of marginalisation. For the Somali men, hegemonic masculinity is not seen as an important part of the social construction of the male, whereas for the African Caribbean men hegemonic masculinity may have become more salient due to marginalisation. This has led to the African Caribbean men creating communities in which their masculine status can be nurtured, and for the White Working Class men the social construction of masculinity seemed to be differently defined when the men talked together, and illness became a strategy for competing for status.

In trying to understand male order amongst Muslim men in the UK, Siraj (2014) conducted qualitative research using semi-structured interviews with British-born Muslims to examine how masculinity was constructed for Muslim men in the United Kingdom. Siraj (2014) concluded that the meaning of masculinity for these men was heavily influenced by their religion; their religious practices dictate that men are responsible for caring for the family, and being supportive and caring of their wife. Masculinity for these men is seen as being constructed through religion. Masculinity is not talked about as being powerful, strong or in control; rather it is talked about

as being responsible (Siraj 2014). The findings of Siraj (2014) were supported by the talk of the Somali men in this study, who talked about their fathers being responsible for bringing them to the UK during the civil war.

#### **11.2.4 Summary**

After applying a constructivist grounded theory approach these data have generated a grounded theory that proposes men's views of their bodies are influenced by the social construction of the body, and this is thought to be theoretically rooted in the concepts of habitus, field theory and hegemonic masculinity and applied to the theoretical framework of embodiment. These concepts are seen to account for the differences in the way the men understand and perceive their risk for prostate cancer.

In relation to this study, influenced by experiences and social and cultural capital, the interaction between habitus and field is understood as the creation of a social space. Of importance to this research is the relationship of the body to a person's social environment, in which the body can be understood as influenced by the social context. The importance of Bourdieu and his work on habitus and field theory provide a background to understanding how the body is understood with regards to the life journey and the interactions of experiences in the creation of identity.

Community identity is also seen as a core component of embodiment for the men in this study as an explanation for the perceptions of prostate cancer risk. The body is seen as being constructed via the everyday experiences of the men in this research.

What the men say about their bodies, in relation to health and illness, is embodied by their individual constructions of the body and in relation to their experiences and interactions with others. All of this is influenced by the norms of their cultural group.

Using the theoretical framework of embodiment in trying to understand how men differently perceive their risk for prostate cancer, the concept of the social construction of masculinity cannot be ignored. Hegemonic masculinity is important to this research because it helps explain the relationships between men who live in distinct cultural groups. It is of particular importance to the experiences of the African Caribbean men possibly perceiving themselves as subordinate males, and the consequential risks the rejection of illness brings. Conversely, it is proposed that the White Working Class men may accept illness risks, and then use illness experience in socially acceptable talk.

The effects of hegemony on Somali masculinities are less well defined in this research. The work of Siraj (2014) is seen as contributing to understanding the role of Somali masculinity and supports the findings of the study, that the role of the Somali male is to be caring, responsible and supportive of their family. In relation to Somali masculinity, Connell (2016) makes reference to global gender order and the recent Islamist insurgencies being the most patriarchal (male controlling) of any current global regime, although this was not found in this study.

These apparent differences in social constructions of manhood is important for this research because it may influence the way masculinity is embodied for the men in

this study, based on their cultural experiences and the field against which the men have formed their identity. In summary, perceptions of risk for prostate cancer are created through the understanding of the body from its relationship with social history and social context.

The following sections of this thesis will discuss a review of the literature focusing on the theoretical positioning of this research and the experience of the body. This review will help establish the contribution of this study to the current body of literature, relating to the proposed grounded theory generated from this work.

As has previously been discussed, the men recruited to this research were older men, to meet the age-range for men at risk of prostate cancer, and were recruited from areas of social deprivation to allow for the effects of deprivation on the findings of this research. Therefore, for the purpose of clarity, the literature will be discussed through the lens of older men's perception of risk based on culturally embodied experiences, which include the effects of socioeconomic status on masculinity.

### **11.3 The Body**

Analysis of the interview and focus group data found differences in the way the men viewed their bodies, notably in relation to their social context. The White Working Class men appeared the least concerned about illness risk, and saw changes to their bodies as a normal part of growing older. This could be explained by research examining embodied experiences of ageing and the effect on views of the body,

which found that White men were not concerned about changes to body image as they aged, and were instead concerned about maintaining a healthy body to prevent illness, which they felt was inevitable (Liechty et al. 2014). In this study, especially in relation to protecting the body from the natural decline of ageing there are some similarities to the findings of Liechty et al. (2014). White Working Class men talked about taking care of their bodies to protect themselves from illness, whereas others were passive in their views about their bodies and illness. This is similar to the Somali men in this research, but the reasons for this are different and are discussed on page 343.

In a seminal text about hegemonic masculine body image and embodied masculinity experienced through illness, Charmaz (1995) used a grounded theory approach to study identity dilemmas in men experiencing chronic illness. Although not using the exact phrase, Charmaz (1995) draws on the concept of hegemonic masculinity when she discusses the threat of illness to men's masculinity by relinquishing their male dominance and the man's place in gender order. In research by Stewart et al. (2011) chronic illness and older age are recognised as related, influenced by the long-held stereotype that being old is being ill, and therefore the comparison of the work of Charmaz (1995) and the current study is of interest in understanding self-identity and illness. This finding is supported by Oliffe (2006) who recognised the widespread belief that decline is a natural process of ageing.

Charmaz (1995) theorises that men coping with chronic illness use bracketing as a way of managing the changing identities of their bodies. Charmaz considers bracketing as a way of putting a frame around illness to separate the experience

from the everyday masculine identities of men with chronic illness, including social interactions through which they embody their masculine identity. This is similar to the findings of Kelly (2009) who found that men with prostate cancer found ways of reframing their bodies to meet their new understandings of masculinity. The men in Kelly's research talked about difficulties in discussing illness with other men and conversely for some men the experience of prostate cancer provided a way of opening up to others about vulnerability and changes to their bodies.

In this study, the social talk of the White Working Class men did not appear to be framed by the presumed social image of hegemonic masculinity. The men appeared to be very happy to talk about their unwell bodies, and in the focus group this included men who had confirmed chronic illness (diabetes) and those men who had symptoms that could constitute a chronic illness (in this case, urinary frequency). This finding is supported by Oliffe (2007) in a study of masculinity over a life course in relation to a prostate cancer diagnosis. During this ethnographic study, he observed men with a diagnosis of prostate cancer taking part in a prostate cancer support group. He explains how, "many men spoke simultaneously at groups meetings" (Oliffe 2009, p15). It is possible that this observation and the analysis of the conversations between the White Working Class men in this study relate to the findings of Charmaz (1995), in bracketing a social space to discuss the unwell body. In this study, this could be related to the socioeconomic status of the White Working Class men and their acceptance of illness; the reasons for this are discussed further on page 361.

The African Caribbean men in this research talked about concerns over body image through the process of ageing, but for them their talk was about the body not functioning as it had done when they were younger. Unlike the white men in the research by Leithy et al. (2014), the African Caribbean men in this study did not talk about maintaining a healthy body to prevent illness or decline of the body, they were more concerned about maintaining a healthy body image. In this study, hegemonic masculinity, being competent and powerful, is seen as important for the African Caribbean men and the relationship of the decreasing ability of the body to perform is seen as related to the identity of the body, in the context where competence and physical strength are dominant characteristics (Connell 2005).

In relation to the African Caribbean men, Maliski et al. (2008) studied the effects of a prostate cancer diagnosis and treatment on African American and Latino American men, collecting interview data from 78 men recruited from a state-funded prostate cancer treatment programme. The African American men spoke about maintaining a silence about their cancer diagnosis so as not to lose their strength, control and independence (Maliski et al. 2008). Maliski et al. (2008) describe this coping strategy as particularly relevant to the African American men in their research, rather than the Latino American men, as the African American men talk about their past experiences of subordination influencing their construction of masculinity. This is related to the field theory of Bourdieu, drawing on the influences of the social field on the men's habitus and their social construction of male identity, which has been discussed as important in understanding the findings of this study.

Similar findings have been published by Campbell et al. (2012) in a study of masculinity and prostate cancer in African American men. Campbell et al (2012) accept that African American men are particularly vulnerable to threats to their masculinity based on their subordinate experiences as black men, and report that older black men have stronger beliefs about masculine control of emotions compared to younger men. Campbell et al. (2012) also believe this may be due to the changes in masculine attitudes in second generation black men, who have taken on some of the cultural norms of their wider society and may have experienced less racism, as multiculturalism becomes the norm.

These findings are reflective of the findings of this study. The African Caribbean men talked of racist experiences as younger men, and it has been theorised that this has influenced their identity as men and their acceptance of illness. Although the men interviewed for this research had not experienced prostate cancer personally, the African Caribbean men talked about difficulties in accepting the image of an unwell body, to a greater extent than the White Working Class and Somali men. It had been theorised that this was due to increased exposure to unwell bodies as younger men, but in light of the literature, it is thought that this difficulty could also be due to unsettling concerns about threats to their carefully crafted hegemonic masculinities.

Friedman et al. (2012) published results to support this finding in a study of communication about prostate screening in men without a diagnosis of prostate cancer. Their research was conducted in America where routine PSA testing for African American men is recommended. Friedman et al. (2012) used focus group



methods and found that men were concerned about prostate cancer and the threat to masculinity because “they got to be macho” (Friedman et al. p479). It is recognised that research conducted in America with black males limits comparisons with the current study because of different threats to black masculinity and access to healthcare. Edwards (2006) writes that African American men in the United States appear to have had a very salient experience of emasculation and the effect of this on their hegemonic masculinity may be more pronounced than in African men in the UK. Research addressing a black man’s experience of prostate cancer in the UK and their understanding of risk appears to be limited and this may be because literature in the United Kingdom appears to be catching up with this minority-related health concern.

However, the threat of illness to the sense of embodiment in black masculinity may explain why the African Caribbean men in this study talked about prostate cancer awareness campaigns not being of relevance to them. In a seminal text on black men and health, Staples (1995) draws attention to black men taking pride in their bodies to maintain a feeling of strength and power, and this is thought to be related to emasculation. Other research has suggested that black men don’t engage with the unwell body for a fear of being vulnerable (Connell 2005; Maliski et al. 2008), and it is suggested that it is for this reason that the African Caribbean men, and not the Somali men, in this study talked about an image of unwell Black men with prostate cancer as being more salient to them. They did not say that they would be put off by the image, rather that it would generate further questions about their risk. This is an important insight when considering engaging the men at the highest risk for prostate cancer, with prostate cancer campaigns.

Research suggests that Black men are more likely to engage in behaviour increasing health risks, such as not engaging with preventative healthcare, because their sense of hegemonic masculinity has been made salient through a process of emasculation (Marriott 2000; Edwards 2006). However, this does not explain why all the Black men in this study said they would be happy to take part in prostate cancer screening if it was available, and already placed faith in the screening they took part in (such as bowel cancer screening).

In relation to prostate cancer screening, there is a substantial amount of literature that supports the idea that men have concerns about the trauma of a digital rectal examination for prostate cancer diagnosis (Kelly 2009; Lee et al. 2011), and this is thought to be exacerbated in Black men because of concerns over masculinity in relation to non-acceptance of homosexual sexual behaviour (Odedina et al. 2004; Friedman et al. 2012; Anderson and Marshall-Lucette 2016). Some of the African Caribbean men in this study said they had experienced a rectal examination and, although traumatised by the event, did not see this as a barrier to seeing a doctor if concerned about prostate cancer. This finding is supported by Seymour-Smith (2016) in a UK-based study of white men with a diagnosis of prostate cancer and men without a diagnosis. Seymour-Smith et al. (2016) report that the men they interviewed were concerned about the thought of a rectal examination, for reasons related to homophobia, but were able to negotiate this fear with concerns about their own health and the sanctioning of the examination by a healthcare professional. The findings of this study reflect those of Seymour-Smith et al. (2016).

For the Somali men in this research, the body was seen as potentially at risk for illness, in this case prostate cancer, as the men aged; but this did not appear to be located in terms of masculinity. The Somali men were not dissimilar to the White Working Class men in their acceptance of the unwell body. They did not talk about ageing restricting the physical ability of the body; rather they talked about ageing and illness in terms of interrupting the natural life course for men in their community who wanted to return to Somalia when they are older<sup>4</sup>.

Relevant to the discussion of Muslim men's views of their bodies, Naeem (2003), in a study of Muslim men with diabetes, analysed survey data relating to the men's understanding of their diabetes management with a focus on diet and lifestyle factors affecting the men's health, such as strict Muslim dietary rules. Unfortunately, this research did not provide any analysis on the role of masculinity and management of chronic health conditions by Muslim men, but one finding that could be relevant to this study is the high proportion of the men who believed Allah was responsible for their diabetes, so that it is therefore thought to be out of their control (Naeem 2003).

It is acknowledged that the research of Naeem (2003) is dated, although an assumption is made that Muslim beliefs don't change over time, despite recent extremist cases, and so this finding may go some way to explain why the Somali men in this research talked about their bodies as outside of their control. The men didn't make specific reference to Allah being responsible for illness, although participant

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<sup>4</sup> The cultural rules of the Somali men returning home as older men was not discussed directly. It is not known from this research if it is only the men who return home as elders or if this also applies to the women.

015 did refer to God (Allah) being the only person who knows when we are going to pass. The discussion here could develop into the role of religion in fatalism and particularly cancer fatalism, seen by Powe and Finnie (2003) as the inevitability of death when cancer is present. However, only participant 015 talked about the progression of illness being controlled by God and he later talked about his faith in doctors being able to treat someone with cancer. Therefore, fatalism is not viewed as particularly relevant to the Somali men taking part in this study, although it is recognised that this will need further exploration with future research regarding Somali men and prostate cancer.

The insight that Somali men believed that the health of their bodies was outside of their control is relevant to their perceptions of risk. Siraj (2014), in a study of men's perceptions of masculinity found the Muslim men talk about religion organising their lives and dictating their beliefs, and that this is particularly salient amongst men of low socioeconomic status. The Somali men in the current study all lived in areas of deprivation, therefore if a comparison is made with Siraj (2014) it is reasonable to conclude that for the small number of Somali men in this study, masculinity and health are embodied in the strong influence of religious practice. Islam is seen as the basis of habitus of the Somali men, and their beliefs about the body and risk for illness are thought to be highly influenced by this.

On the discussion of older men, there appears to be a paucity of literature on the trajectory of the lives lived by Somali men who migrated for work or to flee civil war. In this study the men talked about wanting to return to Somalia when they are old; they said they wanted to go back because it is there home and they love it there.

One recent publication of interest to this research is a qualitative study by Nielsen et al. (2017) who examined the experiences of older migrants in Denmark. As with most of the men in this research, Nielsen et al. (2017) interviewed men who had fled from civil war. The similarities with this study are the feelings of being without citizenship expressed by the participants in the work of Nielsen et al. (2017). The Somali men in this study viewed themselves as having two countries, possibly creating a feeling of living in limbo, which is also recognised by Nielsen et al. (2017).

Unlike the findings of the current study, Nielsen et al. (2017) do not report that the men in their research were keen to travel home as they got older, although this was found by Lagace et al. (2012) in a study of perceptions of ageing amongst Somali elders living in Canada. Lagace et al. (2012) report that Somali men interviewed for their research felt that they were without roots and still maintained a strong connection to their homeland, and this supports the findings from the small sample of Somali men in this study.

Lagace et al. (2012) conclude that the elder Somali men in their research wanted to return to Somalia because services for older people in Western countries were not being perceived as sensitive to the cultures of the Somali men. However, in the research area used for data collection in this study there has been provided a home specifically for Somali elders, but the men still talked about wanting to go home. It is felt their desire to return home is driven by their desire to return to their heritage. This is supported in research by Silveira and Allebeck (2001) who write that during interviews with Somali elders living in London, men harboured hopes of returning home to be with family in their later years.

Other recent literature relating to Somali men and their identity has focused on Islamophobia and new forms of masculinities (Harris 2016). This is of interest to the insights from this study because of the possible changing nature of masculinity in Muslim men. (Carter 2017) discusses concerns about possible isolation of Muslim men, and this could be important in understanding how Muslim men construct the image of maleness in the future, based on the role of religion in everyday Muslim identity.

### **11.3.1 Summary**

The men involved in this research talked openly about thoughts of health and illness and this has provided an insight into how they view the unwell body. For the White Working Class men, the unwell body is seen as a normal part of growing older and they therefore appear more accepting of illness. Research has supported the concept that White men are accepting of the declining body (Liechty et al. 2014), although the actions taken by the men to counteract the effects of ageing may be affected by the embodiment of socioeconomic status, culture and sense of masculinity.

In relation to the African Caribbean men in this study, concerns about ageing and the body were more related to changes to the physical ability of the body and the men were seen as less accepting of illness being inevitable as the body ages. The acceptance of health screening by these men may be related to their desire to maintain a healthy body image because of concerns about hegemonic masculinity

made salient through the risk of emasculation (Edwards 2006). It appears that for the African Caribbean men, hegemonic masculinity and acceptance of illness and health risks are more complex than for the White Working Class men. From the small sample in this study, the African Caribbean men appeared to have a need to maintain their masculinity as a public image, and the men in the focus group described this when they talked about men going outside of their area to attend mass screening events.

The Somali men also appeared to have complex feelings about the body in relation to ageing. For these men, it seemed that they felt trapped by the older unwell body and this is supported in research by Legace et al. (2012) and Naeem (2003) but not by Nielsen et al. (2017). The men talked about wanting to return to Somalia when they are older and in this study this is thought to be because of a desire to return to their homeland. This is recognised by Silveira and Allebeck (2001) who believe that the men in their research could not return home once they had accepted medical help because they could not access the same help once in Somalia. In this study, the men talked about wanting to reduce their risk for illness by being provided with information about preventative health care, and this was seen to be the case at the prostate cancer talk attended during field work for this research. However, the men did not talk about taking up screening opportunities. It is not clear if this was because of a lack of knowledge or a desire to return to Somalia preventing access to a possible diagnosis (Naeem 2001).

The Somali men seemed to embody masculinity in a different way to the White Working Class and African Caribbean men. Their religion places the male in a

patriarchal position, and they talked about being responsible for their families and taking care of their wives. The talk was not as such related to hegemonic masculinity; the men didn't talk of being in control and strong - instead they talked about being responsible. This has been supported by the work of Siraj (2014) who accepts that masculinity is embodied by religion for Islamic men. Carter (2017) has discussed the othering of Muslim men and concerns about the changing life trajectory in terms of habitus, field and cultural embodiment for Somali men. This is an area that will need further exploration in relation to feelings of masculinity and acceptance of male illness, such as prostate cancer.

In relation to discussions of the body, it has been difficult to find literature to support the apparent misconceptions made by the men in this research, especially in relation to symptoms of prostate cancer. As proposed in chapter 7, this is thought to be related to the men's views of their bodies and of male gender and embodied masculinity through their experiences of being men in the UK. This area needs further development, but it is an important insight to contribute to the discussions of understanding the apparent disparities in prostate cancer diagnosis. The fact that the African Caribbean men thought prostate cancer was related to their testicles may contribute to their low levels of prostate cancer diagnosis despite their increased risk. This could be due, at least in part, to hegemonic masculinity concerns, although it is acknowledged here that the sample size for this research is small so any reason given for the apparent misconception should be treated with caution.



The remainder of this discussion chapter will focus on a further review of the literature in relation to the everyday lives of men and their experience of the body. This is important to the grounded theory generated in this study because ideas about the body and illness are thought to be constructed from the men's experiences of the body in their everyday lives. The grounded theory generated from this research proposes that the social construction of the body is important in helping men perceive their risk for prostate cancer. The findings of this small study suggest that part of the social constructions of the body are the everyday social interactions that are seen to influence the men's views of their bodies.

#### **11.4 Everyday masculinity**

The African Caribbean men in this research talked about being judged for being different and facing racism, and restricted opportunities as younger men. Edwards (2006) refers to this experience as black emasculation, in which black men have become and continue to become less masculine through a process of racism and Western imperialism. The effect of this on the men's views of their bodies, in relation to the embodiment of masculinity, has been discussed in section 11.3. The following section will address the findings in this study that suggest the process of emasculation has brought communities of African Caribbean men together, in the formation of a buffer from the status they are awarded in a predominately white country.

Edwards (2006) explains the differences between black and white masculinity through the words of Fanon (1970, cited by Edwards 2006), who believed that black

men were 'catching up' with white men as the latter considered themselves to be superior. Although dated, this opinion is important to this research because the African Caribbean men taking part in the research were young men in the UK in the 1970s. In this study, participant 019 articulated the opinions of Fanon when he talked about white men thinking black men were "down the food chain" (participant 019 IT, p25). Edwards (2006) believes this type of thinking has led to an inferiority complex amongst black men, perhaps not surprisingly, and Staples (1995) theorises that this puts black men at an increased risk of health problems related to attempting to maintain mastery over their environment, and therefore rejecting concerns about illness.

As previously discussed, the African Caribbean men in this research were accepting of potential health risks, and talked openly about this during the focus group. However, this was reconciled with the men talking about going away from their local community if there was a risk of others knowing they were accessing healthcare, and this is thought to be because of the interaction between building a safe community whilst at the same time wanting to maintain the embodiment of hegemonic masculinity; possessing a fit, strong and healthy body (Connell 2005).

In research addressing the effects of racism on health, Sellers and Shelton (2003) found that black men and women who identified closely with a black community felt that this helped protect them from the effects of stress related to racism. These findings support the theorising generated from analysis of the data in this study; that community is seen as important for the Black men because it has become a part of the embodiment of being a Black man. It is argued here that racial identity for the

men in this study includes acknowledgement of the difficulties they have faced as young men growing up in a white country, which has driven the men together. This is supported by Case and Hunter (2014) who believe that the self, as embodied by racial identity, can act as a filter for racial stimuli and therefore, the importance of community identity becomes important in protecting self-worth.

This may help to explain why the men in the African Caribbean focus group talked about health knowledge and experiences using the pronouns 'we' and 'us' instead of 'I' and 'me'. The men talked about health in terms of the needs of the men in their community and how changes to healthcare approaches could help men like them. For the African Caribbean men in this study, health was a concern for the community and they talked about the importance of community knowledge to improve their health experiences.

Marriott (2000) also theorises about black men in a white country and their embodied experiences of being black, which generates an understanding of their place in society. Marriott (2000) suggests that in order to find status as a black man, the men have drawn together and built a community within which they can find a purpose. It is postulated that because of their experiences of living in a minority, compared to the white population, social construction of the body for black men includes understanding their body as part of the normative understanding of their communities. For example, Connell (2005) believes that for the black male, masculinity is embodied by configuration of hegemonic masculinity or gender order as created by cultural beliefs.

Related to the body and community Wang et al. (2017) examined the use of community as an education tool in focus group research with older African American men. Wang et al. (2017) write that the men commented on needing a male lead in the community, someone who they respected as a role model and viewed as a leader amongst the community, having earned respect by being an exemplar to the community. In the current study, participant 030 talked about this when he mentioned a well-known member of his community who had had prostate cancer and how he was keen to talk to him about this experience. Participant 016 also talked about the importance of a male lead in the community. It is postulated here that whilst in their community masculinity for the African Caribbean men is socially organised, insights from this study and the findings of Wang et al. (2017) demonstrate that the men clearly understand the hierarchy amongst fellow African Caribbean men. This will be relevant to the understanding of the men's responses to community-based prostate cancer awareness events.

Weng et al. (2017) also found the men were comfortable talking about health in a group, and in fact asked for more opportunities to explore health matters together. The men expressed the opinion that a focus group exercise would give the men an opportunity to realise they need to share health talk with other men in their community (Weng et al. 2017). This supports the finding of the focus group in this study, in which the African Caribbean men were happy to share their health experiences.

However, Weng et al. (2017) followed the thematic analysis of Braun and Clarke (2006), which does not allow the researcher the flexibility of theoretical sampling to

test the themes emerging from the data. Although there are similarities in the findings of this study to those of Weng et al. (2017), by following a particular analysis framework Weng et al. (2017) are somewhat restricted in the depth of their analysis. The current study has added to their findings about the importance of community, through theoretical analysis and sampling, which has produced insights into how the men actually interact with each other and the influence this will have on their perceptions of health.

The African Caribbean men used the most banter in their focus group discussion, compared with other men in this research, and appeared to enjoy the opportunity to share anecdotes whilst also positioning themselves within the group. This has led to an understanding of how the men can learn from each other if given the forum to generate talk, including an unstructured approach in which the men are allowed to share their experiences. The use of the focus group task seemed to be a good way of allowing the men to open up about prostate cancer without directly challenging their masculinity by asking specific questions about their own experiences.

The exploration through the data analysis on how the men communicated with each other has also added to the richness of the data for the Somali men. The Somali men were also found to think about health in terms of the community and this may be because of the desire to maintain their religious identity (Robinson 2006).

Robinson (2006) maintains that certain ethnic groups are more likely to build a community to protect their identity and to manage the stress of acculturation as they adapt to a larger dominant society. Lagace et al. (2012) refer to this as the Somalis experiencing their new life as immigrants through the lens of their country

of origin. Like Carter (2017), Legace et al. (2012) believe that this has been exacerbated in recent years following the upsurge in Islamist extremism, which places Muslim communities at risk of facing an increased prejudice and discrimination.

In this research, the creation of a community for the Somali men appears to be based on their desires to return home. The creation of the community has meant that the men's religious practices have remained salient and part of this practice is that the men look after each other and help their brothers (Siraj 2014). In the case of the Somali men, the term 'brothers' is used to denote biological brothers as well as those acquired through marriage, and they share a similar place in the community hierarchy (Siraj 2014).

Similarly to the African Caribbean men in this research, there also appears to be a hierarchy in the role of the male in the Somali community. During the focus group, it became clear that the elder in the group was given the most respect, and this appeared to be due to their apparent wisdom rather than prestige or experience, as it seemed to be with African Caribbean and White Working Class men. Lagace et al. (2012) recognise that the Somali elders are expected to play an important role in the community and also in the education of younger men. During the focus group for this study the Somali elder was looked to for final suggestions of how to complete the tasks. It was also evident in the focus group that the men had a reciprocal and easy nature between them. Like the African Caribbean men, the Somali men talked in terms of 'we' and 'us'. Their discussion about health was based on the needs of the community and sharing of health experiences and knowledge with each other.

Lagace et al. (2012) recognise that reciprocity and interdependence are an important part of Somali culture, and members of the wider community, outside of the family, are expected to help each other. In this study, this has been supported by the talk of the men in the interviews and in the manner in which the men spoke to each other during the focus group. Despite the similarity in the use of the pronouns 'we' and 'us', the style of the men's talk was quite different to the interactions between the men in the African Caribbean focus group, which could be an important insight in understanding how Black men differently communicate their risk for prostate cancer and how to best inform the men at most risk. For the Somali men, the nature of reciprocity appeared to make the sharing of health knowledge a normal part of cultural health.

In contrast to the Black men, the White Working Class men appeared to have a very different approach to community. This has been found in the interview data and during the interactions between the men in the focus group. It is theorised that the White Working Class men have not had to build a protective community, or establish a community based on their country of origin, because they are the dominant cultural group in this research. The men talked about sharing of health information in groups rather than in a community, established through their interests such as spending time at the allotment.

In order to fully understand why the White Working Class men in this research talked about their bodies in the context of individuals and learning about health in groups, the literature has been searched for white masculinity and deprivation,

which is also important to this research. People living in areas of deprivation are more likely to report poor self-rated health (Wen et al. 2003) and are less likely to engage with health-related activities (Wardle et al. 2003). The difficulties faced by people living in areas of deprivation can be understood through Bourdieu's theory of social capital (Crossley 2014).

For Bourdieu capital depends on social recognition and as discussed in section 11.2.1 it is thought that someone's economic capital can be low but their social capital high, depending on how others react to individual sources of capital (Crossley 2014). In this study, it is suggested that the Black men (and particularly the Somali men) have a sense of high social capital because of the communities they belong to, creating social resources. For the White Working Class men, social capital is seen as more ambiguous. These men do not appear to have a structure for their social identity and it is suggested that in order to fulfil the desire for social capital, which Bourdieu sees as important to self-worth (Crossley 2014), the White men in this research talk about their identity in relation to health experiences (social exchanges) and their membership of groups.

In research examining social capital, neighbourhood and health Browne-Yung et al. (2013) studied the opportunities for creation of social capital in areas of differing socio-economic status. The research, which included participants from a known area of deprivation and those from a more affluent area but on a low income, found that those living in the area of deprivation were more likely to take advantage of networks within their neighbourhood, than those who were on a low income in a more affluent area. Browne-Yung et al. (2013) conclude that those people from the



most deprived area took opportunities to increase their social capital, such as becoming involved with local government health initiatives, because they were less concerned about the response of others, when compared to the more affluent. This may be what is being seen in the findings of this study in relation to social capital for the White Working Class men, and their relationships with local groups of men from similar backgrounds.

In an interesting longitudinal study of ageing, health and socioeconomic status, Springer and Mouzon (2011) found that white men who were high in hegemonic masculinity, measured using an eight-item scale devised to measure dimensions of masculinity (Springer and Mouzon 2011 p216-217), and from a high socioeconomic background were the least likely to access preventative health care, such as cancer screening. Spinger and Mouzon (2011) concluded that possessing a high sense of hegemonic masculinity creates vulnerability in men who have to confront illness, and that this is exacerbated when socioeconomic status heightens the embodiment of masculinity leading to increased risk-taking behaviours.

The findings of the research by Springer and Mouzon (2011) should be interpreted with caution because of their use of a scale to measure hegemonic masculinity. Connell and Messerschmitt (2005) in their rethink of the concept of hegemonic masculinity, emphasise the fluidity of the concept and this questions the use of a static scale of measurement.

Hegemonic masculinity is seen as a fluid concept in this study, and this is particularly emphasised in the way the White Working Class, African Caribbean and

Somali men are seen to embody this concept differently. As an example of this, the White Working Class men did not appear to feel threatened by talk of their bodies, in relation to illness, compared to the African Caribbean and Somali men.

However, drawing on the findings of Springer and Mouzon (2011) it may be that masculinity is constructed differently for white men of low socioeconomic status, compared to white men of higher socioeconomic status, because the men of low socioeconomic status men are less concerned about being perceived as vulnerable, and are therefore more accepting of the inevitable effects of ageing.

In comparison with the work of Springer and Mouzon (2011), the current study has used a more dynamic measurement of deprivation (National Statistics 2015) in selecting areas to recruit men for the study. The tool used by Springer and Mouzon (2011), whose data were extracted from a larger longitudinal study, selected men who had completed high school education, and were not stratified on any other measurement of deprivation. The current study has therefore added to the work of Springer and Mouzon (2011) by supporting their findings that socioeconomic status, as more fully defined in this research, could have an effect on hegemonic masculinity in relation to health.

In the focus group with the White Working Class men, the men talked openly to each other but unlike the Black men did not use the pronouns 'we' and 'us' when talking about health. The men spoke more in terms of 'I' and 'me' and it is theorised that this is because the men have not had to go through a process of acculturation; they have not experienced the effects of minority living or the creation of a community as

protection from the process of emasculation. However, the White Working Class men may have had to accept that they are living in a socially deprived area. In order to maintain a high self-worth it appears the White Working Class men have joined groups within their own habitus to lessen the threat to their masculinity, by possibly being perceived as subordinate to more affluent men.

This interaction with socioeconomic status, social capital and habitus is important for this research because it provides an insight into how the social construction of masculinity for the White Working Class men is influenced by interacting with similar others. These situations can be used as an opportunity to learn about their health.

#### **11.4.1 Society and education**

In chapter 2, socioeconomic status and increased health risks, including risks for cancer, were discussed. The Marmot review of 2010 made clear the link between socioeconomic deprivation and health, concluding that people who are less favoured and live in the poorest areas would, on average, die seven years earlier than those in the least deprived areas (Marmot 2010). This thesis has presented the proposed grounded theory that social construction of the body is important in helping men understand their bodies in society, which mediates the way men understand their risk for prostate cancer.

The relationship of education and socioeconomic status is an important consideration of this proposed grounded theory. The men in this research were

recruited from areas of deprivation, due to the high numbers of ethnic minority men living in areas of deprivation (Shi et al. 2013; Longhi 2014; Di Pietro et al. 2016). Recruitment of White Working Class men to this research has allowed for consistent comparisons between the Black and White men. The men interviewed for this research were asked to complete an education status questionnaire, as used in the 2011 census (see appendix VI).

Table 5 provides a summary of the educational levels achieved by the participants; vocational/work related qualifications were the most commonly held by the men in this research, rather than school and university qualifications, which may be held by men people from more affluent areas (Marmot 2010). Eylert et al. (2013) suggest that poor access to education reduces an individual capacity to make informed decisions about their healthcare. Similarly, Tremblay et al. (2014) and Lamb et al. (2014) bring to our attention the concern that as cancer treatments develop, individuals are being asked to make a decision on which treatment to accept, which could create confusion and disengagement for those less educated. This is important when considering education campaigns aimed at those at high risk for prostate cancer.

The findings of this study have provided evidence that the African Caribbean men may have been disadvantaged in access to education in the UK, because of the apparent racist attitudes at the time of their time of migration to the United Kingdom. Staples (1995) comments on this in a discussion of institutional racism experienced by young black men and economic marginalisation of black men as a result of this. The Somali men in the current study were assumed to be poorly

educated, because of their apparent inability to write in English or Somali at the time of providing consent for this study. This insight is supported by Connelly et al. (2006) in a review of literature on older refugees living in the UK. The review found that a lack of education at the time of migration, for the older generation has created a generation of people who are unable to use written English and creates dependency on the younger generation and a lack of engagement with public services (Connelly et al. 2006).

The lack of access to, and poor quality of, education for the men in this study is important for the findings of this research. Bourdieu believed that education provides a division in class structure, through the acquisition of knowledge by the more affluent to enhance the position of the least socially deprived (Robbins 2014). Education is seen as sorting and selecting individuals under the structure of capitals and fields within which they will form their identity (Thomson 2014). The men in this study are seen to construct their identities from their social field and education is an important source of capital within these fields.

Education and poor health are inextricably linked (Marmot 2010), and evidence shows that poor health status is associated with dropping out of, or never attending, secondary education (Winding et al. 2013). The findings of this study must be considered against this background, as must recommended strategies for increasing prostate cancer awareness in the men at most risk. It may not be enough to provide these men with campaigns targeted at their understanding of the body in the social context, without considering their level of attainment. Bourdieu would call this paying attention to a person's habitus and the field against which they were formed

(Bourdieu 2007), which is part of the complexity of increasing prostate cancer awareness amongst the men at the greatest risk.

#### 11.4.2 Summary

The everyday body has been discussed as being different for the White Working Class men, the African Caribbean men and the Somali men because of the experience of living in a deprived minority or majority population. In the case of this research, this is seen as affecting the Black men because of the history of being a minority colour or belonging to a minority religion in the UK. For Muslim men in the UK this may have been exacerbated by recent Islamist extremism, and understanding the effects of this on the social value of the male is seen as important in finding ways to help Muslim men accept a uniquely male health problem, such as prostate cancer.

The Black men in this research appear to have coped with their experiences of being viewed as different by building communities to act as a buffer from their experiences of racism, and to maintain a place for their religious identity. This creation of community space means the men talked about health as a community concern. They accepted that they need to know about their risk for prostate cancer but appeared to feel more comfortable talking about how they could help each other. For the Somali men, this nature of sharing information is also influenced by their cultural ideas of reciprocity and helping their brothers.

It has been theorised that the White Working Class men, in this small study, join groups with similar men to find men of the same socioeconomic status, so their

masculinity is less threatened by the presence of more affluent men. This can only be deduced from the talk of the White Working Class men as belonging to groups where they share health experiences, and this deduction is supported by the work of Browne-Yung et al. (2013) and Springer and Mouzon (2011). The ease of sharing health information has been seen in the focus group with the White Working Class men. However, the men didn't consider themselves to be part of a community and talked about health in terms of their individual experiences. This is understood as the most salient difference seen between the Black and White men in their talk about the everyday body and risks for prostate cancer.

Living in an area of deprivation, including problems with access to a good education has been discussed as affecting all the men in this research. Poor education is seen to be important when considering the proposed grounded theory and the application of this to education strategies applied to these distinct groups of men. It is understood that poor education is linked to living in an area of deprivation and that for the Black men this is compounded by their historical lack of access to education and educational exclusion after migration to the UK.

### **11.5 Overall summary**

The findings of this research have been discussed through the framework of embodiment, using the lens of the social construction of the body, hegemonic masculinity, and the field and habitus theories of Bourdieu. It is understood that the main differences in perceptions of prostate cancer risk, between the Black and

White Working Class men in this research are based on their perceptions of perceived risks to the body, mediated through their social experiences and social constructions of the body.

The mediating factors that are thought to constitute the differences between the groups of men in this research are based on views of the body and acceptance of illness, as well as the body as constructed through a community setting or as an individual. The process of emasculation of the African Caribbean men is seen to have created a sense of pride in these men, and consequently developed concerns about acceptance of illness that is seen as a threat to the men's masculinity. The Somali men in this study talk about illness as a threat, but for reasons relating to the patriarchal position of men in their communities and their concerns about wanting to go back to Somalia as they age. The White Working Class men are seen as more accepting of the threat to their body from illness; the unwell body is viewed as socially acceptable and at times a talking point in the relationships between the White men.

The effect of deprivation and education has been discussed in relation to further understanding the threat to masculinity faced by all the men who took part in this research. Poor educational attainment is likely to contribute to lack of engagement with healthcare services. This is seen as particularly important for the Black men in this study, who have experienced deprivation and exclusion from teachers during their school years and the apparent lack of opportunity to be educated after migration to the UK.



The Black men, who are at the highest risk for prostate cancer, have complex supportive needs in relation to understanding their risk for prostate cancer. It is the position of this research that the complexity of the position of the body in society needs to be understood by third sector organisations and healthcare practitioners before these men can fully engage with their increased risk for prostate cancer.

### **11.6 Strengths and limitations of this research**

The use of a constructivist grounded theory in this study has generated in-depth knowledge of the participants everyday lives, derived from time spent in the study areas as well as through interview and focus group data collection. The use of this approach has led to data collection and analysis based on the everyday lives of the participants to generate a theoretical understanding of their perceptions of their bodies in relation to the risk of prostate cancer.

The theoretical analysis of the data, including memo writing to explore the researcher's thinking throughout the analysis, has allowed the researcher to delve deeper into the categories emerging from the data through theoretical sampling. Charmaz (2014) guides the researcher to use memo writing to assist in the development of theoretical categories and to shape the directions the researcher should pursue. This has been the case in this study; the process of analysis allowed a depth to the researcher's understanding.

The maintenance of a research diary has also been useful as a chronology of the researcher's experience of the PhD journey, and the influences of the experience of

the researcher on the research findings (see appendix II for diary extracts). This has helped to create transparency in the involvement of the researcher with the data, and this is particularly important in the case of this research because of the potential for the researcher's own clinical experience to influence the course of the interviews and the data analysis (Arber 2006; Jack 2008). This use of reflexivity is also a strength of this research and has allowed the interview and focus group data to be scrutinised whilst attention is given to the preconceptions and experiences of the researcher.

This research could have been conducted using an ethnographic approach to gain in-depth understanding of the participants' social worlds. The use of ethnography would have provided more data on the multiple dimensions of the participants' worlds, which may have added depth when theorising about the participants' habitus and the consideration of field theory. Ethnography is considered an acceptable design framework in constructivist grounded theory (Charmaz 2014). To complete an ethnography thoroughly, however, requires a substantial amount of time in the field of interest, such as in the seminal work of Wyatt (1943) and Bourgois (1991). Therefore, comparing three distinct cultural groups using an ethnographic approach would possibly have required a team of researchers to collect data, which is considered outside the scope of this research. A constructivist grounded theory approach using interviews and focus groups has allowed the depth of understanding required to make comparisons between the men involved in this research and generate a meaningful grounded theory.

It is recognised that the main limitation of this research is the number of participants involved. A total of 17 men were interviewed for this research and three focus groups were conducted. These data need to be interpreted with caution, because of difficulty with transferability, and further research will need to be done to build on these findings. The Somali men were underrepresented in this research, because of limitations of access to these men and the translator. However, these data have created some useful insights into the lives and religious beliefs of the Somali men in relation to the body and health, which could be developed with further research.

The interview and focus group data used for this research needs to be interpreted and understood as relevant to a particular time and place for the men involved. In the words of the influential philosopher of mind, body and the self, George Herbert Mead, the researching of sociological process is an instance of what takes place, assuming that different reconstructions of reality are possible (Mead 1926). This is not given as a defence to potential difficulties with the transferability of this research, rather to acknowledge that what has been found is relevant to the men in this research, and could form the basis for further research examining the social construction of the male body across cultural groups and the effect this has on their perception of prostate cancer risk.

A further limitation of this research is the context in which the data were collected. To clarify, the data were collected from men living in a small city in a country that has a high sense of nationalism, developed from historical isolation from England (Pitchford 1995). During the coal miners' strike in the 1980s, the economic

exploitation and stereotyping of Welsh miners has left the Welsh people feeling exploited, although some would argue that this exploitation is no worse than that faced by the working-class people of England at that time (Pitchford 1995). In more recent work, multiculturalism and integration in Wales is considered to be in its infancy (Jordan and Weedon 2015), and is thought to have only come to the attention of the Welsh Government since devolution of power in 1999. It is recognised that this research has been conducted with Black men who are living in a minority within a country that still feels the effects of being historically annexed by England, which may produce a minority identity amongst the general population. Pitchford (1995) believes this may raise the potential for on-going exclusion of ethnic minority groups. It is also worth considering here Bourdieu's field theory and the complexities between cultural and economic capital; distinctions between people may be more salient in the location of this study.

### **11.7 Conclusion**

The findings of this research have been discussed in relation to the theoretical positioning of the research and comparisons with recent literature focusing on men's health in the social context. The men's views of the body are influenced by the cultural embodiment of masculinity, which includes their comprehension of masculine identity through the lens of hegemony, and based on the men's habitus and their opinion of their position in the social field. It is theorised that this influences the perceptions of prostate cancer risk as experienced by the men in this research.

There are differences between the groups of men in the way that they accept changes to their bodies, in relation to illness and ageing. For the men at the highest risk of prostate cancer, Black men, their acceptance of this risk is mediated by their experiences of the social field, the importance of religion and their embodiment of masculinity. For the African Caribbean men, the process of emasculation appears to have left the men viewing a fit and healthy body image as a defence against the prejudice they have faced. For these men illness is a salient threat to their hegemonic masculinity and facing a uniquely male health problem, such as prostate cancer, requires a confrontation to their masculinity, which may prevent African and Caribbean men seeking a diagnosis of prostate cancer.

The Somali men face uncertainty in relation to their masculinity in a different way. For these men masculinity is embodied in their religious beliefs and it is felt that the position of patriarchy in relation to Islam diminishes the salience of hegemonic masculinity. However, these men feel that they would like to return to Somalia when they are older, and illness is viewed as a threat to their ability to travel. It appears this may lessen their engagement with their bodies in relation to health, which is complicated by the men appearing to avoid a diagnosis so as not to feel trapped.

The White Working Class men seem to have experienced an entirely different social field but their habitus could be affected by their relationship with deprivation. These men are accepting of illness as a normal part of ageing and appear to make social connections through their discussions of health concerns. Because of this, the White Working Class men are seen to perceive their risk for prostate cancer as

accompanying old age and appear to be the most likely to access healthcare services with concerns relating to prostate cancer. The role of hegemonic masculinity for these men could be mediated through their position as men living in a socially deprived area.

For this reason, it is proposed that the White Working Class men in this study are the most likely to share their health experiences. These men, living in an area of deprivation, do not appear to feel the need to maintain their masculine status and they access groups of similar people through which they can discuss their experiences. The focus group data have demonstrated that the White Working Class men, although often members of a group activity, view their health as an individual concern. Conversely, the Black men talk about health as a community concern.

For the African Caribbean men, it is theorised that this is based on their experiences of living in a minority and the creation of a community to act as a buffer from racism and discrimination. The men seem to have developed a sense of viewing their bodies in relation to other African Caribbean men in their community, which can create a barrier to accessing prostate cancer information as well as create a space for sharing health concerns, particularly if an African Caribbean male role model is acquiescent. The Somali men also talk about health as a community concern and this is understood as influenced by the Islamic practice of reciprocity. The men talked about sharing their health knowledge with their brothers and there is no talk amongst these men of accessing healthcare as a threat to their masculinity.

The limitations of this research have been recognised. It is understood that the findings of this research are reflecting a moment in time for this small group of men but it is also felt that this work provides insights into understanding masculinity in the context of the socially constructed body, and the influence this may have on the way the men perceive their risk for prostate cancer. The strengths of this research are in the methodological approach used to collect and analyse the data, and in the flexibility and reflexivity of the researcher to develop an insightful grounded theory.

## 12.0 Recommendations and concluding remarks

### 12.1 Introduction

Black men in the UK have twice the risk of prostate cancer compared to white men and are 2.4 times more likely to die from this cancer (Jack et al. 2007; Ben-Sholmo et al. 2008); (Grulich et al. 1992; Nanton and Dale 2011). Despite this, black men are less likely to be diagnosed with prostate cancer, and anecdotal evidence has shown that these men are under-represented in prostate cancer clinics in South Wales. An initial review of the literature showed empirical evidence that black men had concerns about the testing involved for a diagnosis of prostate cancer (Pierce and Chadiha 2003; Gonzalez et al. 2008; Lee et al. 2011), and that black men lacked knowledge about prostate cancer and their specific risk (Maliski et al. 2006; Allen et al. 2007; Odedina et al. 2009; Odedina et al. 2011).

There appeared to be a lack of evidence focusing on what was driving the men's concerns about prostate cancer testing and why the men lacked knowledge. It was felt important to understand the differences between Black and White men in the constructions of their perceived risk for prostate cancer, so that future work to engage the men at most risk could be more effective.

Based on this premise, this research has used a constructivist grounded theory approach to study how men from distinct cultural groups, without a diagnosis of prostate cancer, perceive their risk for this male health concern. The methodology has allowed the researcher to remain flexible in the approach to sampling and data collection; new approaches to data collection were generated from theoretical analysis revealing categories of theoretical interest. This has allowed the findings of



the research to provide a depth of understanding for the small number of men involved in this research.

## **12.2 Contribution to the literature**

This research has added to our understanding of why Black men are less likely to be diagnosed with prostate cancer, compared to White Working Class men, by postulating differences in the habitus of the Black and White men and the influence of the field on the way these men embody masculinity. In literature relating to prostate cancer knowledge and concerns amongst black men, masculinity and emasculation is considered but not explored in depth. The findings of this study have shown that the small number of African Caribbean men in this research do not view images of healthy looking black men on prostate cancer literature as relevant to them. There is evidence that the process of emasculation may have heightened hegemonic masculinity in African Caribbean men (Staples 1995; Connell 2005), and the finding from this study that African Caribbean men would consider an image of an unwell man with prostate cancer to be more salient, has added to this literature.

The current study has also added to the literature by providing more depth to the discussion on social identity with regards to hegemonic masculinity and the relationship of emasculation to perceptions of prostate cancer risk. The research has gained specific insight by comparing three groups of men from distinct cultural backgrounds, which has highlighted the areas of most difference. There have been distinctions made between the Somali men, African Caribbean men and White Working Class men and the nature of hegemonic masculinity. A direct comparison

of these groups of men has generated insights into the structure of the field from the work of Bourdieu (2007), and the use of field theory to consider the influence of social, economic and cultural fields in the differences in perceptions of prostate cancer risk.

The inclusion of Somali men in this research has demonstrated the differences in the way the distinct groups of men communicate with each other about health. It was felt that this was important in understanding the social construction of identity for the men in this research. The difference between the styles of talk (use of pronouns I/me or we/us) has contributed to the literature in understanding how men who are culturally different understand their bodies in relation to the people around them. The status of the White Working Class men living in areas of deprivation needs to be cognisant of the challenges faced by people living in these areas and the effect of the economic field on their attitudes towards health. For the White Working Class men in this research, the findings have added to literature suggesting that men living in areas of deprivation are accepting of illness, and this supports research that suggests that men living in areas of deprivation feel less threatened by illness when compared to more affluent men. This study has offered insights on the effects of deprivation and masculinity on the acceptance of illness, by comparing three distinct groups of men.

There appears to be no literature found to explain the apparent misconceptions the men make about the symptoms of prostate cancer, and the differences in these misconceptions between the groups of men. In the introduction to this chapter it was acknowledged that there is empirical evidence demonstrating the lack of

knowledge in some men about the prostate and prostate cancer. The small number of men in this research appeared to make clear and differing misconceptions, and it is felt that this is an important contribution to understanding perceptions of prostate cancer risk, and which is in need of further investigation.

### **12.3 Recommendations**

The main finding to come from this research is the differences in the social construction of identity between the White Working Class men, African Caribbean men and Somali men. This has been shown to be particularly relevant in the talk of the men and the use of the pronouns I/me by the White Working Class men and we/us by the Black men. This is an important insight for guiding third sector organisations in how to develop their campaigns about prostate cancer risk for Black men. It has been suggested that current prostate cancer literature for the lay person is more conducive to raising awareness in the White population because of the language used to explain prostate cancer symptoms and risk (Prostate Cancer UK 2015a,b). It is a recommendation of this research that further investigations seek to establish the credibility of this finding so that information about prostate cancer for Black men can be written in a way that is relevant to their social construction of the body as a community concern.

With regards to the African Caribbean men, it is also recommended that further evidence be sought on the use of an image of an unwell man to promote prostate cancer awareness. The caveat to this is the concern that this may exclude Somali men, who could find an image of an unwell man increased their concerns about

being trapped in the UK with an unwell body. With careful research on the use of images to inform Black men of their risk, changes could be made to find better ways to support those men at most risk for prostate cancer.

The experience of working on this study has highlighted my own limitation in understanding the influence of social constructions of the body in everyday life and the way people manage health and illness, despite receiving a high level of education and working in a clinical role for 20 years. It is possible a contribution could be made to enhance education on cultural competence for undergraduate and postgraduate nurses, to include depth of understanding on the influence of the field against which individuals foster their ideas about their body and health.

## **12.4 Future work**

### **12.4.1 Implications for future research**

Before consideration is given to applications to practice and education, this study would need to be extended to include research using cohorts of African Caribbean, Somali and White Working Class men living in Wales and in other small city areas of the UK. This would generate data from a larger sample and allow comparison of the differences between groups of men with differing experiences of social construction of the body, based on integration and involvement with deprivation.

### **12.4.2 Implications for practice**

It is felt that a greater understanding on the social construction of the body could contribute greatly to the supportive care of Black men with prostate cancer, who may have different needs from their cancer survivorship support, compared to White men. Cancer survivorship is now a recognised pathway for cancer patients

and all men with a diagnosis of prostate cancer are offered a place on a survivorship programme (Macmillan Cancer Support 2017).

In the author's clinical experience, the survivorship programmes offer group education sessions run by clinicians for all men with a recent diagnosis of prostate cancer. Based on the findings of this research these may be preferable to white men with prostate cancer, whereas Black men may consider this public arena a threat to their masculinity or not suitable for a reciprocal knowledge base.

#### **12.4.3 Implications for education**

Campaigns by third-sector organisations, aimed at educating men about their risk for prostate cancer, need to consider how men understand their risk for prostate cancer, based on the social construction of the body and the acceptance, or not, of the unwell body. Based on the findings of this small study, thought could be given to how men from distinct cultural groups might relate to information about prostate cancer and how this would be shared differently amongst men to generate prostate cancer awareness.

#### **12.5 Dissemination**

After completion of this study some time was spent with the men who had been interviewed for this research, or those who had taken part in a focus group. This occurred during events organised by the Black communities, and in a health awareness event with the White Working Class men. It was not intended that these events would be a process of member checking or co-production. The men were

naturally curious to know about the outcome of the research, and the findings about views of the body from a community or individual perspective were shared. The men agreed that they viewed the unwell body in the way described, and the Black men agreed that they would appreciate prostate cancer literature with more inclusive language. All the men had been given information about prostate cancer after they took part in the research, and they were reminded at these opportunities for dissemination that they had misconceptions about the symptoms of prostate cancer.

The findings of the research have been presented at a Wales Gene Park raising awareness event for clinicians and lay people (Wales Gene Park 2017). The use of community engagement in this research is now part of teaching opportunities made available to fellow PhD students, as part of the Cardiff University Graduate Training College. The research findings have also been presented at the Institute of Cancer Research to a team of researchers who are hoping to recruit African Caribbean men without prostate cancer to research involving prostate cancer genetics screening (PROFILE study).

It is hoped that presentation of this research will highlight the need to consider the men's social constructions of body image, when talking to men about prostate cancer screening if it becomes available for the men at the highest risk. Education has been given to Registered Nurses taking an MSc Cancer Care module at Cardiff University, about this study and personal insights into social construction of the body. The nurses agreed that they had not thought about the body and cultural competence in this way.

## **12.6 And finally...**

This work has used the flexibility of the grounded theory approach to provide an in-depth analysis of the differences in the social construction of the body in the everyday lives of the men involved in this study. Theory has been generated to suggest that attention must be paid to these differences before health engagement strategies can be effective in reaching men at high risk from prostate cancer. It is hoped that this work will contribute to lessening the disparity in prostate cancer diagnosis between Black and White men and between men living in areas of deprivation, compared to those in more affluent areas.

It is also hoped that an insight into the field against which a person understands their body will be passed on to junior and undergraduate healthcare professionals, to facilitate a partnership approach to healthcare management.

## **12.5 Personal reflection**

The process of conducting this research has provided me with insights into the assumptions I had as a prostate cancer Clinical Nurse Specialist, on the way men understand their bodies and tolerate illness. After many years of clinical practice, it had not occurred to me that the way a person understands their body in a social context, influenced their understanding of conversations about their health.

Now, in my role as a Lecturer in Adult Nursing I will prioritise sharing the knowledge I have acquired whilst doing this research, with undergraduate and

newly qualified nurses to broaden thinking about the body in the social context and cultural differences in the generation of ideas about the body and illness.

From very early in the research process I became aware that I was not going to be able to find men to take part in this study by spending time sitting behind a desk. I knew I was going to get my feet on the ground and use creative ways to recruit men to take part in my research. This process required a lot of effort; weekend and evening work to build relationships of trust and reciprocity. I am pleased that I have had this opportunity; the process of engagement has opened my eyes to the ways in which people manage their lives, and I feel I have softened in my approach to those who share different constructions of reality to my own. I have widened my understanding of social networks outside of my own white middle class world. I am also pleased to have learnt to play dominoes.



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## List of appendices

### Appendix I: Search strategies for literature reviews 1 and 2

#### Search strategy for literature review 1

Database used	Year accessed	Title of search	Search terms	No. of hits	No. kept
British Nursing Index	2012/2016	Cancer of the prostate and risk	Prostate cancer, prostate neoplasm, risk, screening, diagnosis	420	52
ProQuest	2012/2016	As above	As above	870	10
Medline	2012/2016	Prostate cancer	Prostate cancer and Black	140	7
Scopus	2012/2016	Risk perception	Risk and perception and health	386	15
	2013/2016	Ethnicity and health	BME and health and migration	25	8
	2013/2016	As above	Health, heritage, acculturation	485	10
Ovid	2013/2016	SES and cancer	Deprivation, health, cancer, socioeconomic status,	94	8
		Prostate cancer and ethnicity	Prostate cancer, ethnicity, race, African, Caribbean,	329	9
Cited references					14



## Search strategy for literature review 2

Database used	Year accessed	Title of search	Search terms	No. of hits	No. kept
OVID	2016/2017	Community cancer	Perception, cancer, risk	705	2
			SES, perception, cancer, risk, deprivation	348	8
	2016/2017	Cancer education	Prostate cancer, education, black men, males, deprivation, socioeconomic status	438	22
CINHAL	2016/2017	Health behaviour	Risk, risk reduction, attitude, behaviour	705	3
			Black, minority, ethnic, BME, health, risk attitude, behaviour	97	6
	2016/2017	Cancer education	Black men, African, African Caribbean, Somali,	0	
Scopus	2016/2017		Deprivation, health, cancer, masculinity, men	361	23
Medline	2016/2017	Approaches to cancer treatment	Cancer, multidisciplinary team, prostate cancer	11	3

## Appendix II: Extracts from PhD dairy

### **Visit to Annual General Meeting Area B Community Centre**

I attended the AGM on a Sunday afternoon. The AGM had been arranged to elect new members to the committee and suggest ideas for fundraising. The African and Caribbean community largely populated the meeting; there was no representation from the Somali community. There were two policemen present and a priest. The police were there to engage with the community and this seemed to be effective.

There seemed to be a problem with time keeping and the meeting started very late. The Chair had to make a point of saying that if people did not attend committee meetings they would be removed from the committee; this is obviously a problem in this community. There is a need to improve Saturday and Sunday attendance in the bar area to make the community centre run effectively. There is a fundraising event for Marie Curie on Eater Saturday, which has been organised by a resident in Area B.

There was talk of having more Caribbean presence in the community centre and possibility of putting on a Bob Marley event to mark the anniversary of his death. It seems there may be no one to drive this forward. There has also been a need identified to improve services offered at the café. I may think about this in terms of involvement with the community centre. I spoke to

some committee members about my research ideas and they were defensive of being used a research project without any benefit to the community. They seemed reassured when I told them I'm a Nurse and that I don't intend to do the research and then leave the community. I want the work to be mutually beneficial.

### **Interviews at restaurant Area B**

I went to restaurant at 19.30 to interview men about their understanding of prostate cancer. I was invited there by (name given) who runs the restaurant and manages the (name given) Association. I was nervous about going to a male only venue on my own and tried to get a male to accompany me. I couldn't find anyone so I asked my husband to pick me up at 20.30 and made it clear to (name given) that I was being collected and only had 1-hour. I wondered why I felt unsafe in this male only environment and decided on four factors:

Language – the predominant language spoken at is Somali although Arabic is also spoken. They watch (name given) TV, which is broadcast in Arabic and appears to be news channel. When I have sat in the meeting area drinking coffee they have changed to channel to Sky News. I have the impression that they felt obliged to change the language and media to suit me, although I was the only native English speaker in the room. Most of the men speak some English although some are illiterate. This appears to come from the timing of immigration to the UK during the Somali civil war in the 1980's. Men who were in their teens at this time were not educated in the UK may not have learnt to read or write in English. Older men also have this problem but

appear not to be concerned about not being able to read English. Their spoken English is good enough for a basic conversation and I interviewed one Somali elder who understood most of my questions. He was very pleased when I gave him information on prostate cancer written in Somali.

Culture – the role of the female is very different in Islam. The role of the women is bound by personal law such as that in the Quran and impacts on decision-making about most of her lifestyle choices (how to be educated, who to marry, when to have sex, use of birth control, property rights and employment). It is unusual, but not impossible, to see a Muslim woman talking to men about health, particularly with her face uncovered. These men must have felt uncomfortable in my presence, although they did not show this. I could see metaphorical shutters raise when I mentioned that I was a Clinical Nurse Specialist as though this legitimatised my position and allow me access to this community. There is definitely a feeling that I need to be giving something to the community in return for them spending time with me talking about health.

### **Reflection on interviewing as a nurse researcher**

The first thing I had to get used was being quiet and allowing people time to speak. I listened back to my first interview and cringed at how I had turned it into a conversation with me dominating proceedings and providing clinical information. Where is the quality research data in that?

I spent the first 10-years of my nursing career working in A&E where the clinical approach was about investigating and reaching a diagnosis quickly. Short answers from patients were best and if there was a danger they were about to drift into a topic unrelated to their A&E attendance we skilfully got them back on track; the pressure of the 4-hour transit time target hanging over us. Cancer care is different, we have more time and the superfluous bits are important. The patient and their family have to live with the diagnosis and we need to know what they're doing for their holidays and how their diagnosis might affect their plans.

However, I didn't learn to stop talking. I needed to be in control of the consultation, collect clinical information and tell patients how we were going to treat them and what it was going to be like. Without realising it, I approached my research interviews in the same way. I let the participants speak, and if they were at risk of drifting of topic (cancer and prostate cancer) I moved them back round to it. Worried that information about their friends or their home life was not relevant and would be a waste of data collection. It was only listening back to the first two interviews that I realised I needed to explore more and keep quiet.

I also learnt not to treat interviews as an opportunity to give men information about prostate cancer, the therapeutic interview. Reading back my first transcript there was far too much talk from me about prostate cancer. As the men knew I was working as a Clinical Nurse Specialist in prostate cancer they, not surprisingly, had questions about their risk for prostate cancer and the

symptoms. I quickly learnt to start the interview process by informing the men I would discuss prostate cancer with them at the end of the interview, and that they would receive written information.

### Appendix III: Example of field notes

Working with MY – MY is the self-appointment head of the (name given) which he runs from the male only restaurant. He still feels very attached to Somali and feels strongly that he is from Somali Land and not Somalia, which is a division created during the civil war.

He has a feeling of pride about his organisation although, like a lot of men from this community, does not want to be proactive in getting things organised in promoting themselves. The Somali community feel a little chaotic, from the eyes of a Western female. These are some of the reasons why this may be:

Poor English

Poor literacy

Lack of integration

Cultural norms:

Structure of daily life

No expectations to be on time and stick to appointments

Deference to authority (possibly white authority)

Different expectations of health outcomes

Men in this community talk about how they enjoy attending events put on for them but they would not go to an event outside of their community. For this reason it is quite difficult to access men in these areas as it is easy to feel intimidated by a culture so different to a white Western culture that we are

used to. When I go into the male only restaurant I feel anxious as there are only Somali men in there but I don't feel any resistance. They are open to suggestions and want some interest in their culture but don't want to be proactive.

The event in (place name) was suggested by MY himself and he promised access to RSH, a retirement home for Somali seamen. I left this contact with him as the timing of the talk to men at RSH had to be arranged around. He did not organise the event and when it got closer to the time I took the flyers Tenovus had made for the event to show him. He was disappointed that the (name given) Association had not been mentioned on the flyer and was quite dismissive of what we had done. He perhaps wanted this to be seen as a project that he has been involved in and instigated but without putting the work in. I guess that is not so different to some people in the culture I'm used to but I would find it easier to communicate with them about it.

I felt worried that he would not arrange the event at RSH because we had snubbed the (name given) Association link. I tried to find a contact at RSH myself but without luck. It reminds me of the (event name) where I worried for weeks that nothing was getting organised, and in fact I was right about that but it was okay in the end. As with this event at RSH the (event name) was also being organised by men of African origin who had not sense of urgency or need to commit to what they have said they will do. This makes it very difficult to stay motivated and want to be engaged; it would be easier to walk away.



I contacted MY 2-days before the event and he had set-up access to RSH but was vague about what time would be best. We had arranged for the talk to be at 2pm but this would now not suit the community because prayer times had changed. Prayers are determined by the position of the sun in the sky. We arranged the talk for 1.30 in RSH.

### The day itself

[...]

MY had been at prayer at 07.18 and had told his community about the event that was happening that day. The van had then seen 14 men from the Somali community visit the van. They told me that MY had encouraged these men to attend after prayer. The staff also told me that white men approach the van individually and they may not have 14 in one day

Mostly to have a look and also to get some information, particularly about testicular cancer as these were men in a younger age group. I did not see these men on the van but PG, the Specialist Nurse working on the Man Van, told me there was no problem communicating with this age group.

[...]

On the day of the Man Van visit I asked the women in the community centre if they could pass the information on to any men who might pass through. I know the women that work there quite well now and they did not seem convinced that they would see anyone who would be interested. There was

very little enthusiasm for something that was happening on the doorstep and a service being provided to the community, for free and within easy reach.

### Divided community

I wonder if this has something to do with the community being divided between Somali people and others. There is a large Somali population in but there are also men of other African and African Caribbean decent, such as Eritrea, Nigeria and Jamaica. The men from Nigeria and Jamaica would use the community centre at a weekend but would not mix with the Somali men. Because I used MY as a contact for the Man Van event the event was largely aimed at the Somali community and so I had the feeling that people who use the community centre felt it was nothing to do with them.

### MY on the van

I met up with MY on the van where he was treated like a celebrity. The van is an American style motor home that's been converted to provide a useful space for men to sit and talk to specialist nurses, counsellors and advisers about concerns relating to cancer. The van has a large seating area with comfortable sofas and a table, a small kitchen area including a fridge and tea and coffee making facilities. Beyond this there are two small rooms that have been sectioned off for counselling and a mobile toilet. The van is black and orange on the outside and grey and wood effect on the inside. On the outside there are charity slogans and a strap line, which says 'changing the face of men's health'. This has been translated into Welsh but there is nothing available in any language other than English and Welsh.

It is so unusual for a non-white man, particularly Somali, to be on the van that he was something of a novelty. His greatest asset is that he speaks good English and seems to understand the value of integration, if only to further his own role as Chairman of the (name given) Association. He was quite full of pride on the van, particularly when everyone wanted a picture taken with him, great media opportunity for the charity. He had done a good job of promoting the event and obviously felt responsible for it going well. We both went outside the van and encouraged passers by to come in and get some information and advice.

[...]

#### Other men on the van

I managed to get some younger men on the van to talk about testicular cancer; I found it easier to approach these men, as I know they would speak good English. They were interested not reluctant to go on the van and although slightly intimidated about going over the threshold this was the same for BME men and white men. A lot of people were curious to know what it was all about and once inside found the predominantly male staff and comfortable atmosphere relaxing. It was also a very cold day and warm on the van that helped me encourage men to go in.

#### The talk at RSH

MY did a very good job of organising the talk at RSH. He had a committee room with 25 men ready to listen to us. He had set out the table and chairs like a conference and was pleased to introduce us to his audience. He ended

up translating the talk and appeared to do a good job. His voice became quite as we tried to talk about rectal examination and erectile dysfunction. Possibly he did not know the translation or there are taboo subjects in this community. The talk was planned to start at 13.30 and the van was parked a 5-minute walk from RSH. At 13.10 MY started to phone me saying he could not hold the men, they wanted to go. I was confused about where they had to go. Prayer had been at 12.20 and was not happening again until 2.41, the men had to eat before next prayer and it may have been causing them some anxiety that they needed time to do this. Food for these men is an important part of their day and grabbing a quick sandwich on the way to prayer is not something they would do. Eating appears to be a shared activity and takes place at the PS, the male only restaurant, which is where we went after the talk. The men are happy to welcome me into their restaurant.

[...]

[During the talk] We had some plastic models of testicles with lumps in them which we passed round and this livened things up a bit. Some of the men flatly refused to touch the models but most were happy to feel. We had two sets which both had lumps and the men wanted to know which one felt normal and which had a lump. We missed an opportunity here to have one set normal and one not; this would have been a better educational tool. PG went on the talk about prostate cancer and the men seemed more engaged. He had got into his stride a little by this time and was using simpler language ... He gave a very good demonstration of a rectal exam, which the

man laughed at and were not at all embarrassed to talk about. In fact it felt easier to discuss than it would with a group of middle class white men who would find themselves staid and reluctant to see the funny side. The group of men themselves stayed for the talk with a little bit of moving around. Some went out to get their friends or have a chat with someone they had seen outside and then came back in again, some got up to go to the toilet or just have a walk around. This is different to the talks I have experienced with the men in Area C, who were attentive to the speaker at all times and only moved around during dedicated break times. I didn't feel the Somali men were being rude; they were displaying a different behaviour in an organised talk that may be cultural-norms for these men. This would need to be explored further but offers some insight into what should be expected when talking to a group of Somali men about health.

Those that spoke English asked questions about prostate cancer and some had already had rectal examinations and PSA blood tests with their GPs. Two men told me they had been diagnosed with prostate cancer. One man had surgery 9-years ago in Dubai and one man had been cured with herbal medicine in Somalia. He has agreed to meet me and discuss this further. The man who had surgery 9-years ago looked the most uncomfortable during the talk and paid the most visits to the toilet.

The feeling from the community was very positive and the men were not at all worried about me talking to them after the talk about prostate cancer and the tests they might need. We had a model of the prostate and its position in

relation to the bladder, which the men found very useful and understood why they would get urine symptoms.

Appendix IV: Recruitment flyer version 1

**MEN'S  
HEALTH  
STUDY**



DO YOU DESCRIBE YOURSELF  
AS BLACK AFRICAN, BLACK  
CARIBBEAN, BLACK BRITISH OR  
WHITE BRITISH?

I AM LOOKING FOR MEN TO  
TAKE PART IN AN INFORMAL  
INTERVIEW TO FIND OUT  
WHAT THEY KNOW ABOUT  
CANCER

I WILL NEED NO MORE THAN  
1-HOUR OF YOUR TIME. YOU  
WILL BE PROVIDED WITH  
REFRESHMENTS AND PAID  
TRAVEL EXPENSES TO TAKE  
PART

TO FIND OUT MORE  
**CONTACT  
SARAH ON**  
**07511 720585**



## Appendix IV: Revised research flyer

**1 IN 8 MEN WILL  
HAVE PROSTATE  
CANCER AT SOME  
TIME IN THEIR  
LIVES**

**THE RISK FOR BLACK  
MEN IS 1 IN 4**

Do you describe yourself  
as White British, Black African,  
Black Caribbean or Black  
British ?

I am looking for men for an  
informal chat to find out what  
they know about cancer

I will need no more than one hour  
of your time. You will be provided  
with refreshments and paid travel  
expenses.

School of Healthcare Sciences

Ysgol Gwyddorau Gofal Iechyd



To find out more...

**CONTACT  
SARAH ON  
07511 720585**





## Appendix V: Extract of field note from time spent in Area B

Today was the first (event name) in Area B for many years. The build up to it has been quite frantic because although I was offered support from the community this has not happened ... this is also true of individuals on the organising committee who talk as though they are on top of everything but are actually not achieving much. These are men who are older than me and have lived with the (event name) all their lives but give across the impression that they will only do something after I have suggested it. Again, I come back to the feeling that this community is not empowered or proactive and I wonder how this affects their relationships with Healthcare professionals and their own health behaviour. Are they less seeking of information about their own health? The NHS, and particularly with cancer diagnosis and treatment, is putting the emphasis of responsibility for healthcare back on to the patient and I wonder if this will work with a community who is used to having services bought to them in other government initiatives around inclusion.

On the morning of the (event name) I arrived at 8am to leaflet all the cars on (place name) asking for them not to be moved during the run ... I got to Area B Community Centre expecting to see all the marshals I'd been promised to find one committee member with a hangover and no sleep and the other looking fed-up, perhaps because it was early. They were waiting for me to provide instruction on what to do with no marshals in sight. I had to find some from amongst my friends, which was a shame because I wanted this to be a community event but the show had to go on.

Eventually the community appeared to take part in the run. The Somali women were not allowed to run because they are not allowed to see people not fully clothed. However, the Somali men were out on (place name) ready to cheer on the runners. I have often seen these men on (place name) in the morning; I think they go early to the Somali shops and sit outside as a way of socialising.

The two committee members did their allocated tasks well. The one with the hangover was asked to look after the Lady Mayoress who had come to start the run and give out prizes at the end. It was important to the African community to have her involved as they felt this gave the event prestige. The other committee member was on the lead bike and did a great job despite not being sure of the route. There was a mixture of runners taking part with 64 in total.

[...]

The (event name) seemed to bring a great sense of joy to an area, which otherwise feels deprived. The community are keen to see this happen again and it will be interesting to see how involved they become. There is something about confidence and lack of empowerment that need to be explored further for differences across both cases.

## Appendix VI: Education questions used in National Census 2011

### Household Questionnaire Wales Office for National Statistics 2011 Census

Which of these qualifications do you have (please tick)?

1 - 4 O levels / CSEs / GCSEs (any grades), Entry Level	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
NVQ Level 1, Foundation GNVQ, Basic Skills	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5+ O levels (passes) / CSEs (grade 1) / GCSEs (grades A*- C), School Certificate, 1 A level / 2 - 3 AS levels / VCEs, Welsh Baccalaureate Intermediate Diploma	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Apprenticeship	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2+ A levels / VCEs, 4+ AS levels, Higher School Certificate, Welsh Baccalaureate Advanced Diploma	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
NVQ Level 4 - 5, HNC, HND, RSA Higher Diploma, BTEC Higher Level	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Professional qualifications (for example teaching, nursing, accountancy)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Other vocational / work-related qualifications	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Foreign qualifications (please state which).....	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
No qualifications	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Downloaded from <http://www.ons.gov.uk/ons/guide-method/census/2011>  
17.03.2014

## Appendix VII: Research interview schedule

The following broad interview topics have been derived from the literature:

- Knowledge and experience of cancer
- Beliefs about cancer diagnosis and treatment
- Knowledge and experience of prostate cancer
- Understanding of personal risk for prostate cancer
- Access to health care services
- Preferred health education strategies

## Appendix VIII: Focus groups card games

### Task 1: Ranking exercise 1

A 60 year old male is getting up 4 times at night to pass water. He's concerned about this because it's a change to his normal routine. Who do you think he would talk to first about his worries? Please rank in order of who he would see first.

HIS WIFE

A DIFFERENT FEMALE RELATIVE

A MALE RELATIVE

HIS DOCTOR

A FRIEND

A RELIGIOUS LEADER

### **Task 2: Misconception exercise**

The following men are worried that they might have prostate cancer. Which man should be most worried about his symptoms? Please rank in order of who should be most concerned.

A 65yr OLD MAN WHO IS HAVING TO PASS WATER MORE OFTEN THAN NORMAL

A 45yr OLD MAN WHO CAN FEEL A LUMP IN HIS TESTICLE

A 50yr OLD MAN WHO HAS SOME PAIN IN HIS STOMACH

A 70yr OLD MAN WHO NOTICES THERE IS SOME BLOOD ON THE TISSUE WHEN HE'S BEEN TO THE TOILET

### **Task 3: Ranking exercise 2**

Someone is trying to improve prostate cancer awareness in your community. What do you think would be the best way for them to make more men aware of prostate cancer? Please rank in order of what you think is the best way to raise awareness.

PUT ON A COMMUNITY EVENT WITH AN SPEAKER ON PROSTATE CANCER

PUT PROSTATE CANCER LEAFLETS IN LOCAL AREAS (GP's surgeries, community centres)

EDUCATE TEENAGERS AT SCHOOL or YOUTH CLUBS SO THEY CAN PASS ON INFORMATION TO THEIR FATHERS

PROMOTE PROSTATE CANCER INFORMATION AT SPORTING EVENTS

PUT INFORMATION IN PUBLIC MALE TOILETS

#### **Task 4 Don't fear the finger picture**

This is an image that is used to promote prostate cancer awareness. What does this image make you think about?



Image used with permission from Pennsylvania Cancer coalition

## Appendix IX: Focus group ground rules

### **Opening the focus group**

Explaining the purpose of the focus group and establishing the ground rules will open the focus group. The ground rules will include:

- Anyone can leave the group at any time if they feel uncomfortable
- What is said in the room stays in the room (confidentiality)
- We want group participants to do the talking
- There are no right or wrong answers
- The focus group will be tape-recorded
- The focus group assistant will be taking notes

### **Closing the group**

The participants will be thanked for taking part in the group. The assistant of the focus group will make a summary of the discussion. This will be read back to the participants and they will be given the opportunity to agree or disagree with the summary. On occasion that a participant does not agree with the focus group summary they will be given an opportunity to discuss this with the focus group facilitator and the rest of the participants, until a consensus is reached on the interpretation for the focus group summary.

Tape recording is stopped once the summary feedback is complete.



Information from Prostate Cancer UK will be provided about signs and symptoms of prostate cancer and other common prostate problems.

Information will also be given with the Tenovus helpline phone number, which is the most accessible number for men wanting cancer advice in Wales.

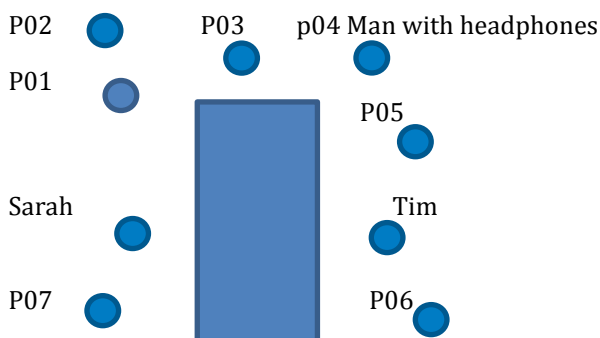
The honorarium for the participants will be the provision of food and drink. It is anticipated the focus groups will take place in a community centre and a community hub with facilities for providing tea, coffee and cold food.

## Appendix X: Example of focus group observer notes

Somali men group

7 men including translator

Location: Office male only restaurant after moving from louder bar area. This was at the request of the participants.



### Task 1

Once the group had moved into the office, Sarah explained the research that was then translated to the group. The group are asked to put in order, a list of people they might speak to if they were a man with bladder problems.

Two participants sat towards the middle of the group read out a list in Somali to the rest.

The group then began discuss between themselves, mostly with the person directly next to them. In English and Somali.

An older gentleman (in the corner) speaks first.

They agree that you would speak to the Dr first.

This decision was largely because the wife would already know.

It was commented that they would often know before you do.

All agreed that a religious leader would not be consulted.

There was then some discussion as to whether a friend would be told. It was mixed as to whether this was the case but further discussion suggested that the interpretations of terms such as “friend” and “conversation” differed.

Some considered discussion with a friend being in a public place whilst others understood it to be a more private arrangement with a close friend.

Final decision was you would talk to a Dr first then a friend (or wife).

Whilst everyone agreed to visit the GP first, one (older) participant said he might ask friends about key symptoms first. He wouldn't tell his wife. Again, this seemed to be because he assumed she would already know.

His friend who he spoke with might then recommend telling the Dr. No other people on the cards were considered.

## **Task 2**

The group begin to talk about the prostate.

An older participant told the group he had a test and it was all fine.

The group were given a list of symptoms.

They were asked to put in order of concern.

This was then translated

Again, a younger participant in the middle, wearing headphones, reads them out to the group

This participant, along with the older man next to him, then begins to choose the order. The others seem to largely be listening at this point.

When Sarah asks if they agree with the order, the others say they do.

Three cards are then handed back to Sarah. The symptoms that would be of concern are:

1. Blood found on tissue
2. Passing water more often.
3. Younger man who can feel lumps

One of the youngest men, sat on the end, told Muhammad Sarah that he has no experience of this.

Everyone agrees they would go to the GP if they had any of the above.

The above symptoms were described as “not normal.”

50 year old man with pains to the stomach was an issue of less concern.

This was because it was felt that this could be something else.

An older participant sat in the corner had some working experience of these symptoms.

Sarah asked the group if they might speak to him first.

They all agreed that this would happen. “Somali’s speak to each other first.”

It was explained that culturally, they will speak to someone who has some experience if the subject matter first.

This is not just about a medical issue but anything.

This would include scholars from the mosque.

It was felt this would be the same for women too.

Especially if the concern was about “the woman’s area” (pointing to the abdomen and below.)

This would happen before talking to the doctor.

### **Task 3**

This task was looking to investigate effective ways in which to raise awareness of prostate cancer in the local community, in this case the Somali community.

Again, the same man reads out the cards and begins to order them (man with headphones).

It appears that he often tends to make decisions on behalf of everyone and others then agree. Others do have their say as well though.

In the first instance it was felt public toilets might be a sensible place to advertise.

The man in the corner then disagreed with this although no reason was given.

It was then stated that anywhere people can meet would be useful place although this statement was then refined:

The community centre and GP surgery were the best places. It was felt that people in this community actively seek out information from these locations with the health centre being the most effective.

It was felt quite strongly that places where people eat, such as the café, should not be locations used.

The surgery is a good place as the wife can also collect information for the husband if they think it is useful.

Again it was re-iterated that the wife might notice problems before you notice them.

It was generally felt that there would be no embarrassment in picking up a leaflet on the subject.

It was felt that what will help you will help others.

Brothers, fathers, cousins etc.

There is a strong feeling of community and looking out for each other.

#### **Task 4**

Sarah then showed the group the “don’t fear the finger” picture.

Feedback included:

- It doesn’t make sense to us.
- We don’t mind the exam anyway as the doctor knows best but we are not comfortable about the poster.
- The poster is “fear itself.”

- It was felt that there was no difference between “a finger down the throat or in the bum.”

There was then a joke that the size of the finger looked ominous and if a doctor turned up with a finger that big, they would run away!

Sarah explained that the campaign was from the USA and it was felt that it was not for the UK.

The poster is embarrassing and worrying.

It also was not felt to “make sense.” It was difficult to understand the message.

And the finger was too big!

It was not suitable

Not good for awareness

The general consensus was that the GP knows what’s good for you and will do what you need.

The group were then asked if they were to talk to each other about concerns (as they earlier said they would) where would they do this.

It was always somewhere private. This could be on the phone or in private but always in confidence.

## Appendix XI: Participant Information Sheet (interviews)



Prostate Cancer UK has provided funding for translation services and income for key stakeholders used in this study

Principle Investigator: Sarah Fry  
School of Healthcare Science, Cardiff University  
Sponsor: RCBC Wales

Differences in perceptions of prostate cancer risk between African and Caribbean men and white British men in South Wales: implications for health policy.

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

### **Part I: Information Sheet for white British men version 1.0**

#### **Purpose of the study**

This study is concerned with perceptions of prostate cancer risk in African and Caribbean men and white men of British origin living in South Wales. This will help to understand reasons for perceived low diagnosis rates of prostate cancer in African Caribbean men in South Wales, compared to the white population. The research findings will also help identify ways of improving awareness of prostate cancer risk, based on the views of the community through a process of co-production.

#### **What will the study involve?**

The study will involve taking part in a 1-hour interview with the researcher, Sarah Fry, who will ask you questions about what you understand about cancer and what you know about prostate cancer. The interview will be recorded on a tape recorder that will be for the use of Sarah Fry only and will be kept in a secure location.

#### **Why have you been asked to take part?**



You have been asked to take part because you are a male adult living in the South of Cardiff who has described themselves as white British origin and who has not been diagnosed with cancer.

**Do you have to take part?**

You do not have to take part in this study. If you decide to take part in this study and later decide to withdraw the information collected in the interview will be destroyed.

**Will your participation in the study be kept confidential?**

Yes. I will make sure you remain anonymous and will not use any words that will identify you in my PhD thesis. I may quote extracts of what you say in my thesis and these will be anonymous.

**What will happen to the information you give?**

The information will be kept confidential for the duration of the study and will be stored in a secure place which is password protected. On completion of the study the information will be kept for 6-months and then destroyed.

**What will happen to the results?**

The results will be presented in my thesis which will be seen by my supervisor and an examiner. The thesis will be stored in a library and may be read by other students. Findings from the research may be published in academic journals.

**What are the possible disadvantages to taking part?**

By taking part in the study I will be asking you to talk about cancer and your knowledge of prostate cancer. It is possible you may feel concerned about cancer after talking to me about it.

**What if there is a problem?**

If you are worried about cancer after completing the interview with me I will give you information about who you can contact for advice. This will be the Tenovus Cancer Charity who will be happy to talk to you on the telephone, or in person, about any concerns you may have.

**Who has reviewed this study?**

The study has been reviewed by the ethics committee at Cardiff University. Approval must be given by the School of Healthcare Sciences at Cardiff University before a study like this can take place.

**What do I do now?**

If you are willing to be interviewed for this research please contact me:

Sarah Fry  
02920 917727  
Frysl2@cardiff.ac.uk

I will meet you and ask you to sign the consent form overleaf before we start the interview.

## Appendix XII: Focus group Participant Information Sheet



Prostate Cancer UK has provided funding for translation services and income for key stakeholders used in this study  
Principle Investigator: Sarah Fry  
School of Healthcare Science, Cardiff University  
Sponsor: RCBC Wales

### **Differences in perceptions of prostate cancer risk between African and Caribbean men and white British men in South Wales: implications for health policy.**

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Consent Form (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

### **Part I: Focus group Information Sheet for African and Caribbean men version 1.0**

#### **Purpose of the study**

This study is being done as PhD research by Sarah Fry. The study is concerned with perceptions of prostate cancer risk in African and Caribbean men and white men of British origin living in South Wales. The research findings will help identify ways of improving awareness of prostate cancer risk, based on the views of the community.

#### **What will the focus group involve?**

The study will involve taking part in a meeting called a focus group, which will last between 40 and 60 minutes. A focus group is a way of collecting information about how people talk to each other while they are in a group. For this research you will be asked to talk about health and prostate cancer. Sarah Fry will ask you and the rest of the group questions about your experiences of friends or relatives with health problems and will then ask what you understand about cancer and what you know about prostate cancer. It doesn't matter if you have not had any experience of cancer or prostate cancer.

There will be a translator present, if required, throughout the focus group. The focus group will be recorded on a tape, which will be for the use of Sarah Fry only and will be kept in a secure location. There will also be a second person present during the focus group who has been asked to join Sarah Fry to make notes of what is said in the group. This second person will then be

able to provide a summary to you at the end of the focus group, so you will have the opportunity to make corrections to the way the group discussion has been interpreted.

**Why have you been asked to take part?**

You have been asked to take part because you are a male adult living in Cardiff who has described themselves as of African or Caribbean origin who has not been diagnosed with cancer.

**Do you have to take part?**

You do not have to take part in this study. If you decide to take part in this study and later decide to withdraw any information about you will be destroyed, and any statement you have made will not be used in the study report or publications.

**Will your participation in the study be kept confidential?**

Yes. I will make sure you remain anonymous and will not use any words, which will identify you in my PhD thesis. I may quote extracts of what you say in my thesis and these will be anonymous. The ground rules of the focus group will be explained when you arrive at the focus group venue. It will be agreed that everyone taking part in the group discussion will keep each other's participation confidential and will not discuss what you say with anyone outside the group.

**What will happen to the information you give?**

The information will be kept confidential for the duration of the study and will be stored in a secure place which is password protected. On completion of the study the information will be kept for 6-months and then destroyed.

**What will happen to the results?**

The results will be presented in my thesis which will be seen by my supervisor and an examiner. The thesis will be stored in a library and may be read by other students. Findings from the research may be published in academic journals.

**What are the possible disadvantages to taking part?**

By taking part in the study I will be asking you to talk about cancer and your knowledge of prostate cancer. It is possible you may feel concerned about cancer after talking to me about it. You may feel uncomfortable talking about health and cancer with other people taking part in the focus group.

**What if there is a problem?**

If you find it difficult talking about health and cancer during the focus group the second person facilitating the group will offer you support. You can leave at any time during the focus group. If you are worried about cancer after completing the focus group with me I will give you information about who you can contact for advice. This will be the Tenovus Cancer Care who will be

happy to talk to you on the telephone or in person about any concerns you may have Tenovus Cancer Care can be contacted on 0808 808 1010.

**Who has reviewed this study?**

The study has been reviewed by the ethics committee at Cardiff University. Approval must be given by the School of Healthcare Sciences at Cardiff University before a study like this can take place.

**What do I do now?**

If you are willing to take part in a focus group please contact me:

**Sarah Fry**

**02920 917727**

**Frysl2@cardiff.ac.uk**

I will meet you and ask you to sign the consent form overleaf before we start the focus group.

## Appendix XIII: Research consent form



Prostate Cancer UK has provided funding for translation services and income for key stakeholders used in this study

Principle Investigator: Sarah Fry  
School of Healthcare Science, Cardiff University  
Sponsor: RCBC Wales  
**Differences in perceptions of prostate cancer risk between African and Caribbean men and white British men in South Wales: implications for health policy.**  
**Part 2. Certificate of consent version 1.1**

I have read the information about this research, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered. I consent voluntarily to be a participant in this study.

Please initial the boxes.

- I am participating voluntarily.
- I give permission for my interview with Sarah Fry to be tape-recorded.
- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
- I understand that anonymity will be ensured in the write-up by disguising my identity.
- I understand that disguised extracts from my interview may be quoted in the PhD thesis and any subsequent publications if I give permission below:
- I agree to quotation/publication of extracts from my interview
- I do not agree to quotation/publication of extracts from my interview
- I agree to my ethnic origin being documented by Sarah Fry

Name of Participant \_\_\_\_\_  
Signature \_\_\_\_\_  
Date \_\_\_\_\_  
Day/month/year

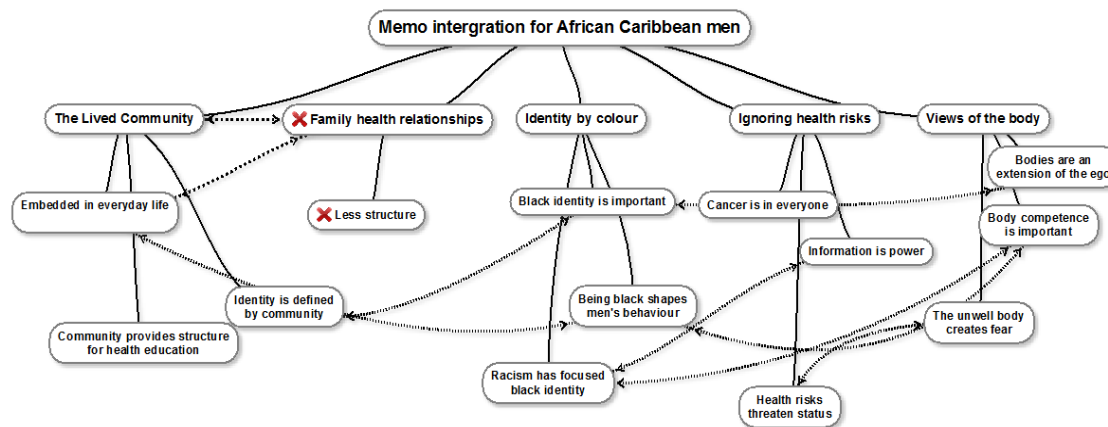
Principle Investigator (name) \_\_\_\_\_  
Signature \_\_\_\_\_  
Date \_\_\_\_\_  
Day/month/year

Appendix XIV: Examples of theoretical coding, sorting and theory generation

Comparison	Line-by-line coding	Focused coding	DM650032
This is different to some of the other en who talk about not wanting to talk because they can't offer sympathy. They don't know what to say. This is amongst the African Caribbean and white men but is more prevalent in the Somali men.	Giving allowance for people to be open. Finding it acceptable to gossip about cancer.	Health as gossip. Health on the grapevine.	R: Yes and obviously there's going to be a grapevine as well, that happens anyway, but you know I think at the initial stage potentially people are able to be a bit more open about it with people close to them.

White men	Focused code	Extract	Sorting	African Caribbean men	Focused code	Extract	Sorting	Somali men	Focused code	Extract	Sorting
13	Body in decline	My wife's cousin, she's probably got a couple of weeks and that's it, she's very poorly at the moment. My brother in law has got prostate cancer which had spread everywhere..."	Views of the body	10/11/12	Ageing body	"...but I've always slept through it but now I find myself now starting to wake up hence I'm thinking well is the bladder getting weaker because I'm getting older."	Views of the body	15	Body as medicine	For example somebody I wouldn't go to anybody to touch my wife or my mum's body but when I talk to the doctors, doctors do.	Views of the body.

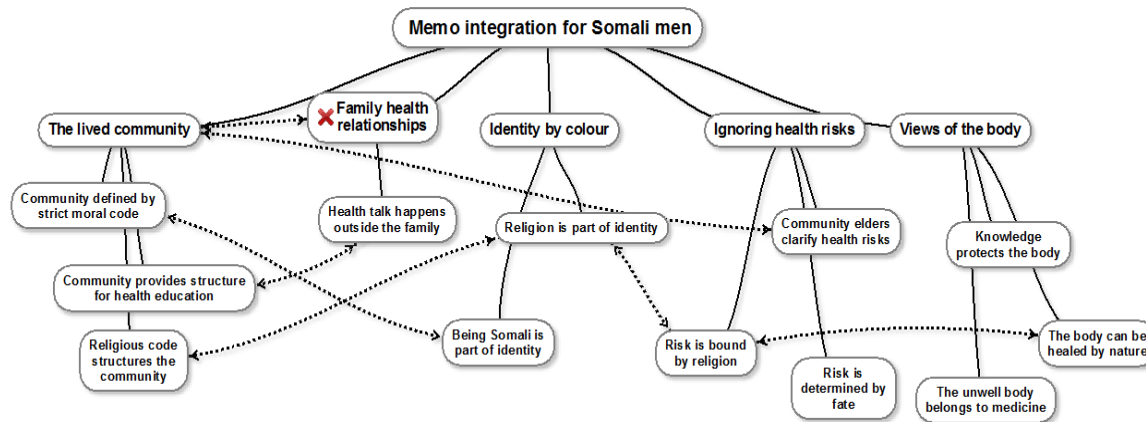
## Appendix XV: Example of memo integration



The community is embedded in everyday lives for African and Caribbean men, the community in this research has grown from the black men's experiences of racism when they first moved to the United Kingdom. These experiences have created men who have fought for their own identity, creating male pride and protection of their black identity. The black community has become home and influences health beliefs and assessment of risk, by drawing on the experiences of others and information filtered through the community structure.

The community is a source of information and reassurance. These men see information as power and include in this health information. However, the importance of the image of a fit and healthy body creates a fear of illness and therefore a conflicting attitude to health information. The men want to be viewed as physically healthy and they also want to receive health information, to create a feeling of power, but they don't want to lose their status in the community through illness.

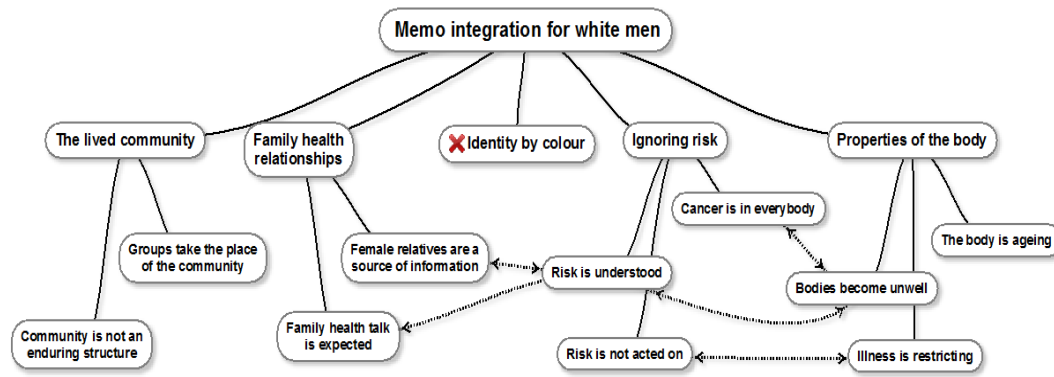
The well body and the image of a fit body is what motivate these men. This is bound in their black identity as lived through their everyday lives and what drives their risk perception and acceptance of risk.



For Somali men their lived experiences are structured through their religion, Sunni Muslim. The lived community, particularly the strict moral code through which they live, binds the Somali's man's interactions with their health. These men judge their health risks based the views of elders in the community and their faith in the medical profession. The men believe that doctors should not be questioned and this is also central to the beliefs of the community. Also central to the community is the belief that fate is responsible for illness. The Somali men talk religion in relation to fate; a higher force knows when your time has come.

The central theme from memo integration for these men is the lived community. Identity by colour does not concern these men and their use of health risk information is embedded in their understanding of the hierarchy of the community and acceptable communication channels. Like the African and Caribbean men these men also believe information is power, but their use of this information is dependant on how it is interpreted through the community.





White men talk less about the colour of their skin than African Caribbean men, and less about the community than both African Caribbean men and Somali men. The white men put value on their family and the health conversations they have within the family. They expect to hear health information from their wives. These men ignore health risk by not always acting on the information they are given, but do respond when the females in their lives put pressure on them.

The men are focused on the unwell body. During group education the men are attentive and were easier to recruit to focus groups and interviews than the black men. They expect illness with age and this is also linked to their family health relationships, through which health and risk is understood.