Unwritten Rules: The Health Information Activities of African and Chinese Populations Living in the West of Scotland.

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Abbreviations

A8 Citizens - Citizens of eight countries that joined the EU in May 2004, including migrants from Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia.

BME – Black and Minority Ethnic

CCDP – Chinese Community Development Partnership

CRE - Commission for Racial Equality

EU – European Union

GG&C NHS – Greater Glasgow & Clyde NHS

HIC – Health in the Community Course

HIV - Human Immunodeficiency Virus

STIs – Sexually Transmitted Infections

TB - Tuberculosis

WHO – World Health Organisation

Abstract

In industrialised societies Black and Minority Ethnic (BME) populations continue to battle against a rising tide of health inequalities that disproportionally affect their communities. To succeed, academics, policy-makers and public health providers need to fully understand the deep-seeded roots of health inequalities; to put into context the barriers facing people with varying heritage and cultural backgrounds. This research recognises information is a privileged commodity and a vital part in the fight to overcome health inequalities. Essentially this PhD presents a unique window into the health information activities of African and Chinese populations by exploring the varying routes through which ethnic identity continually shapes health information seeking and sharing. To achieve this, a pragmatic mixed methods approach was employed. Data was collected from 117 self-completion questionnaires, while ethnographic material was gathered from 36 semi-structured interviews and participant observation exercises spread over 7 months. The works of Sociologist Goffman (1959; 1963) and Information Scientist Chatman (1996) provide theoretical frameworks for data analysis and comparison in this research. Key findings recognise that for both BME communities health information seeking and sharing activities occur within cultural systems and social networks. Participants' perceptions of health ownership, stigma, privacy, and trust reinforce constraints around health information disclosure as well as seeking and sharing activities. Yet, findings also suggest that certain obstacles could be overcome with the assistance of information technology. eHealth (electronic healthcare delivery) offers settings whereby users could temporarily lift themselves out of information poverty and attain culturally sensitive health information. However, in order to achieve greater eHealth uptake developers need to work in conjunction with BME community organisations to raise awareness, build trust and relevance whilst encouraging the development of eHealth literacy skills.

Chapter 1 – Introduction to Research Topic

1.1 Chapter Introduction

This thesis provides a sociological exploration of the health information activities of two Black and Minority Ethnic (BME) populations living in the west of Scotland, arguing that access to trustworthy, supportive and culturally relevant health information is essential in the struggle against health inequalities. Consequently, this research offers new insight into health information activities: exploring how ethnicity shapes social interactions when accessing, using and sharing health information. A mixed methods approach offered fruitful collection in the field, whilst the influential work of Sociologist Erving Goffman (1959; 1963) and Information Scientist Elfreda Chatman (1996) provided theoretical frameworks for the analysis of data. This chapter will outline all the essential elements of this thesis, introducing the social and political backgrounds of this study. Initial discussions will therefore concentrate on Scotland as a social and political entity, asking questions of its multiculturalism and its health culture in order to appreciate the direction of the Scottish Government and NHS Scotland in providing healthcare for the nation. Healthcare provision for BME communities in Scotland is then considered, with particular emphasis on policy development. As a key component to this research, a brief introduction of eHealth is given before moving on to present a historical overview of both African and Chinese communities, focussing especially on the health inequalities both communities confront in Scotland. The chapter concludes with a brief breakdown of each thesis chapter preparing readers for what is to follow in this thesis. This introductory chapter therefore sets the scene for proceeding chapters, defining the social and political backgrounds in which health information activities occur.

1.2 Research Questions

Health information can empower individuals to be proactive about their health to make lifestyle changes as well as medically related decisions. Limited access and use of health information as well as the type and delivery of health information all play a part in the complex picture of health inequalities. Moreover, in an increasingly person centred healthcare system greater emphasis is being placed upon individual choices and decisions. Thus, I would argue having knowledge about health and wellbeing is essential to empowerment, to more positive patient experiences and ultimately better health outcomes. As a result this research will offer a snapshot of health information activities, exploring how ethnic identity shapes these activities to better understand the relationship between health information and health inequalities for BME populations.

To put health information activities into a conceptual framework, Chatman's (1996) theory of information poverty will be applied. Four core research questions below define research enquires and allow research findings to be contextualised.

1. What social and cultural influences shape health information activities for participants?

2. What socio-economic factors impact health information activities for participants?

3. What role does technology have in shaping health information activities for participants?

4. Is Chatman's (1996) theory of information poverty evident amongst participants?

Each findings chapter will present fieldwork outcomes in relation to each research question above; allowing a platform upon which findings and theoretical concepts can be analysed in response to these research questions. Before full discussions begin it is necessarily to offer explanations of key definitions used throughout this thesis. Firstly, central to this study is the concept of information, so this is a good place to begin.

> “…information has become one of the most important primary goods in society. This means that a particular minimum of it is necessary to participate in it. With the rising complexity of society, this minimum is increasing. Moreover, all relative differences above this minimum are leading to more or less participation, productivity, power, self-respect, and identity for different groups in society. These differences are a substantial basis for inequality in contemporary society.” (van Dijk, 2005:142)

van Dijk’s (2005) point that the differences in information acquisition is a substantial basis for inequality is crucial to the investigative nature of this research. When it comes specifically to health information, patients need access to good quality, evidenced based, health information to allow them to be active in their decisions. (Shepperd et al., 1999) Moreover, Nettleton & Gustafsson denote,

> “More and more people are making their own decisions and *reflexively* assessing complex and often conflicting sources of advice and information on health routines, health interventions and on their experiences of illness.” (Nettleton & Gustafsson, 2002: 8)

Henceforth to capture these complex social interactions and experiences an all-encompassing definition of health information is adopted for this research. Health information in this study can be understood as general information about health and wellbeing, information about specific illnesses and diseases, or personal information about individual health. Allowing for such a wide definition of health information permits analysis of many different types of information delivery, as well as, the different social norms and cultural expectations linked to different information types, disclosure and delivery. Equally when it comes to the actions associated with health information in this study a number of terms have been employed. Within the discipline of information science ‘information seeking behaviour’ is the prevailing term, emphasising a cognitive understanding of how individuals search and share information (Savolainen, 2007). In adopting the theoretical framework of Chatman (1996) the expression, 'information seeking behaviour' will be applied when discussing findings in relation to information poverty. Other sociologically rooted terminology has also been adopted throughout, including: 'health information performances', 'health information practices' and 'health information activities'. The term 'health information performances' provides a link to Goffman's (1959) phraseology, while 'health information practices' conveys Savolainen's (2008) sociologically inspired concept. Finally, the phrase most frequently employed, 'health information activities' encapsulates a holistic understanding of the social actions being explored in this research. Moreover, it reflects approaches to data collection as well as fieldwork outcomes which involve the seeking, recognising, using and sharing of health information by participants.

The use of the acronym BME (Black and Minority Ethnic) in this thesis, has been influenced by the adoption of the term by the Scottish Government in the Improving the Health of the Scottish Minority Ethnic Communities Report (Scottish Executive, 2002) as well as its widespread use within the third sector. The Improving the Health of the Scottish Minority Ethnic Communities Report argues that in using this working definition it encompasses all groups who do not identify themselves as 'White', but adds that it is necessary to pinpoint the exact groups to which you refer. Although the term is commonly used it can be unpopular as it can be cumbersome, bureaucratic, and in its shorted form of "BME", reductionist. Nevertheless this social research is conducted in the landscape of Scottish social policy and seeks to be transferable and have potential impact within the Scottish third and public sectors. Henceforth I have adopted the term BME when generally positioning these two communities, although, more commonly I have used the labels of African and Chinese to define the groups that participants identify with. Since this work takes an interpretivist approach I have chosen to use the labels participants gave themselves, and which I set out to examine in the context of health information activities. When I entered the field it became obvious to me very quickly that participants and community workers defined themselves as African or Chinese and that this labelling had an impact on how health information was sourced, shared and used. For the most part African participants talked of one day 'becoming Scottish' and being proud to live in Scotland and have their children attend Scottish schools, but at present they still defined themselves as African, and were extremely proud of their African identities. Associating with their ethnic and racial identities allowed research participants in this study to find support and strength from their collective identities in terms of community connectedness. However this association was a double edge sword, when participants self-identified with a particular ethnic identity they also spoke of adopting self-protecting behaviours, having concerns over courtesy stigma or conforming to social norms associated with health and wellbeing. In essence participants were highlighting that in practice their ethnicity shaped their health information activities.

Most Chinese participants in this research had gone through the UK asylum process but many years ago, only two participants were newcomers with short term leave to remain, and one participant who was British born (he classified himself as Chinese Scottish). Participants no matter how long they had lived here identified themselves Chinese first and foremost (this could be linked to limited English skills or the strength of Chinese culture in the daily lives of participants). In questionnaire returns: 45 respondents identified their ethnicity as Chinese, 56 as Chinese British, 10 as Chinese Scottish and 1 respondent ticked the 'other' category with 5 respondents not answering the question at all. Please refer to appendix I for SPSS output of ethnicity within the sample. Consequently, the social labels used throughout this research have been adopted primarily as a reflection of how participants identified themselves. It is also important to note that throughout the course of my discussion the terms BME populations, BME communities and to a lesser extent BME groups is employed. Once again the use of the term community is an indication of how participants defined others who also shared their ethnicity as well as those who were seen to be different, to be outside the community, like myself. To be part of the African or Chinese community for participants in this study signified a difference in how social interactions between those from the same or even different ethnic communities where performed during health information activities. In this research participants spoke of how their ethnic identity shaped their understanding of health, impacted upon how others might perceive them and consequently influenced how and where to source and share health information.

1.3 Multicultural Scotland?

Although a small nation, Scotland has always seen itself as having a place on the world stage. McCrone (2001) proposes that Scotland, a nation currently without a state, is today remaking its political and social order to question traditional approaches. Instead of being in direct opposition to globalising forces, McCrone (2001) argues that Scotland's strong nationalism is part of the economic, political and cultural globalising forces. The Year of the Homecoming (2009) reaffirmed the importance of Scotland's diaspora groups and cultural links across the world, while the Fresh Talent Initiative (2004) encouraged economic migration to Scotland with the purpose of enhancing Scotland's economic power (Skilling, 2007). Scotland provides a unique setting for this research, especially in relation to its social identities and political environment, which of course influences its healthcare approach. With over a decade since devolution and in light of the independence vote of 2014, Scotland offers a number of variances to its neighbours. In political terms the Scottish government has encouraged the arrival of 'New Scots', to turn around a declining birth rate and encourage economic expansion in the services industries. Scotland has also looked abroad to welcome EU economic migrants as well as international students to bring skilled potential to the country. In addition Scotland's tolerate and inclusive political tone with the (2002) One Scotland, Many Cultures campaign, the (2004) Fresh Talent Initiative, coupled with its approach to the facilitation of asylum seekers and refugees has marked it apart from Westminster (Bowes & Sim 2007; Bowes et al., 2009). Still, there is a strange dualism within the Scottish philosophy, although on the surface a devolved Scotland has been quick to emphasise its' global and multicultural tolerant nature, beneath the surface lies several social struggles, struggles to sit closely to its overshadowing English neighbour, as well as, traditional religious divisions (Penrose & Howard: 2008). In relation to Scotland's customary relationship to minorities, Dwyer & Bressey (2008) make a very valid point,

> "In Scotland the 'significant other' in terms of self-definition was the English, not Blacks or Asians or any other visible minority group." (Dwyer & Bressey, 2008: 96)

As a rule, immigration and specifically the settlement of BME communities in Scotland has not been politically radicalised in the same ways witnessed in England (Hussain & Miller, 2006). Political parties such as the BNP have never truly gained solid support in Scotland; instead nationalistic divides and sectarianism have unfortunately dominated. Hence, with a politically positive outlook on immigration but a divided and decisive 'White' social background, Scotland is only now really coming to terms with issues of multiculturalism. Interestingly, academics have come to argue that the Scottish identity although stronger today, is also a flexible national identity based more on residency and accent, rather than birthplace; making it much more inclusive than other home nations (McCrone, 2001; Bond, 2006). Nonetheless, this is not to say that BME communities in Scotland do not face discrimination and marginalisation, because they do. Pain and Smith (2008) maintain,

> "…. In Scotland as in England there is an all too familiar catalogue of insults, assaults, damage and harm, affected through both personal racism and political extremism, undermining health, welfare and wellbeing, and contributing to the separation and segregation of social life." (Pain & Smith, 2008: 105)

On the one hand Scotland offers a positive political attitude to immigration, coupled with growing BME communities, but added to the mix is a long-held intolerance of the invisible minority of the English (Hussain & Miller, 2006). Although notably, the most marginalised and underserved groups in Scottish society remain BME populations who on a daily basis face economic and social disadvantages (Netto et al., 2011). Consequently, this social and political cauldron makes for an interesting context in which this social research is set.

1.4 Glasgow & Beyond the City Boundary

Although Glasgow is not the political or economic centre of Scotland, its local culture and social heritage lends to a rich social and cultural micro environment, with its social and political character rooted in the heavy industries of the 1970's and 1980's. Thus, Glasgow's traditional reputation as a hardworking, hard man's city has been difficult to shake off. The deindustrialisation of Glasgow over the last three decades shows a broader process of labour globalisation, to compensate this labour migration to developing countries, Glasgow has fought hard to attract investment in the services, finance and retail as well as cultural industries (MacKinnon et al., 2011). However, young people especially in Glasgow struggle to compete in a global labour market. MacKinnon et al., concludes,

> "The recession is exacerbating inequalities produced by the differential effects of earlier processes of global integration..... This is particularly evident for unemployed young people in Glasgow, where the recession has worsened already difficult labour market conditions produced by past processes of deindustrialisation." (MacKinnon et al., 2011: 37)

As a result poverty still lingers, there is no denying Glasgow and its suburbs have some of the lowest life expectancies and some of highest social deprivation in the country (Centre for Social Justice, 2008). Yet, the city has made good attempts to reinvent itself, with the Glasgow Miles Better Campaign, the Glasgow Garden Festival, winning the European City of Culture in 1990 as well as hosting the Commonwealth Games in 2014, leading the city has been branded a "tale of two cities"; a place with shiny new commercial and recreational districts coupled with extreme social decay and exclusion (Centre for Social Justice, 2008). Historically known as the second city of the Empire during the 20th century Glasgow has always had strong ties to the global stage (McCrone, 2001). Today Glasgow is Scotland's most ethnically diverse city with an estimated 8.6% of its population from BME backgrounds (Glasgow Centre for Population Health, 2010). The city has the highest percentage of BME communities in its boundaries even when compared to the capital Edinburgh (Scottish Executive, 2005b). Global patterns of refugee migration and economic changes have subsequently changed the dynamics of the city and its outlining areas. Clark et al., (2008) underlines the impact on the area's identity, when he proposes,

> "With over 100 languages now being spoken in Glasgow on a day-to-day basis, with communities in the city originating from all corners of the globe, it would be disingenuous to argue that the city was somehow untouched by globalisation, untouched by the active processes of migration and transnationalism." (Clark et al., 2008: 56)

Glasgow City Council identifies the geographical profile of the city and indicates that concentrations of BME populations can be found in the city centre, Sighthill and South Side areas (Glasgow City Council, 2012). Unfortunately Glasgow reflects the standard UK pattern of spatial concentration of BME communities, historically linked to areas of urban decay and disadvantage (Pacione, 2005). In the last two decades, the west of Scotland has seen two successive phases of immigration. As part of the dispersal programme in the UK, Glasgow City Council was one of the first local authorities to sign up to the dispersal scheme in 1999 when they agreed to utilised vacant flats in the Sighthill area of Glasgow to house 8,000 asylum seekers who had originally been housed in southern England (Dunn, 2003; Scottish Refugee Council, n.d). Unfortunately, this created a great deal of tension in the area, an area of existing economic decline and social exclusion, however years of community campaigning and investment has to an extent rebuilt relations and fought against negative stereotyping of immigrants. Dunn details,

> "In response to the negative press on asylum seekers the Refugee Council and other groups in the context of Scotland (eg. Scottish Asylum Seekers Consortium, (SASC)) has set about dispelling many of the myths about refugees…" (Dunn, 2003: 141)

After 2004, the free movement of A8 citizens (citizens of eight countries that joined the EU in May 2004) across the EU meant a rise in the number of A8 workers coming to Scotland. Usually young, with no dependants they commonly work in the hospitality and catering sectors (Blake Stevenson Group, 2007). This second wave of immigrants has mainly settled in the East End of the city. Sensationalist media reports have in the past perpetuated negative stereotyping of immigrants in Glasgow. In research carried out by the Scottish Government it was acknowledged that the media played a vital role in perpetuating negative representations of immigrants, especially asylum seekers (Scottish Executive, 2003a). Yet, more balanced and positive coverage by smaller local media outlets have also been reported within Glasgow (Khan, 2011). Thus compared to the experiences of asylum seekers during the last decade, the experiences of A8 nationals in Glasgow, has generally been reported as positive (Blake Stevenson Group, 2007). Recent immigration patterns in the west of Scotland have undoubtedly shaped social attitudes and altered public services. These immigration waves along with the west of Scotland's history of social and economic decline mean Glasgow and its surrounding areas are perfectly situated for this type of social research.

1.5 Scotland's Health Culture

The health of the nation; the Scottish Government's stance on devolved healthcare provision offers a distinctive background in which health information becomes a critical factor in the life paths of those living in Scotland. Unfortunately, Scotland's health record is renowned for its extremes, often labelled the 'sick man' of Europe, Scottish policy makers and health experts have spent the last few decades questioning the social drivers for the rise in poor health. Campbell et al., (2013) argue that the economic restructuring of the 1970's, 1980's, and early 1990's significantly changed income inequalities for Scotland. The long term effect has been a change in health behaviours linked to increased rates of smoking, poor diet, alcohol and drug misuse along with poor mental health, all of which has given rise to a dramatically different mortality rate for Scotland when compared to England and Wales. Moreover, recent analysis of health statistics from all four home countries underlines Scotland's depressing dominance (The Scottish Government, 2010a). In key findings, Scotland fares much worse than its English counterpart, especially in matters relating to smoking, alcohol consumption and obesity. The most notable distinction is the difference in alcohol consumption levels between Scottish and English men and women, with much higher levels of daily consumption for Scots (The Scottish Government, 2010a). Glasgow in particular when compared to other Scottish cities has been spotlighted and its prognosis is poor. Gray maintains,

> "….the strong social patterning of many of the negative health behaviours and other morbidity measures examined accounted for the tendency of Glasgow to have high levels, reflecting its poorer socio-economic position. Improving Glasgow's health thus remains inextricably linked to tackling the problems associated with deprivation and poverty." (Gray, 2007: v)

Gray (2007) stipulates that although some health issues such as obesity and diabetes are obviously not just contained to Glasgow, many health indicators are relevant to the region. The distinctive health behaviours and problems witnessed in Glasgow have led to the phrase the 'Glasgow Effect' (Glasgow Centre for Population Health, 2011). The 'Glasgow Effect' identifies higher levels of mortality and poor health beyond that explained purely by socio-economic circumstances, however, these unidentified factors remain largely under researched (Landy et al., 2010). To offer a brief snapshot of these high levels of mortality; figures show premature mortality in Glasgow standing at a 30% higher rate when compared with identically deprived areas in the UK, such as Liverpool and Manchester (Walsh et al., 2013). There are however positive steps forward, Donnelly (2007) argues that overall Scotland's health is improving, a point backed up by a decline in Scotland's big killers - cancer, heart disease and stroke - between 1995 and 2010 (The Scottish Government, 2011b). The real story behind Scotland's health figures are the multiple risk facts relating to health and therefore health outcomes between Scots living their lives in different areas within very different social and economic conditions (Lawder et al., 2010).

Accordingly those residing in deprived areas face premature mortality from cancer and heart disease at a 15% higher rate compared with the rest of the population (The Scottish Government, 2011c). Moreover, there are higher incidents of low birth weight, and lung disease in deprived areas linked with higher rates of smoking. There is also the usual commentary on obesity and binge drinking yet perhaps one of the more startling statistics relates to mental health. Suicide rates amongst men are three times higher than women but strikingly the rate is three times higher in the most deprived areas (Audit Scotland, 2012). In response to these continued health inequalities the Scottish Government launched the 'Keep Well' campaign, to offer health improvement through enhanced primary care services to deliver preventive healthcare and information (NHS Health Scotland, 2012). Future challenges for the Scottish Government and NHS Scotland lay therefore not only trying to improve the overall health of the general public but to specifically work with those who face health inequalities to provide better engagement and service provision.

1.6 NHS Provision for BME Communities in Scotland

Many BME populations in the UK face health inequalities, suffering from poor health, compounded by a healthcare system which at times struggles to deal with their needs (Szczepura, 2005; Bhopal, 2007). Evidence from Public Health England suggests BME populations have unequal access across NHS services as well as negative patient experiences (Public Health England, 2013). Consequently, this thesis argues that a key component in overcoming health inequalities is access to good quality relevant health information for BME populations. Significantly, though when we look at health statistics in detail, health outcomes and experiences vary across ethnic groups as well as across home countries. If we consider firstly UK statistical information relating directly to illness, we can see as an example that Gypsy/Irish Traveller women are twice as likely to suffer from a long-term illness compared to White women, while Chinese women actually report much lower incidents of illness compared to all other groups (Becares, 2013). Meanwhile, a snapshot of the 2014 census data in Scotland indicates that White British respondents actually have the lowest levels of self-reported wellbeing compared to African, Caribbean or Black, White Other and Asian ethnic, with Chinese groups far exceeding the national average (Scottish Government, 2014). Moreover, when it comes to health care experiences the Patient Primary Care Survey in Scotland showed that Asian, Asian Scottish or Asian British and other ethnic groups tended to report less positive patient experiences compared to African, Caribbean or Black patients (Scottish Government, 2014). The diversity in the life courses and lived experiences of BME populations is reflected in their health outcomes and patient encounters. Although this study focuses on ethnicity as a key influencing factor which shapes health information seeking experiences, it is nevertheless important to acknowledge that other factors such as socioeconomic status, immigration stage, age, religion, living conditions and geographic location all play a part in influencing health inequalities, a discussion which I will develop further in the second chapter of this thesis.

The health of immigrants and in particular refugees and asylum seekers is of particular interest to this discussion since a large number of participants in this study identified as either being a refugee or asylum seeker. It has been documented that at the time of arrival refuges and asylum seekers report good health however this noticeably deteriorates over time. (Bhopal, 2007; Johnson, 2006; NHS Health Scotland, 2009) The Scottish Refugee Council recently published research on the integration of refugees and asylum seekers, the research was entitled, 'In Search of Normality Refugee Integration in Scotland' included a small section focussing on health (Scottish Refugee Council, 2013b). A large proportion of respondents in this research said that their health was reasonably good, significantly though, there was a stark difference between men and women, with a larger proportion of women indicating that their health has deteriorated in the past two years. Women also reported longstanding health problems compounded by the fact that women are in the asylum process for longer periods of time. The report also uncovered a real need for mental health support with emphasis on access, especially because the under-reporting of poor mental health seems to be a common occurrence. Mental health was also a leading health concern for asylum seekers and refugees especially for destitute asylum seekers in Netto's et al., (2011) research on poverty and ethnicity in Scotland.

It should be noted that in-depth social research as well as statistical data relating to the health of BME groups in Scotland has traditionally been very limited. NHS Health Scotland admits that currently little is known about the health of BME populations living in Scotland and their use of NHS services (NHS Health Scotland, 2009; Bhopal, 2007; NHS National Services Scotland, 2011). Ethnicity recording relating to mortality rates and hospital admission has habitually been low, although as of 2012 ethnic identity is now recorded on death records in Scotland, in addition, ethnic group recording for hospital admissions by NHS Boards is on the increase, giving future researchers better resources (NHS Health Scotland, 2013). Director of Public Health Report 2007-2008 briefly mentions the differences in health outcomes experienced by different BME groups living within the boundaries of NHS Greater Glasgow & Clyde. The report touches upon the social determinants influencing poorer health outcomes for Glasgow's BME populations, highlighting poverty, poor education, low employment levels as well as limited access to healthcare service. The lack of statistical data on the health experiences of BME populations in Glasgow is underscored in the report along with its detrimental impact on designing and planning appropriate healthcare services for BME populations. Finally the report underlines the low levels of staff awareness regarding BME populations and suggests this adversely affects their ability to provide appropriate services to diverse BME populations. This final point is further examined in the research findings chapters of this thesis.

To put this study into context, it is now important to reflect specifically on how NHS Scotland has and continues to facilitate health policies and practices for BME populations. The Fair for All (2001) report, the first of its kind in Scotland, set the agenda for tackling barriers to access and improving services for BME populations in Scotland (Scottish Executive, 2001). A number of key points were presented regarding policy and practical facilitation of healthcare delivery for BME populations. When initially published, The Fair for All (2001) report suggested that health boards across the country were at different stages of development (many in the early stages) when it came to healthcare provision for BME populations (Scottish Executive, 2001). The development of strategic approaches to the delivery of healthcare for BME populations was a low priority for many boards, subsequently the report called for a more strategic method be undertaken to address BME health issues across the country. The same report also highlighted a number of areas which needed to be prioritised if barriers were to be eliminated. These areas incorporated the increased availability of interpreting and translation services, the closer integration of all services as well as more culturally competent NHS staff. In addition, the report outlined the need for better understandings of contributory factors leading to healthcare barriers, citing negative healthcare experiences as well as poor quality and lack of relevant health information. The subsequent Fair Enough Progress Report (2003) acknowledged there was a long way to go before aspirations could be met but added that the National Assessment Framework would act as a practical guide for NHS Boards to complete implementation (Scottish Executive, 2003b). The Equality and Diversity Impact Assessment Toolkit (2005) has also set out to improve the way in which NHS Boards integrate practices and policy to encourage a reflection of current equality and diversity legislation (Scottish Executive, 2005a). Next, NHS Health Scotland released the Health in our Multi-Ethnic Scotland – Future Priorities report (2009) which highlighted research and practice priorities, including the creation of a system for ethnic coding, a large health survey across all BME populations in Scotland as well as the facilitation of research projects investigating the health and healthcare experiences of BME communities (NHS Health Scotland, 2009). At the time of writing it should be noted that a multi-agency strategic steering group (SHERSS) has been set-up to coordinate these activities (NHS Health Scotland, 2011). Thus despite frustratingly slow research and policy advancement, it should be remembered, that with a relatively small BME population, ethnicity nevertheless remains an important consideration for NHS Scotland; its continued emphasis on healthcare provision for BME populations is obviously driven by the Scottish Government's social inclusion agenda and is certainly progressive when considered against other comparative healthcare systems (Bhopal 2012; Harrington et al, 2009).

1.7 eHealth in Scotland

> "eHealth has the potential to improve access to the health care system for traditionally underserved populations…" (Ahern et al., cited in Institute of Medicine, 2009)

Palgliari et al., (2005) uncovered a broad range of interpretations of eHealth when they conducted an in-depth review of eHealth definitions; most commonly the term is understood to conceptualise a range of medical informatics applications which offer tools to facilitate and manage the delivery of healthcare, including amongst other functions, health-related information. Hence, eHealth is becoming one essential pathway for health information delivery with the potential to aid individuals in making decisions about their health and lifestyle choices (Institute of Medicine, 2009). This thesis will argue that opportunities to develop ehealth services in partnership with BME communities in particular should not be overlooked as there could be vital engagement opportunities to assist in overcoming health inequalities.

The growth and implementation of eHealth across the UK and beyond has taken many forms, eHealth can start with something internal such as electronic patient records and stretch right across to health decision support systems, health information websites and mobile health communications. There is exciting potential in eHealth; to save the NHS money, to provide additional services, to be flexible for patients and to overcome traditional barriers. However, the right information needs to be adapted and facilitated in the right manner at the right time to different audiences, so as not to miss the potential of eHealth (Kreps & Neuhauser, 2010). Recently Scotland has been acknowledged amongst its European counterparts as a leader in taking eHealth programmes forward (SPICe, 2013). Hence, the Scottish Government has shown a keen interest in the development of eHealth for patient engagement, claiming,

> "eHealth's contribution…will make patient care safer and more effective by making available the right information in the right place at the right time; contribute to 'health literacy' to ensure that all citizens have the necessary skills, knowledge and confidence to manage their own health" (The Scottish Government, 2008: 4)

At present The Scottish Government eHealth strategy (2011-17) is focused on provision for particular patient groups, including older patients, patients with complex long term illnesses and long-term physical disabilities as well as those living in rural areas (The Scottish Government, 2011a). It is interesting to note, King et al., (2010) embarked on research exploring public responses in Scotland to eHealth implementation. Utilising a modified citizen's jury, the topic of eHealth was debated by members of the public. Participants supported the progression of eHealth within the NHS and in many ways viewed this progression as inevitable, however they did stress that eHealth should always enhance rather than substitute face-to-face services. In the case of eHealth and BME communities this principle must not be neglected. King et al., (2010) also suggests there is potential for the rise of a new digital divide, especially for those who have poor access to the new technologies associated with eHealth. Subsequently, for BME communities there is potential that eHealth services might increase rather than decrease health inequalities. eHealth in this study is explored in four forms: NHS 24 (telecare), NHS online (which includes patient-centred websites such as NHS Inform, Health in My Language and NHS SHOW) mHealth (the facilitation of healthcare via mobile phone technology) and finally health information kiosks (self-service touch screen kiosks for patient interaction or health promotion). It was important to focus on the role of eHealth to truly understand the health information activities of participants and also explore the potential for future engage via eHealth. The background of health, health inequalities and healthcare provision in Scotland has been presented, it is necessary to therefore now introduce the participants of this research.

1.8 Selection of Participant Communities

> "…the idea of community is related to the search for belonging in the insecure conditions of modern society; perhaps this explains its enduring appeal." (Delanty, 2010:1)

Community as a concept in Sociology is continually being reinvented but always underpinned by a shared sense of belonging. Throughout this thesis I refer to "communities within communities" this is essential in underlining the diversity within the two ethnic groups I engaged with. Nevertheless in order to understand how ethnicity potentially shapes health information seeking it is important to also understand both BME groups as two distinct communities. Communities of individuals who through this diversity still share different aspects of heritage, ancestry, history, language, cultural and religious beliefs, as well as social networks. On numerous occasions during participant observation exercises and interviews participants voiced their perceptions of identity and community. Africans in Glasgow share similar life experiences (especially in terms of why and how they came to Scotland), speak languages left over from a colonial era, hold the same religious beliefs and continue to build social support networks, like those evidenced in this study. The Chinese community meanwhile represented a traditional understanding of community, occupying a collective physical space in Glasgow's city centre. However, Chinese participants' in this study also identify with the more imagined forms of community, with a shared language, culture and heritage. Notably many of the older participants in this study acknowledged a strong sense of Chinese identity even though they had spent the last two or three decades in Scotland. Exploring the health information activities of two different BME communities afforded me both the time and space to examine these activities in the depths needed to offer analysis, conclusions and recommendations.

There are several justifications in choosing to research African and Chinese communities in this study, including a rise in the numbers of Africans and Chinese people living in Scotland, continuing to change the ethnic make-up of the country (National Records of Scotland, 2013). Firstly, I believe it was important to undertake this research with Africans, many of whom were forced migrants, individuals who are persistently seen as vulnerable because of their route through the UK asylum system (Scottish Refugee Council, 2011b). I appreciated from previous research with local African populations in Glasgow that health would be key factor in the lived experiences of participants. Trauma experienced in their countries of origin or whilst travelling to the UK, coupled with the stress of applying for asylum all impacts upon the health of asylum seekers and refugees. I believed the relatively new establishment of the African community compared to more traditional communities, such as the Chinese and Asian communities in Glasgow, would make for an interesting comparison. In terms of geographic location, I knew African communities were dispersed across the city and beyond whilst the Chinese community is congregated within the city centre. Again, I thought this would provide interesting differences in how both populations sought and shared health information.

I also wanted to explore briefly how experiences of immigration might impact on patient encounters during health information activities. Since there has been little data collected by NHS Greater Glasgow and Clyde relating the BME patients, the NHS Greater Glasgow BME Health Report (2006) was central in informing me with regards to the health service and information up-take. As a result we know that there is low up-take of NHS services as well as a lack of service knowledge by Chinese populations in Glasgow (NHS Greater Glasgow BME Health Report, 2006). The report also stipulates that when asked if they had adequate health information only 69% of Chinese respondents said yes compared with 80% of the White population (NHS Greater Glasgow BME Health Report, 2006). Meanwhile the report showed that African respondents had a greater appetite for health-related information, whilst also regularly attending community gatherings (NHS Greater Glasgow BME Health Report, 2006). The latter point allowed me to consider how I might engage with this particular ethnic group. In summary, this study focuses on the health information activities of African and Chinese communities because they are diverse but distinct communities, sharing common languages, cultural and religious beliefs, shared heritage as well as lived experiences. The recent arrival of many Africans compared to the long established Chinese community in the city makes for an interesting comparison when exploring ethnicity as an influencing factor in health information activities. Moreover, the 2006 NHS Greater Glasgow and Clyde BME Health Report indicated a gap in the needs of both communities when it comes to more formal healthcare and information provision.

Now it is necessary to introduce these communities in greater detail, to put the social and political environments of these BME communities into context for later findings analysis.

1.9 The History & Health of African Populations in Scotland

Data from the 2011 census indicates 1% of the total population living in Scotland identify themselves as Africa, Caribbean or Black, this is an increase of 28,000 since the last census in 2001 (National Records of Scotland, 2013). Interestingly, Africans have long historical ties to Scotland through the 18th century slave trade and the west of Scotland tobacco industry, but in more modern-times African immigration to the UK has been underpinned by applications of asylum. Post-colonial political unrest and civil conflicts in Sub-Saharan Africa have created internally-displaced persons (IDP's), with the eventual consequence of forcing many outside the region in search of refuge. Traditionally there had been a pattern of asylum applicants from former British colonies, but this immigration pattern is now changing with an increase in applicants from countries with no former link to the UK (Mitton & Aspinall, 2010). Significant proportions of the first generation African population in the UK have come through the asylum process, and we know that forced migration and then resettlement has the potential to negatively affect mental and physical health (Palmer, 2007; Scottish Refugee Council, 2011b). It is therefore important to offer a brief discussion on the context of refugee and asylum seeker settlement in Scotland since this also has the potential to shape health information activities.

The Scottish Refugee Council (2010) estimate that since the 2001 Scottish census nearly 18,000 asylum seekers have been dispersed to Glasgow. Of those newly arrived to Scotland, Zimbabweans, Somalis and Nigerians were amongst some of the largest asylum groups in 2009 (Scottish Refugee Council, 2010). The range of African support groups and networks across Scotland reflects this diversity as well as the population's dispersal across the country. The importance of support networks in the form of support groups and the church was another aspect emphasised to me whilst in the field. For those Africans who came to the west of Scotland as part of the first dispersal there were few support networks and with tensions running high and negative media coverage it must have been a challenging time (Bowes et al., 2009). Research on the role of support networks in the early stages of integration in the case of West Africans in the Netherlands highlighted the crucial role of support groups and churches in providing services, facilitating contact with governmental institutions and promoting human rights with West African migrants (Hamer & Mazzucato, 2009). The Scottish Refugee Council discovered that respondents in their research into integration in Scotland listed local integration networks, refugee community organisations, church groups, and social activities groups as communities out-with their local physical community, that they considered themselves part of and vital to community cohesion (Scottish Refugee Council, 2013b). Likewise, ladies from the Barton women's group in this study also identified with a number of communities. They said they felt they belonged to Barton as a locality because they lived there, the women's group itself, as a community of African women with similar life experiences, as well as their church. These different social spaces have the capabilities to be both supportive but also risky places in which health information activities occur. Consequently, these health information channels offer the opportunity to engage in health information activities, activities this research argues influenced by the ethnic identity of participants.

When it comes to physical health, Taylor (2009) indicates that the physical health needs of migrants reflect patterns of illness and disease in migrant's countries of origin, suggesting infectious diseases such as HIV, Tuberculosis (TB) and Malaria as prevalent amongst immigrants from sub-Saharan Africa. Elam et al., (2001) reviewed health surveys among black Africans living in England and identified that health was seen as a particularly relevant topic for African communities, emphasising diet and exercise along with certain conditions to be of importance. Health conditions of concern included: depression, high blood pressure, diabetes, sickle cell, malaria and skin conditions to mention but a few. Participants did not want to be associated with illnesses such as STIs, HIV or TB, they did not want to openly discuss or admit to such illnesses. In Ndirangu & Evans (2009) study of newly diagnosed HIV women from Africa, they acknowledged African immigrants constituted 36% of those living with HIV in the UK even though at the time of writing the African population consisted less than 1% of the overall population. Moreover, they cite stigma as a clear barrier to testing and social support for HIV positive migrant African women. Figures from the Health Protection Agency report (2012) back the previous point, indicating HIV prevalence among black African women at approximately 50 per 1,000 (data from England and Wales). The report also identifies an increased rate of individuals living with HIV in the African population and subsequently emphasises that safe sex programmes and better access to HIV testing remain a priority (Health Protection Agency, 2012). With these figures in mind it was somewhat unsurprising that HIV and stigma figured prominently for African participants in this study. Reflecting my argument that health and the shifting dynamics of ethnic identity are intertwined. Other health topics of concern for participants in this study included high blood pressure, diabetes, and sickle cell disease, and certainly participants were keen to get more health information on these topics. Both African and Chinese participants in this study talked about the importance of good mental health, of feeling ‘strong’ or having a ‘good’ mood. Analysis of the 2001 census by the Commission for Racial Equality (CRE) discovered that given Africans compromise just over 5% of the total BME population in Scotland, they surprisingly account for 33% of the 1.2% psychiatric patients from BME communities (The Scottish Government, 2005). Furthermore, Mclean et al., (2003) claim,

> “The statistical existence of inequalities in diagnosis and treatment of African-Caribbean’s in the UK is well-established, supported by

> sociological explanations of these inequalities which centre on social exclusion in a variety of forms: institutional, cultural and socio-economic.” (Mclean et al., 2003: 1)

Accordingly, mental health is an aspect which needs to be appreciated in the context of the health needs of African populations. The life experiences of Africans coupled with the potential for poverty, social exclusion and racism in Scotland means a holistic approach to understanding health is very much needed, especially if the health information behaviours of participants are to be appreciated. As previously stated, African migrants initially present in the UK in good health but their health later deteriorates due to past experiences, present circumstances and compounded by difficulties in healthcare access (Ochieng, 2012). One real physical barrier to healthcare is language, English language skills vary hugely between African populations; Nigerians for example speak English as their second language and are taught the language in school, while other Africans, such as the Congolese individuals in this study found they are learning English for the first time compounded for some by their limited primary schooling. Mugisha & Nansukusa (1998) identify this language segregation, suggesting African refugees in their study who could speak English would engage with key health professionals with relative ease, while African refugees with no or limited English skills were not able to develop trusting relationships with health professionals and found health settings daunting. Findings from the NHS Greater Glasgow BME Health report (2006) suggested African and Caribbean respondents reported more problems in setting up an appointment with health professionals, more than any other BME group in the study. Conversely African and Caribbean respondents had more positive levels of satisfaction with healthcare services compared to Chinese participants. Although studies like the NHS Greater Glasgow BME Health report (2006) begin to highlight some of the opinions and health experiences of Africans living in Scotland, there undoubtedly needs to be much more focus on the health needs of Africans within research and amongst service providers before a more complete picture can being to emerge.

1.10 The History & Health of Chinese Populations in Scotland

The latest 2011 census data reveals an increase of 17,000 individuals coming to Scotland who identified themselves as Chinese, Chinese Scottish or Chinese British between 2001 and 2011 (National Records of Scotland, 2013). Yet, the Chinese community does not figure strongly in public policy agendas, has few prominent Scottish Chinese representatives in political or public life and as a community figure little in social research, especially when compared with South-Asian populations in Scotland. At a UK level Chan et al., (2007) emphasises that traditionally, little is known of Chinese communities in the UK, and what is, is usually misunderstood, leaving service provision for the community wanting. Gervais & Jovchelovitch (1998) argue that Chinese communities are often referred to as united, heterogeneous but isolated from other communities in the UK. The largest group of immigrants from China to the UK has come from Hong Kong (Karmi, 1996). Most Hong Kong immigrants came to the UK in search of work in the catering industry between the late 1950’s and 1960’s, after which there was successive immigration to the UK for unskilled workers to work in established restaurants and takeaways. In 1997 a small number of Hong Kong immigrants were then given British citizenship with the transfer of sovereignty back to mainland China (Chau & Yu, 2001). Although the largest Chinese population in Scotland can be found mainly living behind the busy shopping district of Glasgow’s city centre, the population here is nevertheless diverse in its make-up. Just as I have argued that African participants identified with a single collective African community, once deconstructed the concept of the African community is actually made-up of many different African communities coming together. The same is true for Chinese participants in this research. In the early stages of fieldwork I was made aware of the different languages, economic and social standings of these different Chinese groups in Glasgow. Differences based on region of origin, so in this case participants were mostly from Hong Kong Island, with just a few from mainland China and Taiwan.

The majority of participants in this research spoke of their country of origin as Hong Kong and had come to Scotland to work in the city’s Chinese restaurants and takeaways. It has been evidenced that Chinese populations in the UK are geographically dispersed largely because of the need to isolate Chinese restaurants and takeaways in different areas in order to reduce competition (Wong, 2006). However in this research the Chinese populations were dispersed within one area of the city, which has traditionally been viewed as the hub of the Chinese community. This area of social deprivation backs onto the central shopping areas of Glasgow and therefore provides easy access for restaurant and takeaway staff to get to work. Generally members of the community who had either owned a business or worked as interpreters lived outside the city in affluent suburbs but frequently visited the inner city community to be involved in community events this was especially true of the female participants I spoke with. Unsurprisingly, community organisations seemed to play an important role for the participants and community workers I spoke with. Participants listed the Chinese school, two Chinese older persons day-centres and of course the Chinese Community Development Partnership (CCDP) as central places to tap into local services, including Chinese language classes for children, English language classes for adults, Chinese traditional dance classes, choir singing and health talks. With rare emphasis on the role of Chinese Community organisations for Chinese populations in the UK Chan et al., (2007) maintain community organisations (like CDDP in this research) are places where social identity is reinforced, social integration is offered, access to essential public services provided and empowerment encouraged. Thus, as a place where ethnic identity is potential reinforced, health talks at CCDP were valuable in exploring how ethnic identity might influence health information activities.

As with social and cultural understandings of Chinese populations, knowledge about the health of Chinese populations in the UK is limited and sometimes contested (Chau, 2008). Taking the example of diabetes, Bhopal (2007) maintains research on the health of Chinese populations is rare, but by taking local health data we can begin to uncover some interesting findings, citing Unwin et al., (1997) Bhopal (2007) suggests men from the Chinese community are almost twice as likely as those of European origin to have type 2 diabetes. Meanwhile, Zaninotto et al., (2007) claim Chinese men in particular, are significantly more likely to have diabetes than participants from the general population. Conversely, the Scottish Health Survey Topic Report, 2008-2011 suggests Chinese participants along with other BME groups have low levels of diabetes, levels which were not excessively different from the national average (The Scottish Government, 2012a). These differences in statistical data showcase a confusing picture on the health of Chinese populations in the UK. Certainly in the case of this research interviewees and community workers perceived diabetes as a real and urgent health concern, granted this might be a reflection of the aging population I engaged with, but during conversations interviewees described how they self-manage their diabetes through diet and exercise, with one interviewee describing their visit to the diabetes clinic.

Since I wanted to explore some of the different ways participants engaged in health information activities I wanted to briefly investigate traditional Chinese medicine and the part this potential plays in health information seeking and sharing within this ethnic group. Contemporary research indicates that traditional Chinese medicine is used in a flexible way in conjunction with western services, while for serious concerns the GP is still the first point of contact (Yu, 2006; Green et al., 2006). However, when it comes to NHS engagement there is historically a low up-take of healthcare services by Chinese communities several factors seem to influence this pattern. Chau et al., (2011) explain how language difficulties offer a barrier to accessing healthcare compounded by health services not culturally sensitive to the diverse health needs of Chinese communities. Within a Glasgow context there have been two relevant pieces of research over the last two decades, these include Liao & McIlwaine (1995) who explored the health needs of the local Chinese community in Glasgow and the NHS Greater Glasgow BME Health report (2006). Research findings from Liao & McIlwaine (1995) study offers fascinating insight into the health concerns of the community. The most significant finding argues that Chinese populations in Glasgow underuse health services, a pattern which was again recorded over a decade later in the NHS Greater Glasgow BME Health report (2006). Within Chinese populations Chau (2008) describes older people, women, and middle-aged men working in the catering industry, as those most vulnerable to exclusion from health services. Similarly, participants from the Liao & McIlwaine (1995) study also indicated language barriers to healthcare services, thus a shared language as part of Chinese ethnicity has the potential to act as a barrier to health information activities, a point discussed in more detail in preceding chapters.

Finally, the NHS Greater Glasgow BME Health report (2006) indicates a lack of knowledge within the Chinese community regarding NHS services, notably though, the survey did not ask Chinese participants about language difficulties which is a major oversight, as language in this and previous research offers a critical obstacle to healthcare access (Chau, 2008; Lai & Chau, 2007; Tran, 2006). The rest of the report mirrors general understandings of the health of Chinese populations, that they consume plentiful amounts of fruit and vegetables each day, that they weigh less but do less exercise compared with White populations (this may reflect the long working hours of Chinese catering staff). When it came to health information Chinese participants were interested in getting information on a range of topics including nutrition, cancer, heart health and mental health. The report therefore offered a constructive if preliminary insight into the health of Chinese populations living in Glasgow. Undoubtedly there needs to be a reversal in the rare phenomenon that is health research with Chinese communities, especially if healthcare services are to establish roots in the community and offer tailored service provision. Now that the wider setting of Scotland has been presented, and the two BME communities included in this study contextualised, it is now essential to offer brief insight into each thesis chapter.

1.11 Chapter Breakdown of Thesis

Each chapter in this thesis builds to offer an appreciation of the academic debates, theoretical frameworks and experiences of participants as well as the health and social policies in Scotland. The next chapter to follow is chapter 2, with a literature review of all relevant scholarly debates. Chapter 2 begins by locating the main sociological debates in the field of health inequalities, and more specifically health inequalities confronted by BME populations living in the UK. Attention then turns to the work of Goffman focusing on his influential creations: The Presentation of Self in Everyday Life (1959) and Stigma (1963). Understanding social interaction as meaning and the idea of performance on a front and back stage are considered. Goffman's (1963) concept of the spoiled identity is then deliberated with particular emphasis on the ideas of passing and courtesy stigma. The next area of interest to be scrutinised comprise of two key sociological concepts; that of race and ethnicity. Understanding the socially constructed realisations of race, ethnicity and racism are important theoretical foundations to later discussions in chapters 4, 5, 6 and 7. Finally the literature chapter introduces information behaviour theories focusing mainly on Chatman's information poverty (1996) but also bring in Fisher's (Pettigrew, 1999; Fisher et al., 2004a) information grounds to add a contextual dimension to discussions of health information seeking.

Chapter 3 begins with the research philosophy of this study and then describes the research methods used to collect qualitative findings and quantitative data during my fieldwork. The driving philosophy behind this investigation embraces an interpretivist stance, and this is subsequently outlined at the beginning of the chapter. Key research methods adopted in this study are then presented along with justification for the combination of methods and practical outcomes in the field. Research settings are discussed with descriptions of the places and people central to this work. Since nearly all interviews with Chinese participants were conducted with the aid of an interpreter the role of interpreters and translators is briefly considered. A large part of the chapter is then given over to discussions on ethical considerations for this research as well as providing some reflexive commentary on my role in the field. The last part of the chapter centres on preparing the reader for the subsequent findings chapters, its details the sample methods used, the questionnaire exercise, the semi-structured interviews along with the participant observation exercise. The chapter is concluded with some brief commentary on how data and findings from the field were analysed and how they will be presented in the next four chapters.

The first findings chapter, chapter 4 concentrates on the first research question of this thesis, exploring the social and cultural aspects of health information activities, spotlighting the barriers as well as the strategies that participants employ to by-pass the obstacles they confront. To root research findings, discussions on community and support networks as well as attitudes to health are firstly presented; this offers the reader a general introduction to the lives of participants. Attention then narrows to examine the health resources of participants, looking at their use of traditional medicine, NHS services and the role of frontline staff in accessing formal services. Since participants indicated that their GP was their main source of health information provision space is given over to consider some of the social and cultural aspects of the doctor-patient relationship. Goffman (1959) denotes that meaning from social interaction is built on past experiences therefore the past experiences of participant's country of origin and their healthcare systems is given brief consideration. Finally the chapter is wrapped up with commentary on three key social and cultural aspects which emerged whilst in the field. The notion of health ownership, stigma and privacy are all evidenced and continue to figure throughout later findings analysis.

Chapter 5 assesses the socio-economic factors involved in health information activities and therefore looks to answer the second research question of this thesis. Education, literacy and language compose a large part of the chapter with attention on the impact of limited education and literacy but most importantly on participants' lack of developed English skills and its subsequent impact on the exchange of health information in healthcare encounters. To complement this, a discussion on the use of interpreters in such settings is also provided. The chapter is then concluded with commentary on the experiences of participants and the digital divide; as witnessed in the field.

Chapter 6 scrutinises the role of technology in the health information activities of participants, in order to answer the third research question. Dialogue begins with a look at the internet and how participants employed the internet in their health information activities. Different types of health information online are explored, questioning issues of trust and the role of more formal health information via the NHS online. The idea of legitimacy and the role of the doctor compared with online facilitates is then deliberated before attention turns to the concept of eHealth and the role it has to play in health information activities. eHealth in this research is understood as, NHS online, telehealth (NHS 24), mHealth and health information kiosks. In this inquiry participant's views and experiences are analysed in conjunction with current policy developments and the potential for future engagement with eHealth.

The final findings chapter, chapter 7 uses Chatman's information poverty to respond to the final research question, asking if information poverty is evident? The overwhelming response is that aspects of information poverty were evident in the field. Each proposition in Chatman's (1996) theory is analysed in conjunction with research findings to offer justification for this response. Specific focus is again given to the role of technology in order to explore information poverty through the application of the internet. A present-day admirer of Chatman, Fisher (Pettigrew, 1999; Fisher et al., 2004a) and her theory of information grounds is then employed as a conceptual tool to explore the physical and social contexts of health information seeking, especially in communal settings.

The concluding chapter assesses the thesis as a whole, bringing all the different and interwoven elements of this investigation together. Chapter 8 therefore begins with a key findings summary, condensing each chapter to highlight the main themes discovered whilst in the field as well as presenting consultation on the theoretical concepts proposed by both Goffman (1959, 1963) and Chatman (1996). The chapter then moves on to outline the rewards in using both theorists to gain better insights into health information behaviours and performances. The overall limitations and strengths of this research project are then presented. Limitations in the research sample and possible concerns relating to transferability along with practical limitations regarding the use of research methods are detailed. The core strengths of this research, include its interdisciplinary style and its potential for impact, both within academia and public policy, are then outlined. Next, research recommendations are described, offering future researchers, policy makers and community members proposals on how to encourage environments for health information activities; opening up access and pursuing equality for all BME populations with particular emphasis on the potential of eHealth to act as an equalising force in health inequalities. This thesis then closes with a concluding statement bringing together every component of this research to offer relevant and hopefully though-provoking commentary on the health information activities of African and Chinese populations living in the west of Scotland.

Chapter 2: Literature Review & Theoretical Context

2.1 Chapter Introduction

In deciding what theoretical concepts should be included in this review, it was essential to breakdown every element of this study to determine which areas merited greater theoretical focus in order to link together key research themes to scholarly debates. Initially I undertook a broad scooping exercise within the disciplines of Sociology and Information Science. I began with introductory literature from both disciplines identifying key academics and sourcing primary material. Primary material included: key academic texts, journal articles, research reports as well as official statistical data. To keep this literature review relevant, I had to continually compare and contrast different academic viewpoints within the boundaries of this study's focus. Some elements of this literature review provided a backdrop, informing me as the researcher on what themes I should consider and explore whilst in the field. Other elements meanwhile, provided a theoretical backbone to the study. An example of this is seen in Chatman's information poverty, which provided a framework to compare research findings. Showcasing previous research central to both disciplines highlights the space in which this multi-disciplinary research fits; the gap it seeks to fill.

2.2 Identity and Health Inequalities

> "Human fate still rides upon ancestry and appearance. The characteristic of our hair, complexion, and facial features still influences whether we are figuratively free or enslaved." (Haney-Lopez, 2000: 164)

Since this research explores how different social and cultural aspects of ethnic identity shape health inequalities it is necessary to offer theoretical definitions of both ethnicity and race. Within the discipline of Sociology race is understood as socially constructed, but nevertheless remains a controversial concept. With its roots in religious segregation, social Darwinism and colonialism, race has inevitably become heavily contested in academic discourse. Payne (2006) discusses the uneasy relationship sociologists have with the term race; he observes that some sociologists persist in using the phrase primarily because social actors continue to employ and organise their lives around the term as well as it being entrenched in public policy and legal terminology (Rex 1996, Gilroy 1987, Banton, 1998). Certainly in this research participants and gatekeepers referred to themselves as 'black' and since I am adopting an interpretivist approach I wanted to examine race as part of ethnic identity when exploring health information activities.

Miles and Brown (2003) claim that there is no hiding from the concepts dirty past and that by continuing to use the term race, academics only legitimise a concept which should have been consigned to the dustbin of analytically useless terms. This straight talking from Miles (1982) and later Miles and Brown (2003) provide a convincing argument, although, their neo-Marxist approaches are often attacked for their class reductionalism and emphasis on race as solely a political construct (Back & Solomos, 2009, Payne, 2006). Meanwhile Mason (1994) argues that race and racism are entangled concepts which are socially linked and as such should be sociologically explored. Instead of wiping away race from theoretical analysis, Mason (1994) takes up the argument to labour the point that race as a concept should still be employed because both race and racism are mutually exclusive. Mason (1994) also claims that race has never purely relied on scientific justification but rather harboured structural positions and symbolic representations which have re-enforced exclusion. Ultimately, Mason (1994) argues that race is a social relationship that must be understood in terms of its association with racism.

As scholars continue to debate the concept of race, ethnicity and its inclusion of religion, language, heritage, shared values, beliefs and national identity has become increasingly popular in the social sciences (Bhopal, 2007). As a result it is ethnicity as a concept which offers a much more multifaceted idea of identity and which is extremely valuable to this study. Allowing me examine language, religious attitudes, shared cultural values and beliefs and how these aspects of identity impact upon the health information activities of participants.

Barth (1969) best denotes ethnicity as a subjective process of group identification which leads to an exchange of ethnic labels both through ascription and internal self-identification. This then leads on to a continual negotiation of boundaries between differing groups, a point also raised by Nazroo (1998). Significantly for Hall (1996), ethnic and racial identities are encompassed within the notion of cultural identity, which is born out of difference. To have a solid cultural identity within one ethnic group, a comparison with the 'other' must be made. Hall claims,

> "Throughout their careers, identities can function as points of identification and attachment only because of their capacity to exclude, to leave out, to render 'outside', abjected." (Hall, 1996: 5)

Hall (1996) emphasises that identities are constructed forms of closure which through unspoken rules highlight the 'other'. Although identities are traditionally portrayed as social structures which bind people together under commonality, ultimately, Hall (1996) is advocating an understanding of identity which is constructed through difference. Hall (1996) is proclaiming that to have a solid cultural identity a comparison is made, an acknowledgement and even celebration of difference, is played out. It is important to appreciate that identity and the labels stuck onto identity are not produced in isolation. Hall (1996) acknowledges the importance of discourse in the formation of identity, he claims identities are constructed within discourse, discourses that are produced and reproduced in historical and institutional sites. Utilising Hall's (1996) interpretation, it can be argued that difference is at the heart of a multicultural society and is consequently reflected in society's language, reflected in its discourse (van Dijk, 1997). Each group in society has its own series of social norms, values and language which come into contact with each other through discourse; through talk and text (van Dijk, 1997). Taking the idea that each group in society has its own series of social norms, values and language, again affords this research the tools needed to unpick different aspects of ethnic identity which influence health information activities.

This research has incorporated concepts of both race and ethnicity to explore how they impact on health information activities, including patient encounters, social networks, ideas of health and wellbeing as well as notions of stigma and privacy. Bhopal (2007) acknowledges the advantages, as well as, the limitations of using the concepts of race and ethnicity in health inequalities research. Senior & Bhopal (1994) identify the tensions in applying race and ethnicity. Firstly they highlight the issue of heterogeneity within BME groups and argue that simple ethnic categorisation overlooks diversity. Secondly, that the use of race and ethnicity encourages ethnocentricity from health researcher, and finally that both concepts have potentially damaging consequences if used irresponsibly. On the other hand, Bhopal (2007) does concede that race and ethnicity are two of the many ways in which humans differentiate themselves from one another, and are especially valuable when comparing the health and health statuses of differing members of society, he ends with a warning to health researchers, that whilst employing the concepts of race and ethnicity, that we as the research community need to continue to make sure the benefits outweigh any potential harm. One way to achieve this is to continue to investigate and question the disparity in health outcomes between ethnic groups in society.

According to Graham (2007) health inequalities vary over space and time, and can be cast in the frame of individual differences in health and differences in health between ethnic groups. Bhopal (2007) suggests rather than purely exploring health inequalities from the perspective of socio-economic differences which has traditionally been the case, health inequalities can and increasingly are being explored through other social inequalities, including: age, gender, race and ethnicity. Ahmad & Bradby's (2007) further this call, stating the need for wider research beyond simply measuring of health inequalities between the majority white group and BME populations in the UK.

Nazroo's work (1997; 1998) was amongst the first to begin investigating links between ethnicity and socio-economic status, the impact of migration, geographical location and experiences of racism and health. Smaje (1996) also makes the case for a conceptual understanding of ethnicity within health research; an account which views the concept as both identity and structure. Nazroo (1998) agrees with an identity/structural understanding of ethnicity and further suggests ethnicity can be signified by the notion of the 'other'. The complexity of ethnicity as a concept, with its fluid and contextual character, as well as, its positioning within pre-established identities, and its subsequent relationship with health inequalities is emphasised by Nazroo (1998). Conventional debates on health inequalities have taken either a material/structural or cultural/behavioural approach. Although, Smith et al., (2000) offers caution to crude cultural/behavioural assumptions as this can often led to patterns of cultural blaming, what Bradby & Nazroo (2010) refer to as the majority population identifying cultural differences of minorities as the "problematic difference."

Sociological discussions have increasingly taken account of the complexities of the social context in which health inequalities occur (Karlsen & Nazroo 2002; Karlsen & Nazroo, 2009). At a Delphi exercise including academics, policy makers and practitioners, agreement was formed regarding key principles that researchers should consider when investigating health and ethnicity. It acknowledged that various social factors such as religion, migration, culture, discrimination, language as well as socio-economic aspects all have the potential to influence the relationship between ethnicity and health (Mir et al., 2013). This finding underlines the central aim of this research, to offer a snapshot of how social, cultural and socio-economic factors influence the relationship between ethnicity and health information activities.

This study considers how ethnicity impacts upon health information activities and subsequently explores patient encounters with the NHS. Healthcare provision for BME populations specifically has been given an increasing amount of consideration (Ahmad & Bradby, 2007; Bhopal, 2007; Bhopal, 2012). Bhopal's seminal work (2007) identifies institutional racism and stigma as two profound barriers in healthcare provision. On a broader level he acknowledges that many societies see BME populations as persistent burdens upon society, including public provisions such as healthcare systems. Bhopal (2007) also demonstrates the various channels through which racism and stigma occur in healthcare, arguing that: individuals can encounter personal racial prejudice from staff, whilst healthcare policies can overlook the needs of the minority in favour of the majority. Moreover specialist resources although needed, might not exist, and finally that racial discrimination throughout the ranks inhibit BME individuals from employment within healthcare. Institutional racism and discrimination within healthcare provision has also been linked to immigration status, previous research has focussed on identity linked to race, ethnicity or religious affiliation but identity based upon legal status has also been found to be a source of far-reaching discrimination, especially for failed asylum seekers who are often in desperate need of mental health interventions (Netto et al., 2011; Scottish Refugee Council, 2013a). Underpinning healthcare provision for BME populations in this study is the need for reliable, evidence based, culturally sensitive health information. All patients have the right to access good quality health information to inform lifestyle choices and make decisions about their health (Shepperd et al., 1999). Therefore, irrelevant health information or limited access, I would argue, compounds health inequalities faced by BME populations. Interestingly in his assessment of culturally sensitive healthcare systems in Scotland, Bhopal (2012) acknowledges the positive steps forward in the development of Scotland's Ethnicity and Health (Fair for All) policy, where for this research, issues of access, services delivery and community development for ethnic groups are particularly relevant. There is caution however, as Bhopal (2012) maintains there are still real obstacles to overcome.

2.3 Social Interaction & Goffman

Symbolic interactionists (Cooley 1902; Mead, 1943; Blumer 1969) insist humans associate meaning to objects, actions and others based upon the personal meanings they have already been ascribed; meaning is therefore derived from previous social encounters with others. People do not simply react to each other's actions they react to the meanings associated with action. As a result, humans are on a daily basis, following a maze of symbols and interpretations, mastering the meaning of each another's actions (Blumer, 1969). Employing symbolic interactionism as a theoretical underpinning empowers this research to uncover meanings associated within the social interaction of health information performances. As health information seekers search the social world for information they will tap into predetermined meanings associated within their social encounters.

Averse to the label symbolic interactionism, and proposing instead for the development of a whole new domain of behavioural analysis, Erving Goffman's work continues to offer a unique tool in understanding human social life (Giddens, 1988). His concepts explore how individuals navigate their way through a daily labyrinth of social encounters, and as such offers a useful means in understanding the social interactions of health information seekers. Ultimately, Goffman's purpose was to understand the self as a social product: a product of social performance, as well as social constraints and validation played out within the norms of a stratified society (Lemert & Branaman, 1997). This understanding of social interactionism offers a crucial tool in unpicking the meanings behind health information activities. Lemert & Branaman's (1997) perception of Goffman's work (1959) would imply in this study that health information seekers are products of previous health information performances, manipulated by social constraints but also empowered by positive experiences; played out within the expected norms of a stratified society. Interestingly, Goffman's (1959) idea of the individual as a social product connects with Chatman's (1996) information poverty theory in that information seeking occurs in a social context with often hidden restrictions. Goffman (1959) therefore might have argued that Chatman's (1996) descriptions of self-protecting behaviours displayed by information seekers were accounts of front stage behaviour. Behaviours viewed as performance management in the stage-play of information seeking, especially when the health topic being sought is potentially sensitive, or the setting in which seeking is taking place is perceived as risky. Goffman's theatrical metaphors imaginatively express the complex processes occurring during face-to-face encounters, he emphasises the need for individuals to present themselves in socially acceptable manners, acceptable to their social role, status and norms. Goffman proposes,

> "Sometimes he will intentionally and consciously express himself in a particular way, but chiefly because the tradition of his group or social status require this kind of expression and not because of any particular response (other than vague acceptance or approval) that is likely to be evoked from those impressed by the expression." (Goffman, 1959: 18)

Goffman (1959) therefore outlines the need for individuals to present themselves in expected and appropriate manners akin to the tradition of their social status or group. Ethnographic fieldwork in this research has uncovered such behaviours, which again underlines the appropriateness of adopting Goffman's theoretical perspectives. Once again there are links with Chatman's (1996) information poverty; in her propositions Chatman (1996) identifies information leaders as having a central role in selecting and allowing new information to be channelled to insider group members. Goffman (1959) analysis would suggest that this behaviour by an information leader would be an act of conformity, expressions expected of an individual with insider group leader status. Behaviour of this kind is evidenced in chapter five in participant observation analysis of the Barton women's group. Goffman's focus on the 'personal front' which comprises the expressive equipment which is attached to the performer and consequently influences how the performer is perceived by their audience is also pertinent to this discussion. Lemert & Branaman explain,

> "As part of the personal front we may include: insignia of office; clothing; sex, age, and racial characteristics; size and looks; posture; speech patterns; facial expressions; bodily gestures; and the like." (Lemert & Branaman, 1997: 98)

If, as Goffman's (1959) suggests, the personal front influence the audience then undoubtedly it has the potential to influence health information activities. There is the potential to influence the role of the performer, in this case the information seeker and the audience, which might include health professionals, family members, friends or community workers.

There is a growing body of research on the health inequalities of BME populations, coupled with a tradition of sociological inquiry exploring the doctor-patient relationship (Heritage and Maynard, 2006; Parsons, 1975). However, there is still limited analysis specifically investigating BME patient encounters with doctors (Cooper-Patrick et al., 1999). From what limited research has been conducted, especially over the last decade, highlights negative experiences (Campbell et al., 2001; Lyratzopoulos et al., 2012; Peck & Denney, 2012). From a systematic literature review of existing evidence, Ferguson & Candib (2002) propose that race, ethnicity and language all directly affect the quality of the doctor-patient relationship as well as medical outcomes, pinpointing a lack of sufficient health information offered during encounters.

Contemporary scholars exploring social interactions have continued to utilise Goffman (1959) and his original work, as well as adapting some of his understandings for new investigations of the social world. Burns (1992) acknowledges Goffman's appreciation of the potential for communicative technology to change social interactions, and so academics have been quick to consider how the internet and more specifically social networking might change social interaction, social networks and performance management (Dutton, 2010; Kavanaugh & Paterson 2001; Rheingold, 1994; Turkle, 1996). Moreover, Goffman's notion of the 'presentation of self' has been explored through online identities and social interaction (Miller, 1995; Pinch, 2010; Bullingham & Vasconcelos, 2013; Dell & Marinova, 2007). The notion of self-presentation as performance with an audience does not diminish within a virtual setting; on the contrary, social networking and media as well as online forums are settings whereby the actor once again takes to the front stage (Miller, 1995). Since, this research will also consider the use of the internet to simply attain health information, minus a virtual audience it could be argued that the internet in this scenario might provide a setting where information is acquired without the need to enter into performance management. This back stage activity might prepare the performer to engage in social encounters in the front stage, with the benefit of offering the opportunity to attain health information in an informal safe environment without the scrutiny of an audience. Goffman's work (1959) The Presentation of Self in Everyday Life, offers several theoretical stages upon which to analysis qualitative outcomes in chapter four, but, before concluding this section, it is important to briefly highlight some of Goffman's major critics. Although hugely influential across many disciplines Goffman's work does have its challengers (Gouldner 1971; MacIntyre, 1981). Drew & Wootton (1988) contend Goffman's (1959) account of social interaction plays little significance to social structures, and although he discusses the 'personal front', he nevertheless does little to acknowledge the influences of social structures such as class and power, a point also echoed by Gouldner (1971). Another criticism is that Goffman (1959) conducted this work based on extensive reading but limited primary research, while providing no standardised framework for future academics to work with (Lemert & Branaman, 1997). Perhaps his fiercest critic, MacIntyre (1981) proposes that Goffman (1959) reduces the self to an empty role playing form, which is left occupying no social space. Yet, warts and all, Goffman's work (1959) undoubtedly still has much to offer contemporary sociologists, as our social world continues to change, Goffman endures, continuing to provide us with the tools needed to unravel meaning in our daily interactions. This thesis has not sought to strictly apply all aspects of Goffman's dramaturgical model, as it does not seek to explore solely the presentation of self in health information seekers.

Instead it wishes to adopt Goffman's general concept of performance management; that individuals wish to present an 'acceptable person' when engaged in health information activities, and so they must conform to social roles, statuses and norms. Moreover, utilising Goffman (1959) in this manner affords room for Chatman's information poverty framework; both of which will be interwoven through fieldwork analysis presented in the findings chapters of this thesis.

2.4 Stigma

Goffman's (1959; 1963) legendary analysis of the presentation of self would later consider what happens in social encounters when an individual's identity is perceived as 'spoiled'. For Goffman (1963) stigma is the management of a spoiled identity; that individuals with a perceived stigma will attract societal reactions that encompass negative moral connotations and deviant labels to create uneasiness in social encounters (Williams, 1987). Goffman (1963) presents three central stigmas: that of the body, character and social collectives, in this study focus is given to all three. How aspects of ethnicity, such as shared religious and cultural beliefs might impact understandings of the body with consequences to health information seeking activities is important. An example of this can be seen in cultural and religious views on certain illnesses with the risk of stigmatisation may alter participants' behaviour when looking for health information. In addition, how participants view health professionals' perceptions of them and their ethnic group will be interesting, since previous healthcare encounters will undoubtedly shape health information seeking behaviours.

During his discussions Goffman (1963) draws attention to the social construction of health, illness, and disability as he focuses on the difference between the virtual social identity and the actual social identity of individuals. With regards to health related stigma, Scambler (2009) acknowledges that HIV as a chronic illness elicits strong emotive reactions; he argues that negative moral associations and deviant labels are shackled to individuals with the virus. While Carlisle (2001) addresses the need for many HIV positive people to conceal their health status this behaviour Goffman (1963) labels as ‘passing’. To appear to the social world as ‘normal’ and surpass any societal judgements and rejections the individual may face. Fear of disclosure is therefore reinforced by the potential loss of vital support networks, that of family members, friends, colleagues, neighbours, who may judge or reject the individual, and for those who do not, there is the potential for what Goffman phases as ‘courtesy stigma’. (Carlisle, 2001) Stigma is therefore compounded by fear and shame; fear for the individual themselves and the consequences of dealing with a spoiled identity as well as fear of courtesy stigma, subsequently the daily grind of passing is needed to conceal any links to a stigmatised illness. Scambler (2009) calls for a re-framing of the notions associated with stigma, suggesting stigma should be seen as a fluid and changeable dynamic set between cultural norms of shame and blame, always embedded in social structures of class, command, gender, ethnicity etc. Scambler (2009) is making the case that although Goffman’s (1963) work remains important, sociologists can no longer afford to ignore the social structures which dictate cultural norms and shape the ever changeable concept of stigma. Subsequently this study follows Scambler (2009) call to explore stigma and ethnicity in this sociological consideration of health information activities by African participants.

Above and beyond historical stigmas associated with race and ethnicity is the practice of immigrant identity which is habitually linked to stigma management (Knudsen, 2005 cited in Valenta, 2009). It can be argued that negative connotations are bound-up in the immigrant identity this is especially true for those with the asylum seeker label Hynes (2011) suggests a subsequent desperation forms for the label to be removed and a different self to be presented to the settled community. In social interaction where stigma has the potential to interfere in proceedings, power becomes an important aspect to recognise, in many ways stigma is dependent on power (Link & Phelan, 2001). This research uncovers power imbalances between health information providers and seekers, through false impressions as well as stereotypes. In Goffman’s own words stigma is essentially “not persons but rather perspectives” (Goffman, 1963: 163).

2.5 Sociology of Technology

> "…the significance of digital inequalities is clear across a broad range of individual-level and macro-level domains, including life course, gender, race, and class, as well as health care, politics, economic activity, and social capital." (Robinson et al., 2015: 569)

Since technology, and more specifically the internet, plays a crucial role in health information activities, it is important to offer a brief overview of its impact on society and how sociologists have responded to its influence. By the mid 1990's a growing number of UK families owned a personal computer and had increased access to the internet. Yet, it was the expansion of broadband, from 2002 onwards, which provided the driving force for the infiltration of the internet into everyday lives (Gunter et al., 2009). In the last few years the access capabilities of the internet have undoubtedly opened up, with tablet computers and smartphones using WiFi and 4G technology to offer instant connections in more accessible locations than ever before. Yet, the true meaning of access in relation to information communication technology and the internet is not equal for everyone (West, 2011), those in society who face poverty and social exclusion are now shackled with a digital exclusion (Burton, 2014).

Ragnedda & Muschert (2013) maintain that Sociology as a discipline has been slow to contribute to the debates on the digital divide, they find this surprising since social stratification has traditionally been a dominate aspect of the discipline. However, Ragnedda & Muschert (2013) do contend that this trend is changing with the divide now being studied from varying viewpoints. Hence with a growing interest in social stratification and the internet has come a call for a more holistic understanding of the social and political dynamics of the digital divide (van Dijk, 2013, 2005; Robinson, 2015; Warschauer, 2003; Mehra et al., 2004). van Dijk (2005, 2009, 2013) argues that language problems, the absence of culturally sensitive material, as well as limited computing skills, as factors which re-enforce the digital divide for BME populations. Certainly participants in this study discussed many of these aspects of the digital divide yet there were some surprising ways in which they engaged with technology while partaking in health information activities. Thus, rather than continuing to emphasis economic inequalities as the root cause of the digital divide, I would agree with academics such as van Dijk, (2005, 2013) and Robinson et al,. (2015) who propose a comprehensive re-analysis of the divide, what van Dijk (2013) now terms as the 'deepening divide'.

Undoubtedly the internet has sparked an explosion of information and communication, today the internet propels political agendas and social movements; changes social spaces and impacts upon individual and group identities (Cavanagh, 2007). There are empowering and equalising opportunities produced by the internet for BME groups, opportunities which have the potential to resist against continuing social inequalities. Accordingly, Lash (2002) has discussed the 'levelling' effect offered by the internet; whereby social status and normative behaviour can be segregated from the physical world. The bounds associated with social status and identities are therefore reinvented online. Moreover, Turkle (1996) claims the advancement of technological mass media and communication witnessed in the expansion of the internet leads to a freeing of knowledge and its' creation and subsequently an emancipation from traditional social statuses. However, not all academics agree with this level of freedom being associated with the internet. Although Castells (2001) likens the internet to the electricity of the industrial era, he also warns,

> "The internet is indeed a technology of freedom-but it can free the powerful to oppress the uniformed, it may lead to the exclusion of the devalued by the conquerors of value. In this general sense, society has not changed much." (Castells, 2001:275)

Lin and Atkin (2007) outline why Castells (2001) believes the internet is not an emancipatory tool within society, by insisting Castells (2001) and Rheingold (1994) view power and the internet as being inseparable, they argue that power does not simply disappear with the expansion of the internet; on the contrary they maintain that the powerful in society exploit these new media portals to maintain control (Castells, 2001 & Rheingold, 1994 cited by Lin and Atkin, 2007: 32). Ultimately, Castells (2001) is arguing that the internet is socially produced and culturally informed, shifting from the customary deterministic view of technology, to understand how power and social constraints play-out within the network society.

Significantly in terms of ehealth, Robinson et al., (2015) claim it is disadvantaged groups, such as those involved in this research, who experience poor health outcomes who are most likely to lack the access, skills and motivations associated with the uptake of ehealth tools. Suggesting Castell's (2001) views on power and equality on the internet are reflected in the experiences of BME populations and their restricted use of ehealth. Robinson et al., (2015) contend that much more in-depth research is therefore needed to fully understand these how existing inequalities shape ehealth interactions. Finally Robinson et al., (2015) maintain that future research needs to address the potential for mhealth in bridging digital and ultimately health inequalities for disadvantaged groups. This final thought regarding mhealth proves to be valuable when discussing online health information activities with African and Chinese participants in later empirical work.

This discussion will now focus on the sub-discipline of information seeking behaviour which sits within the field of Library and Information Science. Models of information seeking behaviour examine the varied ways in which people seek out, utilise and ultimately share information. Two key theories information poverty and information grounds have both been central to this investigation, offering theoretical frameworks within which data from the field can be compared. In the founding decades of the discipline, focus was centred on the many processes involved in information seeking, however as the discipline has matured, its theoretical understandings and research methods have diversified (Wilson, 2010). Dervin's (1986) game-changing 'sense making' theory offers a shift away from a process centred understanding of information seeking to a person centred perspective, labelled as 'information behaviour'. The seekers' perspective within a social, cultural, physical and increasingly online context has subsequently become a primary area of research for this area of investigation (Metoyer-Duran, 1993; Pettigrew, 1999; Fisher et al., 2004a; Fisher et al., 2004b; Savolainen & Kari, 2004).

2.6 Chatman & Information Poverty

> "...despite the current focus on living in an "information age", we have limited evolutionary understanding of human information behaviour." (Spink & Cole, 2006: 25)

While Goffman (1959; 1963) offers a broad sociological and theoretical context in which to situate this research, the work of Elfreda Chatman (1996) offers a micro level comparative framework. Goffman's work (1959; 1963) focuses on the dynamics of social interaction; whilst Chatman (1987, 1991, 1999) pinpoints and explores the specific social actions of information seeking. Interestingly Chatman (1996) utilises Goffman's concepts (1959, 1963) in her own discussions of deception and the socialisation processes involved in information seeking; therefore the pair seem well-suited for this study.

Contemporary information scientists continue to be influenced by the social sciences; being inspired by theories of social constructionism as well as utilising ethnographic research techniques. As far as Bates (2010) is concerned a new phase is developing in the field of information research with Savolainen's (2007) argument that information researchers need to adopt a term which has a wider appreciation of the social and cultural factors which influence all information activities, calling on the discipline to use the concept information practice rather than information behaviour. Savolainen (2007) argues that information behaviour focuses primarily on the cognitive approaches of information seeking however he does recognise that researchers such as Fisher et al., (2004a) and Chatman (1996) offer examples of research inspired by social constructivist ideas which still locate themselves under the broad term of information behaviour. Significantly, Savolainen (2008) concept of everyday information practices is inspired by Bourdieu's (1990) theory of habitus to emphasise the influence of a socially and culturally determined system of thinking internalised by individuals when seeking, using and sharing information in everyday life. A discussion of information practices along with analysis of key research findings is offered at the end of chapter 7.

Sociologically trained, Chatman (1996) was undoubtedly a pioneer in exploring the social contexts of information seeking. Chatman's work examined vulnerable groups, who were often marginalised and generally underserved in society and found that rather than being information poor because of economic poverty, information poverty was radically shaped by socially regulated attitudes and norms (Burnett et al., 2006). Using a theorist who understood the importance of socialisation in information behaviour was essential to understanding how ethnicity impacts health information activities. Chatman's years of ethnographic work included examining the information seeking behaviours of women enrolled on a subsidised employment programme (1987), janitors working in a university (1991), women living in a retirement community (1992), and female inmates at a high-security prison (1999). Drawing on some of her previous research Chatman (1996) produced the conceptual framework of information poverty, a theory which primarily uses the functionalist approach of Robert Merton (1973) and his concepts of social roles, specifically insiders/outsiders. To truly understand the theoretical underpinnings of information poverty, a brief examination of Merton's (1973) contribution is therefore necessary. As a student of Parson's, Merton (1973) utilised Parson's philosophies and adopted a middle range functionalist perspective. Crucially, Merton's (1973) functionalism acknowledged that not all parts of a modern society would labour as a functioning union. Instead, Merton (1973) admitted that in any contemporary society elements of the dysfunctional could be found in social institutions, norms, values as well as its' belief systems. Central to Merton's (1973) theory is his model of insiders and outsiders, maintaining that insiders are members of specific groups and collectives who occupy specific social statuses.

Chatman's (1991, 1996, 1999) work embraces Merton's (1973) insider/outsider statuses, interpreting the insider group specifically as a collection of individuals who have shared experiences as well as a shared environment. Chatman (1996) argues that this leads the insider group to develop their own unique cultural behaviours and consequently produce social norms which in turn influence the amount, type and acceptability of information being accessed and shared by the group. This produces a situation whereby some information can only be fully understood by other insiders. Utilising this theory allows me to explore insiders and outsiders statuses within the context of ethnicity, essential to later discussions of the health information activities of African women in the Barton group. Information poverty allows me as the researcher to therefore unpick the various aspects of ethnicity such as language, shared cultural and social beliefs and how they impact on health information activities.

Notably, Merton (1973) emphasises the flexibility of insider and outsider statuses,

> "…individuals have not a single status but a status set: a complement of variously interrelated statuses which interact to affect both their behaviour and their perspectives." (Merton, 1973: 113)

Crucially Merton (1973) claims that all individuals will be both insiders and outsiders dependent upon context. Merton (1973) maintains that individuals switch between their statuses dependent upon the situation they find themselves in. Within defined insider groups or for that matter outsider groups, individuals will follow expected patterns of behaviour, adopting the values and norms of the group. Although, Merton (1973) is quick to point out that although sociologically defined, the boundaries between insiders and outsiders are not permanently fixed. He maintains,

> "As the situations involving different values arise, different statuses are activated and the lines of separation shift." (Merton, 1973: 120)

Merton's (1973) insider/outsider model therefore allows sociologists to accommodate for social change and conflict, although it stops short of explaining its origin or place within society. Ultimately, Merton's (1973) insiders/outsiders is a middle range theory offering a means by which academics such as Chatman can begin to explore the social world. To produce the framework of information poverty, Chatman reflects on years of ethnographic research to pinpoint overarching social behaviours and social traits. Hersberger explains,

> "Chatman traced the evolution of many of her previous studies into three new middle-range theories that better explained her lifelong observations of information seeking by various populations in an everyday life context." (Hersberger, 2006: 75)

Primarily Chatman (1991, 1996, 1999) undertook ethnographic research methodologies, to gain an insightful understanding of the social and information worlds of certain peripheral groups. Chatman (1996) uses Merton's (1973) theory to argue that information is regulated between groups in society, that information can be barred from outsiders and kept only for insiders, and that insiders themselves face barriers as information needs to pass through information leaders before it is fully accepted, consequently limiting the range and variety of information which is permitted. Accordingly, the insider status can hinder the information needs of the insider group, ultimately leaving it information poor. This manner of insider/outsider status therefore leads information itself to become political, as it serves as a means of deciding who can and cannot be trusted, ultimately who is a member and who is not (Lingel & Boyd, 2013). Significantly, Chatman (1996) highlights the revolutionary work of Whyte's (1943) Street Corner Society, where the same physical and social setting was shown to exhibit very different sets of social norms and values, as well as, social hierarchies for two groups of young men who live in the same geographical area. Chatman (1996) argues that the different world-views of the young men in Street Corner Society (1943) shaped their information seeking behaviours, norms, values and social hierarchies therefore dictating the flow and acceptance of information and the sources from which they came. Indeed, Chatman (1996) is maintaining that information seeking is governed primarily by normative behaviour, which is ultimately determined by an insider group.

First presented in the Journal of the American Society for Information Science, Chatman's (1996) information poverty would go to be cited extensively, especially in Library Information Science literature (Hersberger, 2006). Within her theory of information poverty, Chatman (1996: 197) offers six propositions to explain the core elements of the concept, these propositions are outlined below.

Proposition 1: People who are defined as information poor perceive themselves to be devoid of any sources that might help them.

Proposition 2: Information poverty is partially associated with class distinction. That is, the condition of information poverty is influenced by outsiders who withhold privileged access to information.

Proposition 3: Information poverty is determined by self-protecting behaviours which are used in response to social norms.

Proposition 4: Both secrecy and deception are self-protecting mechanisms due to a sense of mistrust regarding the interest or ability of others to provide useful information.

Proposition 5: A decision to risk exposure about our true problems is often not taken due to a perception that negative consequences outweigh benefits.

Proposition 6: New knowledge will be selectively introduced into the information world of poor people. A condition that influences this process is the relevance of that information in response to everyday problems and concerns.

Since Chatman's (1996) information poverty theory is being adopted in such a direct manner in this study it is important not only to showcase its propositions but to also briefly link them with the aims and objectives of this research. The first proposition in Chatman's (1996) information poverty states that the information poor routinely perceive themselves as completely devoid of any sources, sources through which they can gain vital information to help themselves. This first proposition offers commentary on perception, the perception of having no available trustworthy and reliable sources. Chatman (1996) therefore argues that an unseen barrier such as negative perception reinforces the limitation of information available; a point explored with participants. The second proposition of this theory is strongly associated with class and power distinctions. In this instance however, race and ethnicity rather than class position are explored; examining how shared identities impact upon information flow within and outwith insider groups. The third proposition emphasises self-protecting behaviours such as secrecy and deception as witnessed by Chatman during her years of fieldwork, these same behaviours are examined in health information seekers within this research. Chatman's (1996) fourth proposition highlights comportments of secrecy and deception, once again, as self-protecting mechanisms resulting from issues of mistrust. In these research findings ideas around trust, both in terms of trusting the information provider (such as health professional) as well as, the health information itself, is significant. In utilising technology to gain health information, it potentially offers a means to bypass the need for such self-protecting behaviours through the avoidance of face-to-face encounters; a point again explored in later findings chapters. Proposition five of Chatman's (1996) information poverty spotlights the perceived risk of disclosing a need for information to others, especially those from the insider group. Ethnographic research with the Barton women's group offers a rich setting through which information poverty behaviours are analysed. The final proposition emphasises the influence of relevance to information seeking, Chatman (1996) contends that new knowledge is selectively introduced into the information world of an insider group, dependent upon its perceived relevance. This is a crucial point, since it is the insider group which facilitate the norms by which its members perform social interactions. Again this pattern of behaviour and the social rules around accessing health information through an insider group will be examined within the context of the Barton women's group. Chapter 7 of this thesis provides the platform upon which fieldwork findings and Chatman's (1996) information poverty framework are evaluated in detail.

Chatman's information poverty provides a useful tool to assist in exploring the social structures and relationships which shape information seeking behaviour; offering researchers a conceptual framework to understand the barriers confronted by different groups in society. Contemporaries of Chatman have picked up the mantle of information poverty and applied it to new social contexts working with diverse social groups and communities (Pettigrew, 1999; Fisher et al., 2004a, 2004b; Lingel & Boyd, 2013). Spink & Cole (2001) undertook research with low-income, largely African-American residents, discovering through a holistic approach, that residents had a lower reliance on formal channels of information, except when it came to information on health and employment. Perhaps most pertinent to this research is Sligo & Jameson (2000) who focussed specifically on health information and promotion, with their study on women of Pacific Island immigrant origin, exploring the barriers faced by their participants in utilising cervical cancer screening services in New Zealand. They discovered cultural associations linked to cervical cancer screening shaped information seeking and although Sligo & Jameson (2000) did find evidence of information poverty, they also evidenced variations to the insider/outsider model. Participants in their research accepted the usefulness of outsider information, although they preferred this information to come through community channels. Furthermore they preferred outsiders to conduct actual healthcare procedures in order to limit the possibility of disclosure within their own community. Sligo & Jameson (2000) suggest the lived experience of 'community connectiveness' produced different outcomes compared with Chatman's participants who were much more socially isolated. Nevertheless, this study offers an interesting use of Chatman's information poverty theory in the context of ethnicity and health information activities.

In recent years, the internet, and how information poverty is replicated in this virtual space has become of interest to academics (Hamer, 2003; Veinot, 2009; Lingel & Boyd, 2013). Veinot's (2009) work discovered individuals living with HIV/AIDs used the internet as an important source of information because it offered an anonymous alternative to close-knit rural community services on offer. Hasler & Ruthven (2011) used Chatman's theory directly, investigating how individuals use the internet to escape information poverty. Hasler & Ruthven (2011) contend that newsgroups provide a virtual environment whereby individuals can express themselves; providing anonymity and sources which are not necessarily available else-where. This seems to be especially true for individuals who feel they have no other forms of support for their information needs. Hasler & Ruthven (2011) use of Chatman's theory informed my ideas of where health information activities may take place, as well as some of the covert reasons why they be conducted specifically online. Using Chatman's work in this way showcases its adaptability, remembering that Chatman (1996) was writing at a time when information access (via the internet) was not as embedded in society as it is today. Nonetheless, there are criticisms of information poverty, Sligo and Williams (2001) emphasis a point also raised by Savolainen (2007) that the theory of information poverty predominately focuses on the characteristics of the individual rather than the characteristics of a community. Meanwhile, Burnett & Jaeger (2011) accused Chatman's body of work (including her other writings not previously mentioned Chatman (1999) and Burnett et al., (2001)) of neglecting the interactions between different information worlds which exist in broader society. Nevertheless, nearing twenty years after its publication, information poverty still provides a unique and functional tool; open to adaption and modernisation, for scholars no matter their academic background.

2.7 Fisher: Information Grounds

Heavily influenced by Chatman's work (1987, 1991, 1996, 1999) Fisher's (née Pettigrew) research also explored the social context in which information activities occur, developing her own theoretical concept of information grounds (1999) and becoming a leading voice in information behaviour research. Fisher's (Pettigrew 1999, Fisher et al., 2004a) philosophy of spontaneous information seeking contexts has been cultivated from Fishers own unique holistic approach to understanding information seeking and sharing as a social by-product. Undertaking fieldwork in community clinical settings, Fisher (1999) examined how information flowed between patients, especially older patients and clinical staff. In conjunction with fellow colleagues Fisher et al., (2004a) later expanded the concept of information grounds, exploring the information needs of immigrants in New York. Information grounds are places where people come together; examples could include the dentist's waiting room or the high school gates, places where information exchange is primarily temporary, and will occur at any time and in any place as a by-product of another activities involving social interaction (Fisher et al, 2005). Fisher et al., (2005) maintains that certain social actors take part in activities that are expected of them and in so doing become part of an information flow. Fisher's (Pettigrew, 1999; Fisher et al., 2004a) theory is flexible, encompassing and recognises the ways and means by which information is sourced and shared within community settings. Fisher et al., (2005) suggest that information is not simply sourced through traditional channels but is also informally obtained. In this sense Fisher claims,

> "Along these lines, information grounds are context rich: Many subcontexts from many perspectives are always at play, and together they form a whole or grand context..." (Fisher et al., 2005:186)

Fisher's (Pettigrew, 1999; Fisher et al., 2004a) information grounds theory therefore stresses the importance of social actors, with defined social roles, where they partake in social interactions with information flow as a by-product. Information grounds are uniquely temporal and can operate in any situation where people are engaging in both formal information seeking, as well as, informal approaches. Similar to Chatman, Fisher's (2004a: 757) outlines the propositions of her information grounds theory, which for reference I have outlined below.

Proposition 1: Information grounds can occur anywhere, in any type of temporal setting and are predicated on the presence of individuals.

Proposition 2: People gather at information grounds for a primary, instrumental purpose other than information sharing.

Proposition 3: Information grounds are attended by different social types, most if not all of whom play expected and important, albeit different roles in information flow.

Proposition 4: Social interaction is a primary activity at information grounds such that information flow is a by-product.

Proposition 5: People engage in formal and informal information sharing, and information flow occurs in many directions.

Proposition 6: People use information obtained at information grounds in alternative ways, and benefit along physical, social, affective and cognitive dimensions.

Proposition 7: Many subcontexts exist within an information ground and are based on people's perspectives and physical factors; together these subcontexts form a grand context.

Information grounds offer information that can be beneficial in terms of physical, social and cognitive needs, making it ultimately a rich source. Although Fisher's (Pettigrew, 1999, Fisher et al., 2004a) work is lacking the years of in-depth ethnographic embeddedness reflected in Chatman's discussions, she nevertheless, offers an encompassing collective approach to information seeking activities in the daily lives of community members, an approach which complements the ethnographic work in this study. Fisher's (Pettigrew, 1999; Fisher et al., 2004a) conceptual framework, like that of Chatman's (1996) will therefore be used as a springboard for fieldwork comparisons in chapter 7.

2.8 Chapter Summary

The multi-disciplinary nature of this research seeks to bridge the gap between information science and sociology by examining the impact of different elements of ethnic identity and how this potentially shapes health information activities. It was therefore essential to outline the sociological understandings of both race and ethnicity. This work fully appreciates that the concept of race is controversial, with a destructive past, and which today remains hotly contested. Yet the decision to employ race as a conceptual concept was taken for two reasons. Firstly, participants identified themselves with racial identities and highlighted their experiences of racism. Thus, in order to follow an interpretivist philosophy and showcase the social worlds of participants there was a need to use their perception of difference. Meanwhile Barth's (1969) explanation of ethnicity, as a label which traces out boundaries between individuals in society, offers particular value to this discussion, as does Hall's (1996) concept of identity based upon notions of difference. These definitions of ethnicity offer an appreciation of the boundaries in which individuals situate themselves and others, inevitably shaping how health information is sourced, used and shared between societal groups. Sociologically investigating health information activities in this manner, with these two particular BME groups allows race and ethnicity to be explored in the context of health information activities for the first time.

To offer greater context on the topic of ethnicity and health an appreciation of scholarly debate on health inequalities was needed. Traditionally discussions on health inequalities have emphasised socio-economic factors as the root causes of health inequalities. However contemporary researchers have begun to put health inequalities into the complex social context from which they materialised (Scamble, 2012; Graham, 2009; Nazroo 1998, Bhopal, 2007, 2012). Pertinent to this particular research is Bhopal (2012) and Lorant & Bhopal (2011) acknowledgement of the development of Scotland's Ethnicity and Health (Fair for all) Policy. They cite the implementation and altering of service delivery for BME populations as the key to encouraging the advancement of cultural sensitive healthcare systems in Scotland. From these discussions form two distinct points; one that the root causes of health inequalities lay in complex social contexts and secondly that, adapting healthcare provision to encourage a more culturally sensitive healthcare system in Scotland will go some way to positively impact health inequalities for BME populations. This research will argue that in the endeavour to strive for a more culturally sensitive healthcare system the issue of health information activities for BME communities must be addressed.

Next, moving on to explore the seminal work of Goffman's Presentation of Self (1959) and Stigma (1963), Goffman's theoretical metaphors undoubtedly offer an expressive and useful tool in explaining face-to-face encounters when engaged in health information activities. When on the front-stage Goffman (1959) argues performers conduct themselves in sociably acceptable manners, conforming to their social role, status and the social norms of the context in which the performance is occurring. In the next few chapters research findings with be viewed through the scope of Goffman's theories. Goffman's (1963) famous assessment of the presentation of the self when the performer is perceived to have a spoiled identity was then considered. Goffman (1963) proposes stigma attracts social reactions that incorporate negative moral associations, and ultimately led to an unease encounter during the performance. Stigma associated with health and illness will be an element of this research as will stigmas association with social identity and immigration labels. Thus, Goffman's theories are employed in a way that updates his concepts to situate them in an information saturated setting where technology provides another stage upon which to prepare or to perform. Once again using sociological theory in this manner to explore health information activities fills an existing gap in knowledge. This research seeks to explore social interactions during health information activities with the prospect of offering a richer picture of the hidden barriers which potentially reinforce health inequalities for BME populations.

The internet inevitably plays a role in health information activities, and as such a brief discussion on the digital divide and the impact of the internet on society as a whole was needed. Mehra et al., (2004) and van Dijk (2009) defined the digital divide as more than simply material difference, stressing the obstacles of poor education, language problems, computing skills and the absence of culturally sensitive material online. Two competing camps then emerge in the discussion of technology and the internet and its ability to offer a levelling affect to disadvantaged groups. Lash (2002) claimed social statuses can be separated from the offline and the online world, whilst Turkle (1996) maintained the internet leads to the freeing of knowledge. Castell (2001) and Rheingold (1994) meanwhile dispute this arguing the counter is true, that actually the powerful in society simply exploit technology as a means of exploiting others. This debate acts as a sharp reminder that the internet is a contested arena, in which power as well as information flows.

Moving now to the final deliberations of this chapter; this was the point in discussions when theories from the discipline of information science were introduced. Chatman's (1996) and Fisher's (Pettigrew, 1999; Fisher et al., 2004a) models of information poverty and information grounds offer constructive theoretical frameworks as well as the opportunity in this research to bring them together in a new and unique way to explore the health information activities of BME populations. The use of information poverty theory is an integral part of this inter-disciplinary research, something reflected in the fact that it forms the final research question. Information poverty uses Merton's (1973) concept of insiders and outsiders to produce an understanding of the information worlds in which the information poor experience limited access, conformity to social behaviours and the need to protect against what is perceived as risky situations. Chatman's (1996) work offers researchers not only a valuable tool when in the field but also a unique insight into the often hidden barriers to seeking out and sharing of information. The final piece of the building block in this discussion was on Chatman's present-day admirer, Fisher (Pettigrew, 1999; Fisher et al., 2004a). Fisher's (Pettigrew, 1999; Fisher et al., 2004a) information grounds theory asserts the social context of information exchange and claims information seeking can occur as an offshoot of another given task which individuals have gathered to engage in. Like Chatman (1999), Fisher et al., (2004a) outlines 7 propositions from which she mounts her argument. Ultimately Fisher et al., (2004a) proposes that information grounds are rich contexts in which information exchanges occur.

This literature review offers the theoretical foundations and context to later empirical work in this study. Understanding theories on ethnicity, race, health inequalities and information poverty were especially important in order to examine how ethnicity impacts on health information activities. Finally it can be argued that this study fits nicely into an existing research gap, bringing together theoretical concepts from both sociology and information science to explore for the first time in detail the health information activities of two BME communities.

Chapter 3 – Methodological Framework

3.1 Chapter Introduction

The purpose of this research is to explore the health information activities of two BME populations living in the West of Scotland. To achieve this, a pragmatic research design was employed for fieldwork stages, underpinning this pragmatic research design was an interpretivist research philosophy. A large part of this social research is subsequently given over to showcasing the voices of its participants, to highlight their experiences. At a functional level, this pragmatic approach involved utilising mixed methods, including: quantitative data collection and qualitative information gathering. This chapter will now outline the epistemological choices and practical obstacles encountered during my research journey.

3.2 Research Overview

A grounded approach was used for this study allowing areas of interest to develop throughout the fieldwork. To complement this, a pragmatic research design, still nestled in interpretivist philosophy was adopted. I choose an interpretivist philosophy to underpin this research since it was my intention to showcase the information seeking behaviours of participants through their own words, using their lived experiences. My aim was also to use methodologies which would complement each other and inform each section of the fieldwork. Using a quantitative tool in the form of questionnaires allowed me to gather quick, quantifiable data which I could then explore further during the qualitative methodologies employed in this study. Tashakkori & Teddlie (2002) describe mixed methods as the third methodological movement and contend along with other academics that both research methodologies can be utilised by social researchers (Howe, 1988; Punch, 2009; Creswell, 2003). Ivankova et al., (2006) meanwhile proposes the rationale for mixing methodologies lies in the fact that neither research methodology alone can offer a complete picture, by utilising both, it permits a more robust analysis employing the strengths of each method; adopting a pragmatists viewpoint.

The methods used in this study included self-completion questionnaires, 36 semi-structured interviews, and participant observations; offering methodological triangulation. In the initial stages of this research self-completion questionnaires were designed for both African and Chinese participants. During the first year of my PhD I considered a number of similar case studies, including how Chatman (1996) and Fisher (Pettigrew, 1999; Fisher et al., 2004a) conducted their own research. I also discussed methodological considerations with fellow PhD students who had completed their own fieldwork as well as my supervisors.

The though process in utilising a self-completion questionnaire at the beginning of my fieldwork would be that ultimately data from questionnaires would form the basis for the development of interview schedules. Semi-structured interviews would then allow for the exposure of behaviours and practices; participants' social realities identified through their own words. To complement this participant observation exercises would then allow for the recording and exposure of attitudes, behaviours and practices which would not have necessarily materialised at the interview stage. The final three methodologies employed in this study therefore provided a complementary combination, both in terms of data collection and analysis techniques. In reality however there had to be some flexibility to this research design, I was only able to conduct questionnaires with Chinese participants and unfortunately could only adopt ethnographic principles in my engagement at health talks with Chinese participants.

This process of change during my fieldwork is discussed in greater detail in later sections of this chapter.

3.3 Summary of Data Collection

Data Collection Activities		**Volume of Data Generated**
Self-completion Questionnaires	350 questionnaires sent out. 117 returned and analysed using SPSS.	Data generated from SPSS included: 7 frequencies and 18 descriptive analysis outcomes.
Semi-structured interviews	6 interviews with members of the Karibu women's group.	Approximately 4.5 hours of interview data collected.
	12 interviews with members of Waverley Care.	Approximately 9 hours of interview data collected.
	14 interviews with members of the Chinese Community Development Partnership.	Approximately 10.5 hours of interview data collected.
	4 interviews with key informants.	Approximately 3 hours of interview data collected.
Participant Observation Exercises	Attending 4 Chinese Community Development Partnership health talks which each lasted 2 hours.	6 pages of detailed participant observation notes.
	Attending the Barton women's group once a week for 2.5 hours over the course of 7 months.	26 pages of detailed participant observations notes.
		A researcher's reflexive diary with thoughts and reflections on ethnographic elements of the study.
		NVivo analysis generated 75 nodes from participant observation exercises, 35 of which then underpinned discussions in the findings chapter of this thesis.

3.4 Research Settings

Exploring the information worlds of two BME populations was always going to generate a multi-sited approach to this fieldwork. Initially consideration had been given to one single site where individuals from different communities congregated however separating out individuals from Chinese and African communities would have practically been very difficult. Consequently, a decision was made that several settings within these specific communities would be much more appropriate. Marcus (1995) proposes that multi-sited spaces of research involve following either: people or objects, conflict or symbols, stories or a metaphor. In this study multi-sited research revolved around people: health information seekers and the theme that connected each research site was information. Each organisation had a role to play in disseminating information to both communities. To engage with African and Chinese populations it was necessary to spend several months before going out into the field making contacts and building working relations. Initially I had very little response from contacts within community groups and charitable organisations, it was only after making contact with those on the periphery of these communities that progress was made. Schensul defines such persons as local gatekeepers "…who control access to resources, whether human, geographic, social or informational" (Schensul, 1999: 81). An example of local gatekeepers in this study was evident when I established contact with the Chinese community. After many months of meeting community leaders, organisers, health workers, charity workers, and volunteers finally contact was established with the three following community groups who were willing to facilitate this research.

Karibu

Karibu is a women's group which endeavours to support African women in the West of Scotland, it assists with advocacy, interpretation, information dissemination as well as offering an informal way in which women can get support to cope with day to day life as an asylum seeker, a refugee as well as those who have settled in Scotland permanently. The group encourages empowerment for women and actively works to raise their members self-esteem and confidence. Karibu offers a number of activities and groups for Africans to attend however it was the monthly drop-in session which I attended. The group meets once a month, during this time there might be a presentation from a public service or charity, they will usually allow time to discuss pressing issues, perhaps around housing, health or welfare claimant issues. After which they enjoy an African lunch together. Although I only attended the group once to introduce myself and my study, some of the members were interested in getting involved eventually leading to 6 separate interviews. These interviews were conducted in a range of settings including, coffee shops, libraries and fast food outlets. After my fieldwork was complete and analysis conducted, I returned several months later to present initial findings and was well received by the members.

Waverley Care

Waverley Care is a registered charity wishing to advance the education and understanding of conditions affecting the African community in Scotland. Waverley Care offers a number of health provisions and health promotion services across the West of Scotland, and in particular it offers support to Africans who need support with housing, training, immigration status as well as healthcare. Additionally the charity trains healthcare providers to be aware of the differing needs of Africans in healthcare situations. At the beginning of 2012, Waverley Care established a women's group in Barton for local African women to come along and engage in sewing activities as well as attend health talks. After a few weeks it was evident that the group was getting stronger in numbers and a permanent group was established with the women making African dresses for a fashion show as well as partaking in a community health course called Health in the Community (HIC) which included health presentations and group discussions on certain health topics. In total 12 interviews came from my association with Waverley Care, these interviewees included a Waverley Care volunteer, members of the Barton women's group and a team member of the Waverley Care project team. Interviews with ladies from the Barton women's group usually happened in the local library while a few other interviews took place in a local coffee shop. After all my interviews were complete and the participant observation exercise came to an end I returned to the Barton women's Group a few months later to present my initial data findings but unfortunately the group had been cancelled. At the time of writing I have been in contact with the organisation on a number of occasions to offer feedback but currently the charity is undergoing staff restructuring as well as the prospect of potential funding cuts and so to date I have been unable to feed back to the community.

Chinese Community Development Partnership (CCDP)

CCDP is a community organisation which aims to build working relationships, as well as awareness of the Chinese community in the West of Scotland. They are an umbrella association that signpost members of the Chinese community on to sister organisations. A strong objective for CCDP is to promote Chinese culture and language so they run a number of projects and have monthly talks on a range of issues, including health topics. Since the closure of a local community centre which dealt with an array of health issues, CCDP has become the central Chinese organisation representing the community as well as advocating and facilitating its needs. CCDP assisted this research in a number of ways most importantly the association gave this research the status it needed to connect with the local community. At the time of writing, CCDP had been informed by the council that their only full-time member of staff was being cut along with core funding. In total 14 interviews were conducted with members of CCDP as well as the CCDP gatekeeper who had provided access to the community. Interviews were all conducted at the local community centre. After all the interviews were completed I returned to CCDP a few months later to present my initial data findings at one of the community healthy talks. My feedback was well received by the community with several members of the audience voicing their appreciation. Naturally, they were very eager that the completed findings be brought to the attention of key governmental organisations.

3.5 Key Informants

The best strategy for any ethnographic researcher is to discover the individuals essential in gaining access. It is also vital to talk to individuals who have knowledge of the research area or communities being researched (Schensul et al, 1999; Kawulich, 2010). Apart from the three key organisations that facilitated this research, other organisations, associations and charities acted as key informants providing networking opportunities as well as background information. To gain an understanding of the challenges faced by refugees and asylum seekers in the West of Scotland I undertook an interview with two development workers from the Scottish Refugee Council. This was a vital opportunity to establish links and also gather valuable information. In addition, I made contact with an eHealth policy development officer at the Scottish Government, again this was crucial chance to gather information on the development of eHealth particularly in the political arena, it also provided me with the opportunity to network. From this interview I was given a contact at Looking Local, an organisation which provides interactive services to councils across the UK. Analysis of these interviews has been included in the data chapters. Informants or gatekeepers did not always play such an active role by being formally interviewed, usually because of time or a reluctance to get directly involved. Nevertheless, they often provided invaluable information regarding the culture and social situations of both communities and on a number of occasions offered me the opportunity to present this research and seek out potential interviewees. These key informants included the co-ordinator of a local multicultural community centre, the founders of a prominent African network and group members of various African associations in the West of Scotland. Informal chats with health workers, volunteers as well as informal meetings with NHS Scotland, NHS Health Scotland and NHS Health in My Language also provided vital background knowledge as well as important contacts in the field.

3.6 Access

In a climate of funding cuts and staff reduction, time is ever more precious to community organisations consequently the case for potential research rewards in exchange for providing access and support must be strong. Hence, the initial stages of my second year were dedicated to emailing, writing and phoning charities, community groups and NHS contacts. When there was a chance to speak to a community leader, or in some cases, volunteers from an organisation every opportunity had to be seized. Building trust and rapport with key informants and gatekeepers is fundamental to any social research (Hammersley & Atkinson, 1995). Bernard asserts, “In the end, ethnographic fieldwork stands or falls on building mutually supportive relations with a few key people" (Bernard, 1999: 348). When working with CCDP it was vital for me to be punctual, organised and appreciative, taking a small gift (such as a small box of chocolates) now and then to show appreciation, this was regarded as polite by the gatekeeper and although the gatekeeper would always reject such small offerings it quickly built a good working relationship founded on continued appreciation. Kawulich insists, "Good manners are an important aspect of this culture, and sincerity goes a long way to opening doors." (Kawulich, 2010: 9). With regards to the African women's groups I worked with, Karibu and Waverley Care building trust was just as important but this was carried out in different ways. In the instance of Karibu an invitation was given to come along and speak with the women's group at their monthly drop-in. After presenting my research to Karibu the group leader encouraged the women to participate and instilled the importance of such social research in allowing their voices to be heard. Championing this research project in such a way, the gatekeeper gave potential participants an endorsement which included a level of trust. The role of the leader or role model as a gatekeeper is crucial in gaining the confidence and conviction of a group/community. Contact was established early on in this research with Waverley Care after meeting with a key informant. Through this contact a connection was made with group leaders and volunteer co-ordinators. Once again, funding and time pressures on this health organisation made it difficult to get my research moving in the right direction. At a monthly staff meeting I presented my research to the staff, this was met with interest but also some reservation. Workers were rightly concerned at the 'over' researching of the African community in the West of Scotland, as another research student from a different university had recently made contact. Rightly, they did not want the community to feel that they were being exploited in some way. It therefore became crucial to convince staff members that I would be respectful of the community's needs and that research findings had a potential to benefit organisations like Waverley Care, as well the community itself. Maintaining contact after this meeting was vital, as was being flexible with my time meeting up when and where was easiest for Waverley Care workers. Several months after making initial contact, one of the co-ordinators suggested I attend a new group which they were starting up in the Barton area. This worker subsequently became a crucial gatekeeper. Being persistent, patient as well as flexible had finally won confidence and trust from the group leaders at Waverley Care. Since many interviews in this research were conducted through an interpreter their role needs also to be considered in this research journey.

3.7 Interpreters & Translators

To offer critical reflexivity in social research, the role of the interpreter within the research process itself should not be hidden but be highlighted (Temple and Edwards 2002; Temple, 2005). 12 translated interviews took place with Chinese participants and 1 translated interview with an African participant. In addition self-completion questionnaires and participant information packs were also translated. A Swahili translator and a Lingala interpreter were employed from the organisation 'Voice-Over Interpreting' a not-for profit social enterprise in Glasgow who provide professional interpreting services for the local community. Voice Over Interpreting were recommended by a fellow PhD student at the University of Glasgow, who is a native interpreter for the local South Asian community. For Cantonese and Mandarin translations my CCDP gatekeeper organised a local and trusted interpreter who the organisation have used for many years. My concern was that interviewees may have felt uncomfortable talking through someone who was a familiar face, with CCDP. However my concerns did not seem to materialise. Participants did not appear to know the interpreter personally and there did not appear to be any issue of withholding information, Chinese participants often detailed their behaviours as well as their health concerns quite openly. As far as I could tell, even though the interpreter was a familiar face they seemed to trust her professionalism, a professionalism which she was sure to convey through her appearance as well as she reassuring words of confidentiality to each participant. For one African interview a female Lingala interpreter was requested by a Congolese lady. Unfortunately, in this case, the participant seemed uncomfortable with the interpreter even though the interpreter remained professional and tried to engage with the participant, nevertheless an uncomfortable atmosphere remained throughout the entire interview. Obviously I could not ask directly what was wrong, but as a possible explanation perhaps the interpreter was from a part of Congo that been in conflict with the area that the participant was from, although this is purely conjecture on my part. Hence, even when researchers do provide interpreter-interviewee matching it does not always provide undistorted communication (Edwards, 1998). In this situation, the presence of the interpreter had such a negative influence on the interview that the data obtained was compromised and will therefore not be included. Rightly, Jentsch suggests,

> "…there needs to be awareness of the fact that the background characteristics of this person can have a decisive influence on the atmosphere of the interview and, as a consequence, on the validity and reliability of the data obtained." (Jentsch, 1998: 282)

A short induction with new interpreters to discuss the roles and responsibilities of each was beneficial. Inductions familiarised the interpreter with the research study, it emphasised the importance of confidentiality (interpreters were asked to sign a confidentiality form, please see appendix A for a copy of this form) and both the researcher's and interpreter's role during questioning (Edwards, 1998). Although no formal debriefing took place, an informal chat about the interviewing process usually occurred, especially after doing a few interviews in quick succession. The dynamics of an interview changes when working with a translator, physically: interviews are carried out in a triangular setting arrangement and the means by which you must contextualise questions also alters, consequently there is more reliance on eye contact, body language, laughing or smiling to engage with participants (Edwards, 1998). Interestingly, the interpreter can offer a dual role as an interpreter, but also as a useful guide. The Chinese interpreter that was working with me often told me what had been discussed in the general greetings between the interpreter and the interviewee at the beginning and end of interviews (when it was perceived that I was no longer part of the conversation). Moreover, she frequently explained cultural or social behaviours which she thought I might not understand. Owen defines these kinds of interpreters as cultural consultants (Owen, 1985 cited in Jentsch, 1998). Yet, interpreters can act as outsiders in some interviews. Just as my positionality was crucial to the dynamics of the interview, so was the interpreter's, Temple & Edwards (2002) define this as 'triple subjectivity' hence the social location of the interpreter becomes important. Temple and Edwards (2002) propose that the interpreter becomes a key informant in the interviewing process and to achieve this, the researcher must have an awareness of their positionality and so carry out interpreter interviews. In this study I did not carry out such interviews but instead felt it was more appropriate to have informal 'chats'. In the case of the Chinese interpreter she opened up quite quickly and discussed her background including: details of her educational status and working career. Hence, for many participants the interpreter shared age, gender and social status, however in some instances the interpreter may have been perceived as an outsider. The Chinese interpreter could speak both Cantonese and Mandarin but this made me aware that with some interviewees there may have also been a cultural barrier, as the interpreter was originally from Hong Kong and some participants were from parts of mainland China. In essence, the interpreter was an insider and sometimes an outsider. In the case of the Lingala interpreter she was the same ethnicity, gender and nationality of the interviewee but interestingly this did not prevent the creation of a barrier between the two. There were several occasions during interviews where the participant bypassed the interpreter and spoke directly to me in English. Participants did this not because they did not like the interpreter, but because it displayed their own power within the interviewing process (Edwards, 1998). In many cases the participant spoke in English to 'show off' their language skills, in many cases the participant would use a Scottish word and this would invoke smiles and sometimes even laughter from all involved. During this exchange I would encourage the participant and their use of English but usually participants returned to using the interpreter as an easier and quicker means of communication.

3.8 Ethical Considerations

When working with communities who are seldom heard; groups which have historically been disadvantaged, such as in this case, a number of ethical considerations must be undertaken. Clearly, having some cultural awareness of the particular groups engaged and represented in this research was vital. However, considering the historical background of these particular communities in the context of Scotland was also important. Understanding what brought participants to Scotland as well as some of the political backdrops to their journeys gave me greater insight. It could be argued that there were added ethical responsibilities to participants and the BME groups represented in these research findings, being continuously aware that findings will represent not only direct participants but also more broadly BME groups. As a result, I have had to consider how data is collated, edited and presented as it will inevitably shape not only the perception of my research but the continued awareness of such BME populations. It has been necessary to be reflective as a researcher whilst also being sensitive to the needs of my research participants and the potential representations of BME populations. Building and maintaining trusting relationships was imperative not only for research progression, but for me: as a representative of the wider research community, and a member of the British Sociological Association as well as the University of Strathclyde. The British Sociological Association stipulates in their ethical guidelines,

> "As far as possible participation in sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain in appropriate detail, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be disseminated and used." (British Sociological Association, 2002: 3)

All interviewees were fully informed about my role, the purpose of the research, and what would be done with the data at the end of the study. All interviewees were given a participant information sheet as well as contact information for the university ethics board and principle investigator if further information was sought. I guided the interviewee through the participant information sheet before the start of each interview and sheets were also translated into first languages if required. In addition, interviewees were given a consent form asking their permission to be audio recorded, and if satisfied they signed the consent form. Only 1 participant requested not to be audio recorded and instead consented to hand-written notes being taking. This participant was new to the country and was in the process of their asylum claim, which was why I believe they were uncomfortable with being audio taped. In the case of the participant observation exercises, members of the Barton women's group were fully informed. At the request of the university ethics board participant information sheets were handed out and once again these sheets were translated into first languages if needed. As time went on and new members joined the group, I informed them about the research and my role. In the situation of the Chinese health talks, descriptive observation or as Robson (1993) and Bryman (2008) define it, complete observation, was conducted. Since these were collective public gatherings in which I took general anonymous accounts of events, informed consent was not practical or necessary. However, I was completely overt in this role and on occasion, when asked, I disclosed fully my position as a researcher and the purpose of my study. All participants as well as gatekeepers have been given pseudo-anonymity in this research; participants choose the name I subsequently used in research findings. Becker proposes,

> "… one should refrain from publishing anything that will cause embarrassment or distress to the people studied if it not central to the research…" (Becker 1964: 284 cited in Hammersley & Atkinson, 1995)

Moreover to further protect participants of the women's group from which so much rich and sensitive data has been sourced, I took the decision to anonymise the group's name and location. I wanted to give the ladies an extra layer of anonymity especially because the group was very small (and therefore known within their community). However, I stopped short of changing the names of the community organisations involved in this study, such as CCDP and Waverley Care. The decision not to anonymise organisational names was taken for a number of reasons: 1.) after trialling a name change with academic peers I was informed that it would not offer further anonymity not already provided at a micro level, 2.) many participants wanted governmental organisations like the NHS to know about their experiences and thereby wanted the community organisations to be recognised, 3.) keeping the organisations names allows for further impact to be made, even after publication. At every stage of this research the protection of participants has remained paramount, from the design of research methods, to the writing up and final dissemination of research findings. This research investigation has never been about health directly; rather it has investigated how health information is gathered and shared within the context of two BME populations. Nevertheless, I was aware from the start that participant's may disclose information regarding their health, especially during interviews. On such occasions I reminded interviewees that they retained pseudo-anonymity in any data results published. When participants did disclose delicate health issues I was quick to show empathy and sensitivity to the matter. If, which was the case in several interviews, participants disclosed information regarding an untreated health problem I advised them to visit their GP, as well as, the use of support services where they would be able to get additional support and advice. To this effect each participant was given a support services list to take away so if they had any further concerns they could contact a health professional or support agency. In the case of one interview further ethical considerations had to be undertaken. In this situation the interviewee changed the arranged meeting point and instead wanted to meet at their local health centre where they were waiting to have their child seen by their GP. The participant said they wished to carry out the interview there and then, however after having a general chat about how they came to the UK, it was clear that the participant's English was limited and their priorities were rightly with their sickly child. Furthermore, the participant had only recently come to the UK and was very anxious about their immigration status. Carrying out an interview at this time felt intrusive and the participant seemed somewhat uncomfortable even though they had given consent. I quickly thanked the participant for their time and gave them the 'thank you gift' (a £5 supermarket voucher) as reimbursement of their time. I commented that I believe the interviewee had enough going on in their own personal life and so would not be included in the study and the interviewee agreed and was happy to end the interview. No transcription of that informal chat was undertaken and no qualitative data has been included in this study.

In the initial stages of this study it was thought research inquires would concentrate on UK citizens and refugees, however during the initial months of fieldwork it became apparent that some individuals (those who had recently arrived to the UK) were at greater risk from a lack of health information. During informal meetings with community leaders, charity workers as well as health workers aspects of this risk for asylum seekers was mentioned. Furthermore, during conversations with African interviewees, concern was raised that asylum seekers were not being included in the study as they believed these individuals to be the most powerless within their community. From the outset it was never the intention of this investigation to concentrate on participant immigration status, nevertheless, as time marched on it seemed to become unethical to exclude their voices from being documented. On reflection, as the fieldwork developed ethical considerations needed to be re-examined or updated. In total, three ethics memos were submitted to the School of Applied Social Science - School Ethics Committee, the number of alterations and the additional information provided in these memos reflects the grounded philosophy adopted for this study.

3.9 Reflexive Researcher

The rise of self-reflexivity in social anthropology and the move to a reflexive sociology have spun critical consideration onto the role of the researcher, to ask what influences have impacted upon the person behind the research and how this invariably shapes research investigations and data collections (Gouldner, 1971; Harding, 1986). The changing role and responsibilities of the ethnographic researcher continue to be debated (Hammersley & Atkinson, 1995; Bernard, 1999; Atkinson et al., 2001). However, broad agreement rests within sociology and social anthropology; that the function of the ethnographic researcher is to be an interpreter of the social world, to offer meanings behind behaviours and patterns evident in the social world. As an interpreter of the social world, the ethnographic researcher must acknowledge that social research is never value free. Crotty proposes,

> "Personal views and beliefs do, however guide our choices between paradigms and methods, as well as our topic of research and what we intend as our purpose." (Crotty 1998 cited in Etherington, 2004: 25)

Moreover, Hertz (1997) argues that a researcher through personal accounting must become aware of their own position and interests to acknowledge how this shapes every stage of the research process. Henceforth, I will briefly outline the influences that have shaped my interpretations in this study. To assist in this task of self-examination I kept a research journal throughout my fieldwork to use as a device for reflection and re-examination. This customary practice allows you the benefit of keeping notes and memos representing your thoughts and feelings as well as experiences which may well be forgotten by the time of write-up (Glesne & Peshkin, 1992; Maxwell, 1996). Watt (2007) stipulates that researchers firstly need to be aware of the personal reasons why they are drawn to research interests, he argues these are subjective motives which need to be disclosed if the research is to be viewed as truly transparent. On reflection, it is fair to say I have always been drawn to researching communities who are often seen as 'outsiders' those who have come to the UK to call it home but find themselves sometimes living on the margins of society. These are encounters that I have also experienced, to settle into a new country, to lack local knowledge and struggle with social expectations and national customs. As a result, I continue to be interested in individuals and communities who have had similar experiences. While I do undoubtedly share some of the same social experiences of coming to Scotland as an outsider, many of my social characteristics are nevertheless different from those populations being researched in this study, thus my positionality needs to be taken into consideration. As a thirty something, White British female interviewer it could be argued that my age, ethnicity, class and gender impacted upon the dynamics of the interviews conducted. Critical theorists have routinely challenged the dominance of elite discourse in academia arguing that instead of the colonial heritage of 'White neutrality' often adopted by the anthropologist or sociologist insiders who study a group with whom they have an attachment, gain better access, and obtain more intimate and reliable data results (Hill-Collins, 1990; Loftsdóttir, 2002). Unsurprisingly though, current conversation has turned to a debate about the researcher as both an insider and outsider, having a dual role, or even a fluid role continuously varying between these polar opposites (Naples, 1998). In this study with respect to ethnicity, I was always an outsider, but at times, with regards to gender, age and class I was also an insider, on most occasions I was both an insider and outsider, dependent not just upon the interviewee, but the context of questions. There is no doubting that being perceived as a 'White British' woman initially put barriers between myself and participants but like all barriers this was broken down and often in surprising ways. As a researcher there is always a need to connect with participants, but this can be done in various ways, using commonality in gender, faith, moral beliefs, class or localism. In the case of this research there were a number of occasions when I connected with a participant over their social position, as a student I could bond with some participants over issues of poverty. The flip side of this was with more 'middle' class, affluent participants there was communality over my educational background. Association with any research or any researcher is in part defined by how the researcher presents themselves to their participant (Maginn, 2007). There is no deception in these changing roles, every member of society has a deck of social identities and on a daily basis they choose which hand to play in order to make social connections.

Unsurprisingly, I found it challenging at first to establish myself and my research in both communities. Kawulich states that,

> "On several occasions, I remember thinking that everyone was looking at me and asking each other if they knew who I was. This is a very awkward feeling—to know that you are a stranger in their midst…." (Kawulich, 2010: 8)

This was especially true in large group meetings, such as community health talks or community events. On one such occasion I arrived to observe a health talk with the Chinese community. It was quickly apparent that I was the only person in the room who was not Chinese and CCDP members quickly started asking what health topic I would be presenting. When I disclosed to them that I was not a NHS healthcare professional, it was met with some confusion and suspicion. Who was this outsider? In this situation it was not enough to divulge who I was or the purpose of my visit it was the acknowledgement of CCDP workers and volunteers during the health talk that lessened suspicion and bred acceptance. In one-to-one situations it was easier for me to build trust and rapport. In some instances during interviews, interviewees would ask for advice or guidance in relation to a health issue. During some interviews however there was more of a general dialogue regarding how to search and gather health information. In these situations I became an informal health information provider. Through the use of the support services list participants were told about different NHS services such as NHS24 or NHS online if they had internet access. This provision of health information led in most cases to participants perceiving me as someone of value: that they could trust but also get useful information from, an action Johnson (1975) calls reciprocity an exchange between the researcher and the participant. A few of the African women from the Barton women's group began to ask me about other topics, questions regarding other African groups in Scotland, employment and even how to start a business. Whether the topic was health or something else I encouraged the women to seek further information through different channels: group leaders, other community organisations, or sometimes NHS staff who attended the group and of course I even suggested they look up their query up on the internet. It was important for me to continually encourage the women to believe that they could find this information; that they could empower themselves.

3.10 Overcoming Challenges

Initially I contacted community organisations and charities to set-up meetings to discuss the project in general and in particular to ask about the research methods being adopted in this study. CCDP was very enthusiastic about the study and agreed to utilise a self-completion questionnaire method to collect initial data about health information activities. However they strongly recommended that the questionnaire be send out translated into standard written Chinese. They suggested questionnaires be posted out to all of their members and the centre used as the place of return. It was to be made clear in the questionnaire that I was a PhD student from the University of Strathclyde but that CCDP was facilitating this research. It was hoped this would give me credibility within the community. Interviews through an interpreter were also encouraged by workers at CCDP who thought as long as a well-respected and trusted interpreter was present, interviews would work well. There was however concern over the idea of participant observation exercises, in practical terms CCDP community workers thought this would be very difficult as classes, groups and meetings which are always held in Mandarin or Cantonese (reflecting the different phases of Chinese immigration to Scotland). Their members had limited English and to force them to speak English, especially when the centre was there to encourage the community to meet and have a space where they could enjoy each other's company and use their first languages, would not have been appropriate. In later months however, my CCDP gatekeeper invited me along to monthly health talks held at CCDP for the community which were usually given by NHS health professionals in English and then translated for attendees. This gave me a unique insight into how the Chinese community acted collectively to gain and share health information.

When it came to working with the African community, I had a different experience entirely. Black African groups are usually amongst the lowest responders to research (McManus et al, 2006). This factor coupled with the sporadic distribution of Africans in Western Scotland was always going to make engagement challenging. Hence, a number of community and national organisations were consulted about the project and its research methods. It quickly became clear that although there was interest in the project, the method of a self-completion questionnaire would be difficult. One such meeting was especially productive: whilst consulting staff members from Waverley Care, enthusiasm but also caution was offered. Staff members did not think a self-completion questionnaire would be appropriate for the African community. Firstly the logistical complexity of sending out the questionnaire to service users was highlighted, issues of confidentiality raised, (because of sensitivities around the service users who attended) staff members were also reluctant to hand out questionnaires as they said it would "eat into their time" with service users. Finally, they thought response rates would be low and suggested I reconsider my approach. In this case, staff discussed the level of suspicion that remained within parts of the community with regards to paperwork. A significant proportion of the African community have gone through the asylum process and are therefore wary of giving out information. Staff members maintained that it took time to build trust and a rapport with service users; that the African community would be much more receptive once they knew who I was and the potential benefit of my research to the community. Obviously, this guidance was invaluable; it allowed me to concentrate on other approaches of the research project and ultimately on methods which would be fruitful. Staff members did think interviews would be productive and that participant observations would function well within for example a women's group, the details and organisation of which would subsequently take a couple of months to arrange. In the field as a researcher I learnt I had to listen and take advice from members of the community and if not from the community directly then leaders who would steer me in the right direction especially when it came to better engagement.

3.11 Sampling Methods

Both quantitative and qualitative approaches were carried out using non-probability sampling, the self-completion questionnaire under the umbrella of convenience sampling whilst interviews employed a snowball sampling technique. Snowballing as a sampling technique has long been adopted by social researchers; early traces of the technique are evident in Whyte's (1943) Street Corner Society. For the quantitative approach, every member of CCDP was sent out a self-completion questionnaire. Interestingly Bryman acknowledges,

> "….when the chance presents itself to gather data from a convenience sample and it represents too good an opportunity to miss. The data will not allow definitive findings to be generated, because of the problem of generalization, but it could provide a

> springboard for further research or allow links to be forged within existing findings in an area." (Bryman, 2008: 183)

This is exactly what the questionnaire data results did, they provided a starting point from which I could develop the next level of my research enquiry. In addition, it provided comparative commentary with existing research findings from earlier studies.

3.12 Questionnaires

Although I took the decision not to use the self-competition questionnaire as a method of data collection for the African population because of strong advice, I nevertheless felt that the questionnaire remained a useful data collection tool for the Chinese population. The self-completion questionnaire stage of this project was therefore aimed at attaining data regarding the community's demographics, use of NHS services and practice of traditional medicine, as well as usage of the internet for information gathering and sources of health information. The questionnaire was fully translated into standard modern written Chinese. The self-completion questionnaire had a straightforward design: the front cover summarised the research and gave completion and return instructions. A page was dedicated to explaining how data from the survey could be useful to service providers and the community, including organisations such as CCDP. In addition, a participant information sheet containing information about the research project, the researcher, data protection and useful contact details was provided. To encourage responses from the Chinese population no identifiable data was taken during this task so participants retained full anonymity as defined by de Vaus (2002). An example of the self-completion questionnaire pack is available in appendix B and a translated version of the questionnaire pack is also available in appendix C. The questionnaire itself had 20 questions in total; all 20 questions were closed questions although space was provided for other answers. Bryman, (2008) discusses 'respondent fatigue' and how the researcher needs to be mindful of using too many open questions or of the questionnaire being too long. Since the role of the questionnaire in this study was to function as a mechanism for the second stage of the project, a standardised format was adopted. Questions were based upon a desire to collect data on health information activities, so only 2 opinion questions were asked and these were not sensitive or challenging, they were questions relating to the amount of health information available and the availability of information in first languages. When designing the master questionnaire I consulted with Dr McLauchlan of the School of Applied Social Science at the University of Strathclyde. Dr McLauchlan had been an advisor on the university Ethics Board for this thesis and advised a number of changes be made. Bryman (2008) encourages the piloting of questionnaires but to also consider the work and opinions of other researchers, those more experienced in the field. A mini pilot was carried out with staff members at CCDP, if the questionnaire had been on a larger scale, and had significant influence on the project then a more extensive pilot would have been undertaken. Instead it seemed appropriate to utilise the cultural and language expertise of CCDP staff members. In total 350 questionnaires were posted out to CCDP community members, and participants were asked to complete and return questionnaires in a time period of 3 weeks. Once questionnaires were posted out, the CCDP gatekeeper asked if I could also develop an electronic version so members of the CCDP computer class could fill the questionnaire online instead of in hard copy. This was duly done, and a total of 8 people completed the online survey and data from this method was collected and analysed in the same way as data attained from the postal collection method. On reflection however, perhaps it would have been advisable to offer participants an online version as well as the postal return so they themselves could have chosen.

Response rates generally from BME groups tend to be lower compared with the white British population (Raleigh et al., 2007 cites McManus et al., 2006). McManus et al., (2006) offers further incite claiming, "… Chinese response rates tend to be similar to, or slightly lower, than response rates for Indians and Pakistanis." (McManus et al., 2006: 128). This would suggest Chinese response rates in general can be quite low in comparison to the White British population, some interesting secondary research carried out by the Picker Institute on behalf of the Healthcare Commission looked at NHS patient surveys and low response rates with BME populations (Picker Institute, 2007). The report cites a number of contributory factors to low response rates within these populations, ranging from: disengagement, misunderstanding, suspicion of the research's agenda, low literacy rates, and language barriers. Disengagement is a common problem associated with postal questionnaires in general, and despite greater investment in survey administration costs response rates have continued to decline (Teitler et al, 2003). Misunderstanding and suspicion were both areas that I worked hard to overcome, using CCDP as a well-recognised and trusted community organisation to facilitate this research was thought to be beneficial, whilst, the purpose of the questionnaire and potential beneficial research outcomes were made clear at the beginning of the questionnaire. Nevertheless, there may have been apprehension as to my role, perhaps potential participants expected a health survey to come from a more recognisable health service provider such as the NHS rather than a PhD student from a university. It is not necessarily a surprise that the response rate for the questionnaire task was therefore quite low. Of the 350 postal and 8 online questionnaires a total of 117 were returned which gives the self-completion questionnaire task a 32% returns rate. Bryman, 2008 cites Mangione's 1995 classification of response rates for postal questionnaires and says a 50% or lower response rate is not acceptable since it affords the potential for bias in the sample. However, Bryman does suggest,

> "On the other hand, many published articles report the results of studies that are well below this level… Mitchell (1985) found a range of response rates of 30 to 94 per cent…. if you achieve a low response rate, do not despair." (Bryman, 2008: 245)

Even if more time, money and a wider sample size had been used in this task, the response rate or data outcomes could arguably have been the same. Moreover, within the limited timeframe the questionnaire achieved it main aims; offering findings which then aided the development of interview schedules for the next stage of this research.

3.13 Semi-Structured Interviews

Undoubtedly the interview stage of this study was at the heart of this research inquiry. Interviews were carried out with both Chinese and African populations, and followed a semi-structured framework, whereby the interview had an overall structure to allow for data compatibility but also offered flexibility and further exploration of participant answers (May, 2001). The format of the semi-structured interview provides a platform upon which to base inquiry. Kawulich suggests,

> "Participants have the power to limit or to grant the researcher access to information. They also have the power to redirect the research to their own ideas of what they feel the researcher should be interested in. Allowing participants to talk off the subject sometimes provides fruitful information for studies on other topics." (Kawulich, 2010: 16)

As previously stated, the interview schedule was developed through the analysis and development of questionnaire data, it was also based upon previous health research studies (NHS Health Scotland, 2010; NHS Greater Glasgow, 2006; Hayter 2005). An example of the master interview schedule used in this study can be viewed in appendix D. The interview schedule was piloted firstly with a colleague to get an idea of its length and any initial problems with wording or layout. The interview schedule included 37 questions with five areas of interest including: community, NHS services, group dynamics, health information sources and the internet. On many occasions, however, alternative or additional questions were asked during interviews. Naturally participants were thanked for their time and offered a transcript of the interview as well as research findings if they so wished. Please see appendix E for an overview of the interviewee sample for this study.

3.14 Participant Observations

Traditionally a research method employed in social anthropology, social scientists across disciplines have come to value the benefits of participant observation; entering a social situation or social group to explore and uncover hidden dynamics at play (Bryman, 2008). In this instance I wished to gain an insight into health information activities, unfortunately language and access barriers prevented in-depth participant observation within the Chinese community. However, I was able to attend a number of health talks and observe how the Chinese community acquired and shared health information, the outcomes of which will be discussed in the following data chapters. I did however have more success in accessing and conducting in-depth participant observations within the African community.

In the case of the Chinese health talks, I listened to the health talks given by health professionals and observed the reaction and interactions of the audience and the discussions that followed. Lewis & Russell (2011) claim ethnography must be understood as fieldwork and in that sense many styles of contemporary ethnography are conducted in fragmented forms and are pragmatically being adapted to new contexts. Lewis & Russell outline,

> "We are proposing embedded research as a situationally appropriate way of 'doing ethnography' that is founded on the principles and practice of immersion fieldwork while being responsive to working with reflexive collaborators, adaptive to the requirements of ethics and other forms of research regulation, and accommodating to audiences eager for new forms of ethnographic output." (Lewis & Russell, 2011: 400)

In relation to Gold's (1958) classification of participant observations, I undertook two roles: a 'participant-as-observer' function as I was an active member of the social setting, but participants were fully aware of my status and a complete observer role where I did not interact with people and they did not have to take me into account (Gold's 1958 cited in Bryman, 2008). In either role it was necessary to evidence behaviours, experiences and general conversations I was witness to. It was beneficial to use a diary to keep accurate records, reflexive commentary and collect additional documentation such as health leaflets, fact sheets, organisational contact details. In the early stages of note taking at the Barton women's group I kept the area of inquiry quite broad, however after a number of weeks at the group and as interviews were conducted and transcribed, patterns appeared and these areas of interest where used as a loose framework for observations. As a result, note taking and analysis began to be shaped by areas of interest and topics discussed by the women, including: social networks and capital, issues of trust, language barriers, and cultural perspectives on health. However, it should be understood that flexibility remained, if an event or conversation relating to health information or information activities occurred then it was still detailed for further consideration. Comprehensive notes were always written straight after the group, usually on the train journey back from Barton as this gave me time to jot down a complete account of that week's meeting and start to link ideas together. These notes were then typed up at a later date and with other research data analysed collectively using NVivo 9.

Ethnographic elements include: observing, taking part, listening, inquiring, analysing and finally highlighting the social world of those who have opened their door to you. Li proposes, "Ethnography is both a process and a product." (Li, 2008: 112). In this project ethnographic research was carried out with the Barton women's group which lasted 7 months with a short summer break for the group for school holidays. Group sessions lasted two and a half hours and were held every Wednesday afternoon. Chinese health talks were more sporadic but generally held once a month for a two hour period, I attended 4 health talks in total. In the case of the Chinese health talks it was a completely observational exercise, where I listened to the talk and observed reactions and interactions. Although some faces in the crowd were familiar since they had been involved in interviews, nevertheless there was no risk of 'over rapport' (also known as 'going native' although this term is now viewed as being derogatory); the idea of the researcher losing their objectivity and engaging in complete socialisation of the culture and social situation they are studying (O'Reilly, 2009). However, in the circumstance of the Barton women's group it could be argued that there was a potential risk of becoming too close to participants. In order to avoid this, a number of preventative measures were employed. Firstly I remained a reflexive researcher, always reflecting back on my place in the social situation and the relationships I had built with participants, this is where diary keeping was particularly useful. Secondly, I maintained overt participation so every group member and beyond knew that "Kirsty was a research student". In order to solidify this, I used appearance as a marker of my researcher role. Many of the women at the group 'dressed up' for the weekly meeting, I had an appearance of a stereotypical student, the uniform of jeans and a t-shirt and backpack. The point of this was to create a little distance from participants, Hammersley & Atkinson (1995) argue that,

> "In overt participant observation then, where an explicit research role must be constructed, forms of dress, can 'give off' the message that the ethnographer seeks to maintain the position of an acceptable marginal member…." (Hammersley & Atkinson, 1995: 87)

I was always referred to as a student and when a new member of the Barton Women's group attended, I introduced myself and the study. In addition, gatekeepers and key informants always referred to me firstly as a student so it was clear from the start what my role was. Finally, I had frequent meetings with both supervisors updating them on the study's overall progress but also discussing any potential fieldwork issues, this method offered a broad risk adverse strategy whereby supervisors could offer advice based on their own ethnographic experiences.

3.15 Data Analysis

My overall approach to data analysis reflects what Flick (2007) defines as a flexible and iterative process, continually reassessing and reflecting on fieldwork data and theoretical frameworks. Managing such a large amount of data from 3 research collection methods required planning and organisation as well as the use of NVivo 9 and SPSS software. To assist me in planning and conducting data analysis I utilised two key handbooks for social scientists; Bryman (2008) as well as Ritchie & Lewis (2005). In addition, I also referred to Hammersley & Atkinson (1995) and Atkinson et al., (2001) and their handbooks on the principles and practices of ethnography.

Once quantitative data was collected from self-completion questionnaires it was input into SPSS and analysed looking in particular at frequencies and descriptive outcomes to get an initial picture of the health information activities. Key findings from questionnaire data then informed the development of interview schedules, especially around issues of health information and the use of the internet. Flick (2007) refers to the use of interview schedules as a means to keep consistency, asking the same questions in the same manner during interviews, maintaining the quality of the research being undertaken. Interview schedules at the development stage were also influenced by Chatman's (1996) information poverty framework. Since this study sought to investigate whether information poverty was evident several questions in interview schedules explored where and how information was sourced, as well as group dynamics and the use of the internet for health information. All of which referred directly or indirectly back to the propositions in Chatman's (1996) information poverty theory. Moreover, during participant observations and interviews, participants would discuss or display themes related to both Chatman's (1996) and Goffman's (1963) theories, I used these opportunities to try and unpick participants' meanings in relation to health information activities. This approach mirrors Hammersley & Atkinson (1995) and their argument for flexibility during ethnographic research in order to attain quality in social research.

Thematic analysis of data from interviews and participant observations was then undertaken to evidence relationships and patterns across the data. From interviews and participant observations I created in total 75 nodes, 35 of which became board codes, central to discussions in the findings chapters of this thesis. During the process of developing NVivo nodes I was once again using an iterative process, reflecting on what participants said or actions undertaken to allow me to test out Chatman's and Goffman's theories and to ultimately permit me to make defining statements. Chatman's information poverty theory with its 6 propositions offered a straightforward comparative framework, whilst Goffman's theories were more abstract, yet his concepts around stigma, especially, were used when analysing both interview and participant observation data with African participants. From the outset I decided to highlight not only patterns of behaviours which were frequent and showed relationships across contexts, but to also present the anomaly; behaviours or situations which stood out, which I believe offer further understandings to the complexities of health information activities within these two BME communities. Once I had completed a process of narrowing down node labels and reflecting back and forth with the theoretical framework employed in this study I then started to consider how present my findings in a style appropriate to the research methods employed and the interpretivist approach adopted for this study.

3.16 Chapter Summary

To summarise, this research has adopted an interpretivist philosophy with the goal of offering insight into the social world of health information seekers through understanding the meaning they attach to actions and experiences. Engaging in interpretivist research holds the danger of relativism, however Seale (1999) suggests that social researchers can be mindful of its traps and adopt it as a useful way of thinking in the field without necessarily subscribing to it as a doctrine. A grounded approach was utilised in the field to explore areas of interest, remaining open to new ideas and possibilities. Still buried in an interpretivist framework this research adopted a dominant/less-dominant design whereby mixed methods were utilised within a single dominant paradigm.

Making the right connections and getting the right research sites was crucial in establishing links with gatekeepers and participants. Multi-site spaces were tapped in to in order to reach out to both African and Chinese communities. As this chapter has detailed there were 3 community organisations/charities which were active in participant recruitment and promotion of this research. While key informants and gatekeepers were essential in information gathering, they offered me insight into both communities as well as putting me in touch with central figures to build useful networks. Interpreters also played a significant role in the process of research gathering during this study. Notably, the Chinese interpreter in this research played a dual role, apart from interpreting for me she also became what Owen describes as a cultural consultant detailing cultural customs and offering insight (Owen, 1985 cited in Jentsch, 1998).

Ethical considerations were paramount throughout this research. I followed the ethical guidelines of the University of Strathclyde, conducting overt social research, where participants were fully informed of my research intentions. I offered information in other languages and asked all participants for their permission to be audio-recorded and for those that wanted a written transcript of the interview this was duly sent out and updates of research progress provided. All participants as well as gate-keepers and key informants have been given pseudo-anonymity. I also took the decision to change the name and location of the African women's group where I conducted in-depth participant observations. This decision was taken because the group was small in number, and was situated in a small African community in the West of Scotland, I believe changing the name and location offers the ladies an added layer of anonymity. Knowing my own responsibilities whilst in the field was important on several occasions participants spoke of untreated health problems to which I advised them to visit their doctor but also gave out information sheets with details of alternative health services and support networks for them to utilise.

During the latter part of this chapter I offered reflective commentary on my research journey, commenting on how I built trust and rapport in both communities. I also reflected on my role as an informal information leader in some situations. Information and support did also come from the communities I was researching, especially at the development stage of research methodology. Key informants and gatekeepers guided me on what would work and what would not for their respective communities. The final part of this chapter is given over to discussing practical methodological matters including: sampling, questionnaire design; semi-structured interviews as well as commentary on ethnographic elements of this research.

This chapter has subsequently offered justification for methodological approaches as well as in-depth descriptions of research experiences during my fieldwork. Utilising a mixed methods approach for this research undoubtedly offered the best of both worlds, it allowed for a step-by-step development of research themes from participants own opinions and experiences, it opened up new avenues of exploration whilst providing an ever constant framework. On reflection, the complexities involved in the design phase as well as in the fieldwork itself, meant it was important to continual adapt to the changing contexts of this research journey.

Chapter 4 – Social & Cultural Influences

4.1 Chapter Introduction

This chapter will articulate, in a systematic way, material gathered during the fieldwork stages of this investigation. Chapters 4, 5, 6 and 7 are structured in the same order as the key research questions. This chapter will respond to question 1 of the four key research questions with a combination of data from the self-completion questionnaire task and findings from interviews, as well as, participant observation exercises. The first research question of this thesis seeks to explore social factors and cultural influences on health information activities. Themes such as attitudes to health, engagement with NHS services, ideas of trust, privacy, and the impact of stigma are all elements which will be analysed. Results from the field will be presented in a mixed format combining qualitative and quantitative findings, thus drawing focus to the research themes rather than research methodology. This manner of presentation creates a picture of the social worlds of health information seekers, showcasing their opinions and experiences. Throughout the chapter there will also be reference to earlier theoretical discussions with specific emphasis on the works of prominent academics, many of whom were considered in chapter 2. The chapter begins by putting the voices of participants into context.

4.2 Community & Social Support Networks

In order to fully explore the health information activities of African and Chinese populations, it is necessary to first understand the wider contexts in which participants navigated their lives. This wider context includes the differing communities to which participants may belong as well as the support networks they may utilise. Participants in this study identified themselves as belonging to a range of communities including communities based on geographical locations, ethnicity, faith ties, and gendered groups (like the Barton women's group). Hence it is important not to overlook the multiple communities that each participant identifies with. During my fieldwork, when I asked participants about community and how they felt about their community, I left it up to them to define their concept of community. I also asked participants about friends and family as well as those outside of their immediate circle.

Usually participants defined their community in terms of a local geographical location or along collective ethnic identities. Findings indicated 21 interviewees of the 30 African and Chinese participants (not including gatekeepers or community workers that I interviewed) acknowledged that they did feel part of their community, while 9 said they did not. Robert, an African man in his forties who was an active community campaigner and journalist describes his attachment through his interaction with facilities such as the local library and church, he also mentions local people that he knows and this indicates a feeling of belonging through association with people not just place. Gail a Chinese lady in her sixties who was retired also makes the same links with church, her art club and local friends. Subsequently, for participants to have a sense of belonging to a community they appear to need physical attachment as well as personal connections.

> *Robert (African male in his forties): I would say I feel part of the community in Shawlands because I attend the local church and I can shop at the local shops around I can use the library you know and talk to people… so I would say I feel integrated in my local community…*
>
> *Gail (Chinese female in her sixties): Well I go to the church… [laughs] I have friends living there and I belong to the Bearsden art club so…*

When participants stated that they did not feel part of their community, they frequently cited reasons relating to isolation or racism, (a phenomenon particularly evident in African respondents). Macy, a Chinese woman in her fifties who was retired, was the only participant to explicitly define her local community to include that of the White Scottish population. However, in the comments below she indicates the isolating affect her lack of English skills has had on her ability to engage with the White Scottish population.

> *Macy (Chinese, female in her fifties): I have some difficulty when I want to communicate with the local community, my English is not good. Lots of Chinese have this problem.*

Sarah, an African woman in her forties who was unemployed, and Tasha an African women in her thirties and a full-time mum of two, described the racism they have experienced during their time in Scotland and how this experience continues to exclude them from the White Scottish population. It is worth noting that Sarah and Tasha lived in different parts of the West of Scotland.

> *Sarah (African female in her forties): Okay but no all people are good, some people are good and some people are not. I live in Barton five years now I can say I live in a flat down stairs there is another flat down stairs, I can say the people down stairs who live in a flat they are very nice people and I got one neighbour they just make me 'why I live in this place?' they are very racist.*

> *Tasha (African female in her thirties): I kind of feel a bit isolated but not only isolated but when you are like walking down the block and people are shouting things at you it's not like you are feeling isolated but feeling like you are not wanted here you know that kind of thing.*

While discussing the topic of community and information sources three interviewees spoke of their own roles within the community, Rebekah an African woman just celebrating her fortieth birthday and a former teacher, now mum of two living in Barton and part of the women's group, Karen, a lady in her late forties, British Afro-Caribbean who identified strongly with her African roots, and Robert, all of whom described their involvement in their respective communities. Rebekah, Robert and Karen voiced feelings of responsibility to others in their communities, and felt a need to share information and ideas, including sometimes health information.

> *Karen (Chinese female in her forties): I don't go often but I try to attend the women's group, I feel someone in my position, I am perhaps better off than a lot of women here in Glasgow, I came up to work here… so I like to give my support and be apart and do whatever I can with ideas and stuff like that.*

> *Robert (African male in his forties): First of all because I feel my place is for the community, and also to share information because I am more engaged than other people in the community so I can share information with them. To share information with people on benefit or health or how to get benefit…*

> *Rebekah (African female in her forties): I think so, to myself I think so because people give me advice and I give others, I don't just keep I share, that is I share with others who want it to share.*

It can be argued that these three individuals because of their backgrounds and confidence to connect with their communities were engaging in informal roles as information leaders. Few Chinese participants mentioned involvement with groups or organisations instead they frequently cited long working hours in the catering industry. Only retired participants spoke of meeting with friends in their communities and undertaking activities, some of whom spoke of a centre in the local area where older members of the Chinese community meet and take part in activities. Cheng a Chinese man in his sixties who was retired was one such participant who told me about the local Chinese older person day centre.

> *Cheng (Chinese male in his sixties): I join a group called Wah Lok day centre*

> *Kirsty: Is Wah Lok very important to you to meet friends and find out what is going on?*
>
> *Cheng: Yes*

The term 'communities within the community' was a phase I quickly became familiar with after speaking with community and charity workers. The African community reflects the diversity of the continent itself, its history and its cultures. Maggie an African woman in her forties who worked for an African charity emphasised the differences between these 'communities within the African community' even in the ways in which they have settled and engaged with Scottish society. As previously stated, it is important to continually acknowledge the levels of diversity within BME populations in the UK (Modood et al., 1997).

> *Maggie (African female in her forties): if you look at the Ghanaian community, they have been a steady community they have been here for a while and they have come for different reasons other than seeking asylum and that makes their interactions within the Scottish community different from those that didn't because they came as students, they came on work permits and so they would probably be a group of people who are self-reliant, they know where to go, they know how to access stuff, so to research so maybe that's why they don't access some of the services, and yet when we look at Zimbabwean communities because more have come in as asylum seekers not so much as students but have become students we find there is less knowledge around how to access stuff and because almost being an asylum seeker comes with it that dependency, everything is almost like given to you, 'you have to go there, you have to go there' 'what you need?' 'go to so and so they will support you with that' 'go to the clinic and then will give you a social worker who has the specialities to deal with this' 'Go to the Scottish Refugee Council they will phone the Home Office' so it is almost like…*

Maggie’s reference to the backgrounds of different African communities and how they have settled and ultimately how they seek out information could necessitate different health information activities. Chinese populations living in the West of Scotland are also diverse, as discussed in chapter one, those who arrived in the 1970’s and to a lesser extent in 1980’s were the second wave of Chinese migrants to the UK from Hong Kong (the first wave of Hong Kong migrants came in the late 1950’s and 1960’s) most came in search of unskilled work in the catering industry (Chau, 2008; Wong, 2006). This group are viewed as the most settled population but as I uncovered, not necessarily the most socially integrated. The second group are younger, and mostly from mainland China who have come through the asylum process, while the third also represent a younger generation but this time from Taiwan, once again undertaking the asylum process. This diversity was first described to me by a Chinese health worker who underlined the diversity, as well as, some of the existing tensions within the community. With different generations, cultures and languages there is sometimes friction between more settled Chinese populations and new arrivals. The differing settlement patterns of the Chinese population may also reflect diversity in their styles of health information activities.

On the surface it is easy to argue that both African and Chinese communities suffer from social isolation, especially those going through the asylum process (Scottish Refugee Council, 2013b). Social isolation was initially identified by The Scottish Government as a major problem in their Asylum Seekers in Scotland Report (2003) citing the ‘no choice dispersal’ policy as a contributing factor to feelings of isolation for newly arrived asylum seekers in the city (Scottish Executive, 2003a). Moreover, the lack of connection with individuals and organisations out-with BME communities, as well as, experiences of racism evidenced by interviewees undoubtedly exacerbates feelings of isolation. Yet, from my observations and interviews I also witnessed connectedness, yes at times there was an undertone of friction between inner fractions but these small close-knit communities also harbour groups, such as the Barton women’s group and CCDP which comprise of individuals who had gone through similar life experiences which provided strong bonds and support networks, to encourage feelings of belonging. Research carried out by the Scottish Refugee Council (2011a) uncovered similar findings. Consequently, social isolation and community cohesion are both evident in this research, certainly racist experiences coupled by the emotion upheaval caused during the asylum process seem to exacerbate feelings of exclusion and isolation, but community solidarity with strong social ties amongst individuals with similar life experiences appears to provide social support systems, evident through the voices of participants and at the Barton women's group and community health talks at CCDP.

Interviewees often described how they regularly talked and shared health information with family and friends, and were regularly viewed as a social network with useful sources of health information, especially if the query or information related to an experience that friend or family member had themselves experienced, as Karen and Ka comment below.

> *Karen (Chinese female in her forties): Yeah, yeah well some of them are going through the menopause as well and we like share experiences and realising that there might be other things we identify that might be associated with the menopause.*
>
> *Ka (Chinese male in his sixties): Every time we meet, friends I usually meet are my age and my problem is their problem to.*

Friends, family members and neighbours were also referred to as key to the facilitation of more formal health information. Vera is a Chinese lady in her sixties and now retired, Vera and Dan talked about family members and friends who helped them source and understand health information on the internet. In the following interview exchanges Dan admits that it is his wife that uses the internet to find health information for him. Vera meanwhile, was an interviewee who did not have access to the internet but instead had family and friends to gather new health information to share with her.

> *Kirsty: Do you ever look up information about health on the internet?*

> *Dan (Chinese male in his thirties): Not yet.*
>
> *Kirsty: Would your wife do that if needed?*
>
> *Dan: My wife, yeah… I have looked up health information my wife did on diabetes and things like that. Because of our age, there are problems with this.*
>
> *Kirsty: Okay has anybody in your family or your friends ever looked up anything for you?*
>
> *Vera (Chinese female in her sixties): Yes*
>
> *Kirsty: Have they ever looked up anything on your health or diabetes on the internet?*
>
> *Vera: Yes they will pick up new information and they will call me.*

Zizi who does not like to use a computer, relies on her daughter to search for health information, in this instance Zizi says "*I tell my daughter and she gets information for me...*" so in a way her daughter is performing the role of an informal information leader, channelling information to her mother.

> *Zizi (African female in her forties): When I want some information I tell my daughter and she gets information for me...*
>
> *Kirsty: So would you use the internet to look up information about your health?*
>
> *Zizi: Yeah, sometimes.*
>
> *Kirsty: But you get your daughter to do that?*
>
> *Zizi: Don't tell anyone! [laughs]*

Macy who did not have a computer at home also confirms the same role played by her daughter in obtaining health information on the internet for her.

> *Macy (Chinese, female in her fifties): I look up things about menopause and things like that, but I cannot remember the websites…usually my daughter look up the websites for me and then I look.*

It became apparent during interviews as well as my time at the Barton women's group that few participants however had wider social networks. Few participants talked of belonging to other groups or organisations. Curiously, none of the members of the women's group had even heard of other African based groups or organisations, even though many of them used social networking sites on the internet. Thus, during my time at the group the ladies appeared to have limited social networks outside of the African community and therefore lacked opportunities and connections to seek and share information from sources outside their immediate social spheres. Their provisions were instead centred on local physical spaces and the women's group itself few ventured to other towns or cities, usually citing cost and time as explanations. Participants' from both communities appeared to lack social networks outside of their communities. This meant they relied heavily on narrow sources of information. For health information apart from traditional sources and the internet, they usually received new information in the form of health talks at CCDP or the Barton women's group, as Doudou suggests.

> *Kirsty: Do you find you have to rely on friends or other people in the community to find out what is going on with health things?*
>
> *Doudou (African female in her twenties): This time I am okay because I got that group.*

4.3 Health Beliefs

Understanding opinions and behaviours towards health and wellbeing is essential in considering the experiences, behaviours and practices of participants and their health information activities. Commissioned by the Health and Education Authority in England, Gervais & Jovchelovitch (1998) offer rare and extensive research findings on the health status and health beliefs of Chinese populations living in England. Significantly, they argue,

> *"Health beliefs and behaviours are largely dependent on cultural backgrounds and people carry with them the assumptions, values and knowledge that belong to their communities and give them a social identity."* (Gervais & Jovchelovitch, 1998: 7)

Accordingly, attitudes to health must be appreciated within their own cultural contexts. Ways of thinking about health and wellbeing do not develop in isolation instead they develop in social and cultural environments with sets of social values, norms and understandings (Gervais & Jovchelovitch, 1998). In this research Cheng's statement below summarises the attitudes of many participants in their understanding of what is needed to live a healthy life.

> *Cheng (Chinese male in his sixties): To rest lots, to get up early, to go to bed early, eat healthy food and do more exercise.*

Diet and exercise were clearly important to participants in striving to live healthily although some, like Tasha below, admitted this was not always possible. Although both African and Chinese participants underlined the importance of diet and exercise they talked about these issues in different ways.

> *Tasha (African female in her thirties): To be honest I don't really pay attention to what I eat, I eat what I like! And so far it hasn't made me sick! [we laugh]*

> *Gail (Chinese female in her sixties): [Laughs]… well try to eat healthily, actually, Chinese cooking is pretty healthy I would say and usually vegetable and fish and occasionally chicken and also some meat but mostly fish… Yeah, not too much sweet and not much alcohol…*

Gail's attitude to diet was common among Chinese participants eating very little red meat, mostly just fish, and buying fresh vegetables from the local Chinese supermarket. Many participants also mentioned the concept of 'clean' foods. This representation of the Chinese population maintaining a healthy diet is reinforced by figures from the Scottish Health Survey Topic Report 2008-2011 which shows 49% of Chinese respondents indicating they eat 5 potions of fruit or vegetables a day compared with just 21% of White British residents (The Scottish Government; 2012a). Gervais & Jovchelovitch (1998) found that food in Chinese culture is closely associated with health, the selection of appropriate food and drink at specific times of the day is seen as integral to good health. Karl, a second generation Chinese man in his twenties who worked as an IT support assistant, talked of still going to his parent's house for meals just so his mum could cook 'clean' food for him.

> *Karl (Chinese-British male in his twenties): Eat clean means, eat fresh, eat fresh stuff not processed.*

> *Karl: …I eat a lot of mums cooking even though I stay with my bro I still go to my mum and dad's to eat because they eat fresh and I am too lazy to cook. I could go home but it is easier to go see them, aye so eating clean and exercising every week.*

African participants meanwhile focussed on the foods they tried to avoid and also spoke about cooking with oil and eating fatty foods. Isa, an African woman in her twenties who was a full-time mum, and Iree, an African woman also in her twenties and an applicant for the British Army, both described their diets.

> *Isa (African female in her twenties): Vegetables… I don't like too much fat not good for health.*
>
> *Iree (African female in her twenties): Yeah not putting too much oil in and spicying those kinds of things…*

African participants during interviews and group discussions talked of blending diets by eating traditional African foods as well as British cuisine. Tasha was one such example of someone getting equated with British food.

> *Tasha (African female in her thirties): I think my diet is seventy percent British and thirty percent African.*
>
> *Kirsty: So bangers and mash… and chips!*
>
> *Tasha: Exactly, exactly. I drag people to Weatherspoons to introduce them to British food and at home, try this, try that!*

Another participant, Rosaline an African woman in her thirties and a full-time mum spoke of the differences not just in food types but also food preparation, cooking and accessibility. Rosaline reaffirms the many issues currently on the Scottish Government's agenda in reducing obesity - with the need for cheaper, more accessible, healthy foods (The Scottish Government, 2010b).

> *Rosaline (African female in her thirties): if I go back to my country. We do not have fat food in my country. All the food is from farm… fresh, you cannot keep food 2 days in fridge, you supposed to cook every day. In Africa, you supposed to cook every day.*
>
> *Kirsty: so it's not ready meals or frozen food?*
>
> *Rosaline: no, you cannot get frozen food there. So you make sure you try to cook fresh here, but it cost a lot of money to cook every day for fruit and vegetables, in Africa everybody have a farm, you can get the*

> *fruit and vegetables, easy. And you can go to anybody's farm and get the mango or orange or banana… but here it is very pricey.*

Discussions on food were often quickly followed by conversations on weight loss and weight control, especially when chatting with African women during group discussions at the Barton women's group. In the exchanges below it is clear that for Rosaline and Grace T an African woman in her thirties who was a full-time mum, exercise is central to losing and maintaining weight.

> *Grace T (African female in her thirties): Yes, yes I started to go Zumba. Now it's one month and… I don't want to eat so healthily… unhealthily! Like butter or many sugar, like many salt and oil. I don't want to be…*
>
> *Kirsty: But do you feel better, healthier from going to Zumba?*
>
> *Grace T: Yes I am feeling better, feel better because I want to lose my weight.*
>
> *Kirsty: so why have you started to go to all these exercise classes?*
>
> *Rosaline (African female in her thirties): because my doctor told me that my ideal weight, is 68, if it's 70 that's fine if it go beyond that… because if I go beyond that, I feel that my back and my waist is paining me, so I try to maintain that weight.*
>
> *Kirsty: so exercises about maintaining weight?*
>
> *Rosaline: Yeah, so want to maintain my weight*

Noticeably, exercise was discussed in different ways between both groups, Chinese participants talked of walking and doing Thai Chi daily, while African participants mentioned exercise classes or exercise videos. This difference is captured by Macy and Doudou; Doudou is an African woman in her twenties and a full-time mum.

> *Gail (Chinese female in her sixties): Yeah, yeah and we walk a lot actually it is important for exercise. We walk around our area every day apart from when the weather is no good we walk for 20-25 minutes.*
>
> *Cheng (Chinese male in his sixties): I started more than 10 years ago (Thai Chi) and then I have been practicing more than 10 years now so I know all the moves and now I don't join a class I just practice at home in my back garden but sometimes we went with a couple of friends to Botanic gardens to practice and sometimes we go to Kelvingrove gardens.*
>
> *Macy (Chinese, female in her fifties): Yoga, stretch and walking. I did not have job at the moment so I do these exercises for 1 and a half hour every day.*
>
> *Doudou (African female in her twenties): Yeah, exercise, I like exercise I used to do them in my home, before I was this size, I was too big and now everyone asked 'what happened to you, what happened to you?' I lose… I am doing exercise in my home.*
>
> *Kirsty: you said before about the Aqua exercise classes, how long have you been going to them?*
>
> *Rosaline (African female in her thirties): just for a month… Yeah, just for a month but this time, sometimes I go to Zumba.*

When deliberating about notions of health, African participants in both interviews and group discussions focussed on mental health issues as well as physical health. Conceivably this could be due to the immigrant backgrounds of many participants in this study (as discussed in chapter 1). Most African participants in this research had come through or were still emerging from the UK asylum process, and alluded to the hardships they had endured in their lives, which possibly explains an emphasis on being calm and happy in order to be healthy. Pauline was an African woman in her forties who was unemployed, while Mrs G was an African woman in her thirties who was a full-time mum of two and prominent figure at the Barton women's' group.

> *Pauline (African female in her forties): I have to be healthy physically, mentally and you know… emotionally healthy.*

> *Mrs G (African women in her thirties): Well mentally, physically and emotionally, I think if I am well emotionally then I am well in every area of my life. I think the emotional it can every other, it can affect your physical life. It can affect all of you, to be well physically, mentally and emotionally more emotionally.*

Overall, from discussions with both BME groups, I would contend both had clear ideas about what it is to be healthy, they understood the challenges they faced in getting fresh, cheap healthy food as well as incorporating exercise into everyday life. Certainly Chinese participants seemed very proactive in being healthy, with their dietary and exercise regimes. The Scottish Health Survey Topic Report 2008-2011 shows 91% of Chinese respondents rated their health as good or very good, considerably higher than the national average of 76%, whilst only 53.7% of those who identified themselves as Black, Caribbean or African rated their health as good or very good (The Scottish Government, 2012a: 14). To sum up this section, I thought it apt to finish with a statement from Mr Lee, a Chinese man in his sixties, and a traditional Chinese Doctor, who outlined what is needed to be healthy.

> *Mr Lee (Chinese male in his sixties): In Chinese medicine they say 3 things very important. One is keep your mind calm and happy. Another is eat healthy food, especially don't drink too much and don't eat too much oily food, deep fried food, more vegetables, more natural*

> *food, in our Chinese class they talk about this, these three things important to keep body healthy.*

4.4 Traditional Medicine

In understanding where and how Chinese and African populations source and share health information it is important to consider not just traditional NHS services but other possible sources of information in the form of alternative and traditional medicine. There was an expectation before entering the field that traditional medicine might play a central role, especially for Chinese participants. The direct consumption of traditional medicine did not have as active a role as expected, with participants only lightly involved in using traditional medicine and always in conjunction with primary healthcare services. Chau et al., (2011) describes the pragmatic reasons for none use of traditional Chinese medicine in the UK, detailing financial costs, the effectiveness of traditional Chinese medicines in dealing with illness and citing the Lai Yin Association (1999) study which raised the issue of availability, regarding good quality traditional Chinese practitioners. However, it was evident in this study that many Chinese health beliefs still transcended from traditional Chinese medical philosophies. Participants in this study, like those in Green et al., (2006) research, often talked about hot and cold, dry and wet as well as the need for balance in a holistic approach to health. Unsurprisingly, Chinese participants during interviews did not ask for a definition of traditional medicine as they simply equated traditional medicine to mean Chinese traditional medicine. Meanwhile, some African participants did ask me to explain further, to which I offered examples such as acupuncture, herbal teas, and massage.

As stated previously, unfortunately I was unable to conduct a self-completion questionnaire exercise with African participants (a full explanation is provided in chapter 3). Hence, all data from the self-completion questionnaire relates to the Chinese sample only. With regards to the use of alternative or traditional medicine, data from the questionnaire outlined an even split. When asked question 3 “Do you use any alternative/traditional health and well-being practices or medicines?" 49% of the sample said yes and 44% said no with 7% of the sample not providing an answer (SPSS output for this question is available in appendix F). This even split was somewhat reflected in interviews with African and Chinese participants. During a conversation with my Chinese interpreter she informed me that many Chinese people living in the area did not have a positive opinion of Chinese doctors. She explained that they had a reputation purely as businessmen and that there was a level of mistrust within the community. Chau & Yu 2004; Chau et al., (2011) and Green et al., (2006) all spotlight similar opinions in their research. Members of the Chinese community often view Chinese traditional doctors as unreliable, because they belonged to a commercial system rather than part of a public healthcare service (Chau & Yu, 2004). The only time I was exposed to this mistrust was during my interview with Kai a Chinese man in his sixties who was retired.

> *Kirsty: Have you ever used traditional Chinese medicine?*
>
> *Kai (Chinese male in his sixties): No because Chinese practitioner is not reliable…*

Most interviewees simply did not open up as to why they did not use traditional medicine and for those that did they described them as one-time events. Paul, a Chinese man in his twenties who worked in the kitchen of a Chinese takeaway, describes his experience.

> *Kirsty: Okay… do you ever use any traditional or alternative medicine?*
>
> *Paul (Chinese male in his twenties): Yes when I was in London I went to Chinese practitioner… I fell and hurt my arm and I try acupuncture.*

Also common in these discussions was the use of traditional Chinese medicine for mild illnesses, while Western medicine was still used for serious more ailments, as evidenced by Ka a Chinese man in his sixties who had owned several Chinese restaurants but was now retired.

> *Ka (Chinese male in his sixties): I usually go to the clinic and use Chinese herbal medicine when I have cold or cough, the other illness I go to GP.*

This use of traditional medicine for mild illness and general wellbeing was also evident with four African participants, Ozzy an African man in his thirties who was a university graduate, Robert, Karen and Rebekah.

> *Robert (African male in his forties): I used to say the traditional was more….Herbal tea…everybody can get it, I use both.*

> *Ozzy (African male in his thirties): …my grandfather used these herbs, he used to stir it and drink it, so I did take it and it make me, actually it makes me the person I am today.*

> *Karen (Chinese female in her forties): Definitely, my own… actually on my mums side of the family there're very much into all that natural remedies… the use different types of bush, anything that is growing and they will identify it as good for different conditions.*

> *Rebekah (African female in her forties): Yes there is this tea here… green tea it's like a traditional tea we have in Nigeria, when I saw it I thought it would be the same, in Nigeria we collect grasses I don't know if you call it grasses here but we cook them and the smell is just like that green tea.*

However the remaining 13 African participants who did not use alternative or traditional medicine did not give much in the way of detail as to why, and since the aim of this section of the interview was to gain context around health information activities, the issue was not explored further. One final point of interest should be considered, when asking African participants about traditional medicine some participants seemed a little unsettled by the question. In the final stages of interviewing I started to reflect that African participants were perhaps linking the terminology of alternative or traditional medicine with that of traditional bush doctors or possibly religious practices associated with West African countries. Doudou's reaction, her need to convince me, that she has never used 'those medicines' possibly verifies this assumption.

> *Doudou (African female in her twenties): No I know some people who use it, who use it back home they use those medicines when they go to the doctor but no not for myself. No, since I was born I have never used those things.*

In short, alternative and traditional medicine was employed by Chinese participants in a limited but flexible manner in combination with Western medicine and NHS services this outcome reflects previous research conducted with Chinese populations in the UK (Liao & Mcllwaine, 1995; Chau & Yu 2004; Yu, 2006). Chau and Yu (2004) suggest traditional Chinese medicine and Western medicine are both employed. Western medicine is usually seen as more effective when dealing with serious illness but both systems of healthcare are nevertheless seen as complementary to each other. Even when traditional Chinese medicines are not fully utilised by sections of the population, traditional Chinese health practices remain embedded in Chinese culture and identity and consequently continues to influence attitudes to health (Gervais & Jovchelovitch, 1998; Chau & Yu 2004). African participants had very limited use of alternative or traditional medicine and therefore do not seem to rely on it as an alternative source of healthcare provision.

4.5 NHS: Services and Frontline Staff

Since health information is usually accessed through NHS channels, I though it important to form an understanding of how participants felt about the NHS and how they interacted with NHS services. The Chinese population sampled in the questionnaire exercise consisted predominantly of older age groups (please refer to appendix G for the age and gender breakdown of the Chinese questionnaire sample). This representation of an aging population possibly reflects its use of additional NHS services, including physiotherapists and hospital in-patient services. Like questionnaire respondents, most interviewees spoke of seeing their doctor and dentist, and a few described times when they have needed more specialist attention. Ying is a Chinese woman in her forties who worked in the kitchen of a Chinese takeaway but was forced to retire due to a long-term illness.

> *Ying: I have seen a psychiatrist and been offered counselling.*
>
> *Gail (Chinese female in her sixties): ….I have used the physiotherapy centre when I had a frozen shoulder…*

Up-take of NHS services by Chinese populations living in the Glasgow area has traditionally been low (NHS Greater Glasgow, 2006). Gervais & Jovchelovitch, (1998) suggest this trend is because Chinese communities have a lack of knowledge in relation to the range and accessibility of NHS services open to them. However, when it came to usage in this study, data from the questionnaire indicated regular usage of NHS services. Question 2 of the questionnaire asked: "Over the last year, how often have you used NHS services?", 55% of the sample used NHS services at least once every 6 months, while 21% said at least once a month and 18% at least once a year. A smaller number, 3% said they used NHS services once a week and the remaining 3% said never (please refer to appendix H for SPSS output of NHS service usage split by gender). As previously discussed the age skew of the sample must be taken into consideration when reflecting on the usage of healthcare services. Opinions of NHS services from interviewees were mixed: both positive and negative examples of engagement with NHS services were expressed. At first, Cheng's standard answer of "very good" was frequently provided.

> *Kirsty: Do you ever use other services like, dentist, nurse or podiatrist?*
>
> *Cheng (Chinese male in his sixties): Yes.*
>
> *Kirsty: How do you find these services?*

> *Cheng: Very good.*

However, after further probing, many interviewees started to relay personal experiences and opinions of involvement with NHS services. Nadia is an African woman in her thirties who works in an office. After initially detailing a personal health concern, Nadia expressed her feelings of frustrations as to the reactions of health professionals because she feels that a potentially serious health matter is not being properly addressed.

> *Nadia (African female in her thirties): Yeah… sometimes I don't feel like they are listening when I am explaining, they don't like examine you, they don't go further, all I get is I refer you to the hospital straightaway and when they do you have to wait for a long time, months and months, to get appointment from that hospital you have been referred to and then when you do end up going to the hospital sometimes… don't help…*

Nadia's use of the phases '*don't feel like they are listening'* and *'don't help'* clearly illustrates her exasperations. She does not feel health professionals are taking her concerns seriously and this forms a barrier between her and healthcare professionals. Karen also vented her irritation with the manner in which she feels the NHS manages women's health concerns. From her personal experience Karen believes there is gender inequality in relation to how women's health issues are handled by the NHS at large.

> *Karen (Chinese female in her forties): Researched it first and then went to the GP but I didn't find him very helpful…*
>
> *Kirsty: Did he mention HRT?*
>
> *Karen: hum… don't trust it… I did make that quite clear*
>
> *Kirsty: But that was a long time ago have they not got anything else they can give you?*

> *Karen: No if this was a man's issue they would have got something in place, but women's issues are never taken seriously that's what I think.*
>
> *Kirsty: Okay, why do you think women's issues are never taken seriously?*
>
> *Karen: Because women are marginalised in society. You know we live in an unequal society.*

Rosaline also commented on her dissatisfaction with the way her son and herself have been treated in the past by NHS frontline staff and doctors. She spoke in detail of her concerns that her son's health was not being treated properly and that access to healthcare was sometimes difficult or even prevented.

> *Rosaline (African female in her thirties): yeah, I think there is a problem, with the… sometimes I feel that when I phoned them and you know I am not from Scotland and they… then the person asking, you say please I don't understand could you speak slowly, sometimes they are angry. There is another problem, there are two people there one is a man and one is a women. Last year, my boy, he is sick and I phone and the doctor say okay it is not serious, so we wait for next week and the following week he couldn't sleep in the night so I took him to Wishaw General Hospital so I don't know another 2 weeks the same boy the same again, it's not asthma but he find it hard to breath so I phone and they say can you bring the boy and I say yes, and because he was not very well I took a taxi to the place and there was a lot of traffic and I couldn't reach there so maybe I am 10 minutes late and the doctor say I couldn't see because I am late. And the boy is sick!*

Notably, Rosaline pinpoints frontline staff and their lack of patience and empathy as an initial barrier to healthcare. This complaint was similarly voiced by Nadia, who is left feeling frustrated when phoning the GP's receptionist.

> *Nadia (African female in her thirties): …but what I don't like about my GP is phoning, speaking to the receptionist, honestly she talks to me like I am deaf, I am not deaf, maybe I am foreigner but I understand. She does not need to shout at me I understand.*

In these examples the conflict between patients and frontline staff is perhaps exacerbated by different cultural expectations within this social interaction, as Maggie, an African charity worker describes below.

> *Maggie (African female in her forties): It's a two way process. You get the receptionist, the African patient doesn't look at the receptionist face, they are looking down, they are looking away, the receptionist feels 'she is being so rude!' and the person thinks 'why is this receptionist not so friendly?' so there you go it's already there is a communication breakdown, the African patient is thinking racism, discrimination, the receptionist is thinking oh… I really can't understand this culture, what is really happening with this patient? Why don't they look at me? So what is going on the patient thinks she (the receptionist) is in a position of authority which I don't look in their eyes I look away, that's the African way of respect, you know so it's those little things that once you know you kind of begin to pick them out, you realise there is more to the work that we do, even in the way in which people access services, which is not just about having a leaflet there or an interpreter but the little things that go with that.*

Issues of frontline staff and a lack of cultural training was also raised by Sheena a Scottish women in her thirties who worked as a development worker at the Scottish Refugee Council. Sheena proposes that frontline staff are indeed 'gatekeepers', an assertion true, on many levels. Frontline staff remain gatekeepers, not only for direct access to the doctor, but also gatekeepers to a positive experience of the NHS and the subsequent building of trust within healthcare generally.

> *Sheena (White female in her thirties): Sometimes what we find is that training and awareness are a big issue with frontline staff, sometimes the receptionist might get overlooked whereas the GP they have that, sometimes you feel sorry for them because how are they supposed to know who is entitled to what but at the end of the day they are the gatekeepers if they make a mistake the implications are huge….*

Figures from the 2007 GP Patient Survey by the Department of Health for the UK Government outlined 3 main groups who are more likely to report negative experiences of trying to access their GP. These included younger people, patients registered at large GP surgeries and patients from BME groups (Department of Health, 2007: 4). The 2007 GP Patient Survey also reported that while almost 9 out of 10 White British patients were able to make an appointment with a specific doctor, patients from BME groups were less likely to do so (Department of Health, 2007: 45). In Rosaline's description she immediately recounts the barriers she has experienced from frontline staff in accessing healthcare for her son. Consequently, frontline staff play a vital role in building reassuring and constructive relationships with BME populations. Tasha's statement underlines this point when she demonstrates the link between how she feels she gets on with her doctor: "*very well. I get on very well*" and how frontline NHS staff react to her in the GP surgery: "*it's something when you walk into a GP's and they know your name*". NHS services are being used by both communities, however African participants emphasis a clash in accessing healthcare and the role of frontline staff in this process. A process which has a significant impact on their perception of the NHS and the quality of care it provides.

4.6 NHS Health Professionals: Confidentiality & Trust

Whilst discussing NHS services with participants, attentions turned to the key player in health information dissemination, that of the doctor, consequently I explored this topic in a little more detail with participants. A recent study carried out by the Scottish Refugee Council (2013a) highlights the key role GP's have in the health of asylum seekers in particular. As asylum seekers often have to move around the city they are dispersed to, they frequently have to change doctor. Pauline was one such participant who talked about the upheaval she had experienced since moving to Glasgow.

> *Pauline (African female in her forties): …I spent 3 months in Maryhill in temporary accommodation… when I first came here I was in Ibrox and at that time I was asylum seekers and you aren't allowed to say no… then I move from Ibrox to Springburn in October or November then I moved to Govan…*

The Scottish Refugee Council's (2013a) research, suggests this constant moving, not only causes physical disruption, it also causes mental anguish as asylum seekers are forced to re-tell each new GP their individual story, as well as, their health problems. (Scottish Refugee Council, 2013a) This constant need to re-register with GP's surgeries and other healthcare providers affects continuity of care for patients, evidence of which is found in other BME communities, most prominently in the Gypsy-Traveller community (van Cleemput, 2000). When questioned, all participants in this research said they were currently registered with a GP and most with a dental surgery. The need to trust your doctor was obviously very important to participants. Kohn (2008) suggests that people's trust with their doctor is based upon personal experiences, as well as the doctor's certificates on the consulting room wall. Trust with the doctor obviously provides a supportive and open channel through which healthcare can be offered, yet, it also encourages trust of the healthcare system as a whole. (Anderson et al., 2003) Robert was outspoken on the need for the NHS to involve itself visibility within the African community to build greater trust.

> *Robert (African male in his forties): The most important thing is to build trust, some of them…. in the Black community, in the African community people are so suspicious…*

Robert explained during our conversation that a lack of trust with authorities was common within the African community. Issues relating to authority and welfare he suggested came from past experiences. Africans may have been badly treated by authorities in their countries of origin, which unfortunately leaves a lasting legacy. Secondly Robert emphasised fear, fear within the community, created during their experiences of the asylum process. He described how claimants have to detail personal accounts of traumatic experiences and this can include specifying health problems and illnesses both physical and mental. Robert believes there is a fear within the African community that this health information is shared between government establishments and ultimately may help to decide asylum claims.

> *Robert (African male in his forties): I would say if something is more private……refugee or asylum seeker the pressure of the system, all the mental torture they receive in that system creates fear. Things cannot be easily said or easily shared, they will keep it because…..someone will come maybe someone will take that….information and do something with it.*

Sheena from the Scottish Refugee Council was also concerned about how health information is shared and possibly used in asylum claims.

> *Sheena (White female in her thirties): …before they come to us they will have often not always been to the screening unit in Croydon to log an application and at that point they will be asked questions about their health as well but what is done with that information is not clear you know they are not supposed to use the information they take at the screening interview to make the decision on the asylum claim later on, we know in some cases that does happen, so… but they are not supposed to legally, they are not really referring people to other services because often people are dispersed from Croyden to Glasgow to Cardiff to Birmingham to somewhere else in the country.*

Consequently, this mishandling of health information and lack of transparency within the process clearly breeds fear and mistrust. Robert emphasised the need for health professionals to stress the levels of confidentiality when disclosing health problems and the need for more one-to-one interactions between African's and NHS health professionals.

> *Robert (African male in his forties): They must know that it is kept confidential.*
>
> *Robert: Aye, aye… The NHS they need to upgrade they need to update something has to be done on their communication strategy with the community how they work… visit people in their own house, where people passing by can come…*
>
> *Kirsty: Why do you think going to people's houses is important? How is that different?*
>
> *Robert: It gives more confidence to people to speak if health is a secret for them then it keeps it private. Then the people will give them information.*

In the aforementioned Robert puts prominence on the environment in which health information is given over, that people will be more trusting and willing if the environment encourages confidence through notions of confidentiality and privacy. On the contrary Chinese interviewees acknowledged that they trusted their doctor and when asked why this was, most thought he/she was a professional. Moreover, Wong's (2006) study testifies that the majority of Chinese people regard their GP as the first person to turn to for help when they are ill. Dan is a Chinese man in his thirties who worked in the kitchen of a Chinese takeaway and represented effectively the attitude towards doctors for Chinese participants.

> *Kirsty: okay and do you trust what the GP… the advice the GP gives you?*
>
> *Ying: I believe in professional.*

> *Macy (Chinese, female in her fifties): Yes I trust the doctor because he is a professional.*

> *Dan (Chinese male in his thirties): Because he is my GP and I have to trust him and he can help me.*

One issue that was prominent with Chinese interviewees was the seeming lack of time doctors had and how this impacted on patient-doctor confidence. Although Gail had a good relationship with her doctor, she said her husband did not and this was because of one particular consultation described below. Karl and Macy also echoed the idea that the doctor did not have time for them. Regard is also highlighted as a crucial factor in the development and maintenance of the doctor-patient relationship. Regard in the sense that the doctor needs to appear interested and 'on-side' with the patient (Ridd et al., 2009). Subsequently the development of regard within the patient-doctor relationship is linked to the time and attention given to patients and their health, a point exposed in this research.

> *Gail (Chinese female in her sixties): Yeah she listens, sometimes I think my husband's experience with her was not very good because one time she was careful about the length of the appointment and he had a lot of problem and he ask… and she said sorry we have already gone over time… blah, blah, blah… and so he lost confidence in her.*

> *Karl (Chinese-British male in his twenties): Now generally I go to my GP or now because GP's are generally quite busy straight onto the internet.*

> *Macy (Chinese, female in her fifties): ….some of the doctors are good and some of the doctors are a bit impatient.*

Another feature of the patient-doctor relationship highlighted by Chinese interviewees was that 'things are done differently'. Cultural understandings and expectations of health and how health is treated were discussed. Fang is a Chinese woman in her twenties who was a full-time mum. In Fang's description below she clearly feels disappointed that in her view the doctor is perhaps not taking her seriously.

> *Fang (Chinese female in her twenties): Depends, sometimes I feel so bad and doctor says go home and drink water. Doctors here in comparison with Chinese doctor, they don't give you medicine until you are really ill. It's not that the doctor is not concerned with your illness it's just they different.*
>
> *Kirsty: Culturally different when it comes to health?*
>
> *Fang: Probably a bit.*

The perception that doctors did not take patients concerns seriously was also expressed and expanded during discussions with African participants. Mrs G said she didn't trust her GP 100% because every human being was able to make a mistake but she also voiced her frustration that the doctor would always give her the same advice no matter her health concern.

> *Mrs G (African women in her thirties): They say go to your household and drink water… just drink water and you will be okay and you are thinking what is wrong? If I am feeling headache and I go there they will just tell me to drink water, if I have headache drink water to and I just rest and everything… but if it's something I don't understand I don't know…*

However, not every participant I spoke with had negative experiences with their doctor. Lady Hay is an African lady in her twenties and a full-time mum. Both Lady Hay and Rebekah described their doctors as professionals who listened to their concerns.

> *Lady Hay (African female in her twenties): Oh they are professionals, specialists …so they are professional*

> *Rebekah (African female in her forties): Yes it's a man at the doctors and he good. He sits down and listens attentively and give you what you want.*

Overall, there was a mixed response from participants on the topic of doctors. Individuals who did express concerns like Mrs G and Fang were clearly frustrated by their doctor's apparent lack of action. Moreover, Robert's concern that the African community are especially vulnerable because of their previous life experiences, and subsequently are in need of greater attention in order to build trust is an essential conclusion when contemplating the barriers to health information activities. Thus trust and privacy were frequently expressed as two critical concerns to the doctor-patient relationship. Issues of trust and confidentiality were two factors which emerged from discussions about the doctor-patient relationship. Confidentiality was of prime concern for the African community and this once again might reflect the number of African participants who have gone through the asylum process. Within the Chinese community there was concern over regard for the patient, especially in relation to the amount of time and the level of interest in patients and their health conditions. However, there was an established level of trust associated with doctors because of their professional status within the community. For African participants meanwhile there was a spilt, some mentioned a level of trust within the patient-doctor relationship, but for others there were clear feelings of frustration and disappointment over regard, with an apparent need to build stronger trusting relationships for the community.

4.7 Country of Origin's Healthcare System

Healthcare systems in countries of origin, was not a topic initially considered. Nevertheless, during early interviews with Chinese participants they mentioned their countries of origin and the healthcare they had or in some cases were still receiving. After one particular interview where this subject had been broached, the local interpreter told me that for many Chinese living here, if they have the finances, they go back to Hong Kong for healthcare, especially if it was viewed as a serious health concern. Gervais

& Jovchelovitch (1998) discuss this pattern of return as common amongst the Chinese population, however, they proposed that experiences of a different healthcare system can lead to unmet expectations when utilising the NHS. In the following exchange with Kai I asked him for his opinion of the Chinese healthcare system.

> *Kai (Chinese male in his sixties): I cannot tell because when I see a doctor in Mai Chow they ask you a lot of things in detail but here the doctor always look at the screen of the computer, I don't know if it is modern technology or something*
>
> *Kai: In Mai Chow we usually go to the same doctor because it's a private practice and you become quite friendly over the years, every time I went he know what's wrong with me. But here it's not as good, the relationship is not as good.*

Kai's focus on the doctor's interaction with him is important to consider, especially in relation to the previous discussion on the patient-doctor relationship and, the GP Patient Survey (2007) indicating that patients from BME populations were less likely to get appointments with the same doctor. (Department of Health, 2007) Cheng and Macy also stressed the speed and thoroughness of the service in Hong Kong.

> *Cheng (Chinese male in his sixties): Hong Kong is much more convenient, if you pay you can be seen in 24 hours and if you have no money you can go to the government hospital it's cheaper.*
>
> *Macy (Chinese, female in her fifties): I think Hong Kong system is better! …I thought they were more professional and more thorough…. things can be dealt with much more quicker than here.*

The intention of this line of inquiry was to get interviewees thinking about how healthcare and access are structured differently in different countries. Not every Chinese participant returned to Hong Kong, many cited the costly flights as one reason. Moreover, not everyone I spoke to thought the Hong

Kong healthcare system was better; Ka thought medical equipment was better and waiting times less in Scotland.

> *Ka (Chinese male in his sixties): It is better equipped here.*
>
> *Kirsty: Better facilities or better medication?*
>
> *Ka: Medical equipment, because the population is not as big as Hong Kong so you don't have to wait too long.*

Ozzy was the only African participant to compare healthcare systems, highlighting the influence that British colonialism has had on the Nigerian healthcare system. This is possibly an influence to consider in African communities; their familiarity with a healthcare system and its engagement style.

> *Ozzy (African male in his thirties): Actually Nigeria was colonially British as well so there are similarities in what they do, how they visiting, and stuff like that. I would say the most different part… there were many similarities in what we do with the British… in the UK so to say but the standards is quiet low back home.. it is quiet low and in terms of care…*

It is important to note that two participants in this study were from second generation BME populations and so their country of origin was obviously the UK. This topic was not explored during every interview nonetheless it is interesting to consider how healthcare systems and information provision within participants' countries of origin continue to influence participants' perceptions and engagement with the NHS. In some cases, as documented participants utilised the services of both healthcare systems, further research into this area of interest could gain a fuller understanding of the influence of previous healthcare experiences or current dual experiences on current health information activities.

4.8 Health Ownership, Stigma & Privacy

It became evident during this research that cultural views on health and wellbeing influenced active health information behaviours and practices, in particular cultural attitudes centred on issues of health ownership, stigma and privacy. Subsequently it is important to analysis these topics in greater detail. Beginning with a discussion on ideas of health ownership; Chinese participants often referred to health as primarily their own responsibility. That the doctor's job was to try and make them well at times of sickness, but on the whole their health was down to them. Cheng and Mr Lee underlined this point on health ownership in the statements below.

> *Cheng (Chinese male in his sixties): The western people do not do as many exercises as Chinese do because there are a lot of Tai Chi class, Ku Foo class and a lot of people walking.*
>
> *Mr Lee (Chinese male in his sixties): Yes I think everyone Chinese do more… they more aware, they know more about their health.*

Gervais & Jovchelovitch (1998) acknowledge that Chinese holistic health beliefs are deeply entrenched and that these all-encompassing representations of health associate health with issues of lifestyle, social networks and environmental conditions. Chinese interviewees participated in active informal health information activities amongst family and friends and talked of simply knowing what to eat and do to stay healthy. Embedded in Chinese attitudes and practices to health were therefore ideas of health ownership re-enacted through preventative forms of healthcare. Daily living as told by participants in this research, revolved around preventative healthcare measures through diet, exercise and proactive mental health activities. However, this ethos of detached preventative care; relying on yourself as well as informal support networks for health information may result in a crucial time delay or an overall lack of possible engagement with professional healthcare services (a point discussed by Chinese community workers but not directly spoken about by interviewees). During their research on the health seeking activities of older Mandarin speaking Chinese living in Los Angeles, Pang et al., (2003) attributed, in part, this reluctance to seek assistance from outsiders as a central barrier to healthcare. Thus, health ownership must be understood as a central part of health information activities for Chinese participants in this research.

During conversations with community and charity workers it became apparent that they play a vital role in signposting individuals or at least encouraging them to use different health information sources, which in this example by Maggie included using the internet.

> *Maggie (African female in her forties): I don't think so no, part of what we do when people come to our project is 'do you have an email address?' is the first kind of question for contact and if people say no we ask 'do you use the internet?' and then we ask 'would you like to gain computer skills?' so…. You know it is one route where we are trying to encourage people so people have another source of information.*

However Maggie also highlights the risk of stigma associated with certain illnesses and the consequences for service users of Waverley Care. Maggie suggests particular illnesses suffer from associations of stigma because they are usually associated with ideas of sin (*Maggie's own definition*).

> *Maggie (African female in her forties): I mean it is quite interesting in terms of when we look at chronic illnesses, I think one of the changes with HIV is, because it is concerned one of those… hum… morally linked illnesses you know it's most like…. it's a sin, it's a sinful disease or you know….*

Maggie goes on to detail the level of fear at being associated with Waverley Care because of its work with HIV positive Africans. Here Maggie is emphasising Goffman's (1963) fear of stigma itself; an individual does not need to disclose to the community their HIV status positive or negative, simple being associated with a HIV charity, in this case Waverley Care will mean the individual faces stigma by association.

> *Maggie (African female in her forties): I mean without even talking about facebook that thing there is always that worry about being associated with the Waverley Care, being seen walking through this door, being associated with being positive so the first question with something like that would be 'why are you putting something about HIV on your profile or on your wall?' or 'why are you liking that organisation?'*

Interestingly, Maggie explains how the internet becomes an important research tool for positive Africans to avoid stigma.

> *Maggie: …we do recommend certain websites, especially in support groups, because people want to come…. You know when someone is diagnosed with HIV it is not that they are knowledgeable around issues with HIV so one of the things we try and do is in your own time, if you don't want to carry a leaflet or carry a booklet then have questions about 'why are you carrying this?' try this website or this one, in your own time, look it up and get to know what other people are saying, other people who are living with HIV as well, what information is out there you know about living healthily or living a healthy life so we do signpost people to websites.*

This was the first time a favourable link between privacy and the internet was expressed. Maggie in the statement above is emphasising problems associated with individuals attaining health information on HIV, she is suggesting that to bypass the risk of physically carrying around a booklet on HIV, service-users should utilise the internet instead. Veinot's (2009) work discovered that people living with HIV/AIDs employed the internet as a crucial source of health information mainly because of the anonymity it offered, especially as an alternative to rural community health services which were viewed as risky, risky in the sense of disclosure, in the same way that carrying around a HIV health booklet presented a risk for Waverley

Care service users.

Whilst working with the Barton women's group Norman reiterated the social consequences of HIV related stigma within the African community, and the role of faith and faith leaders in reinforcing this health related stigma, a point also expressed in Maggie's comments below. Maggie told me of a health leaflet that Waverley Care had developed to talk about chronic illness and the role of faith in the lives of positive Africans.

> *Maggie (African female in her forties): This was really about HIV but to make this more accessible to other people we had to bring in all the chronic illnesses and these are the questions that we are getting and put these questions to faith leaders in Glasgow, both African faith leaders, Scottish faith leaders and ask them you know can illness come to a person of faith?, taking medication is it a measure of your faith?, cos these are issues even up to now with someone who is HIV positive who will believe that if I am prayed for I don't need to take my ARV's but how come if someone is diabetic the pastor is not telling them not to inject themselves? How come if someone is asthmatic the pastor might not tell them to throw away their inhaler? And for HIV why would the message be different? And so these were the kind of questions we were trying to address.*

Maggie informs us in the statement above that the health leaflet had to be labelled for chronic illnesses with the intention of talking covertly about HIV. Maggie's point about "*How come if someone is asthmatic the pastor might not tell them to throw away their inhaler?*" underlines the different ways illnesses are labelled, the differences in the judgements and prejudges attached to them, especially for an illness such as HIV. This response by faith leaders once again, reflects Goffman's (1963) concept of the spoiled identity and how others attach deviant labels and negative moral attributes to those with stigmatised illnesses.

Maggie further asserts the isolation as well as the limited sources of information and support that positive Africans face. She expresses this with her references to how faith leaders respond to questions about their congregation and HIV.

> *Maggie (African female in her forties): The response from the faith leaders…. A few were quite negative, a few said we don't have HIV in our churches which is obviously…. If someone is saying that obviously they are not knowing their congregation, and no one in their congregation would have the confidence to go up to them and say….*

During one afternoon at the Barton women's group, I wanted to follow up on some of the points Maggie had made about faith leaders and stigma. I asked Norman what he thought the role of faith and faith leaders had on African communities here in Scotland. He made the following points: that the church plays an important role in the lives of Africans because of the life experiences many have gone through, and that fears of going to hell or being saved and going to heaven are very real because of those life experiences. That the church is a very powerful tool in lessening the isolation of the African population as it promotes inclusion and connections between different Africans communities. Moreover, Norman suggested that people feel indebted to their church because of the actions of the church in their country of origin. He commented that in many cases people have found sanctuary and support from the church after traumatic events, after which they now believed it their duty to 'give something back'. This makes the church a very powerful social influence, influencing people's ideas and attitudes towards health and practices of health disclosure. Interestingly, when I asked about behaviours such as, unsafe sex or drinking and whether there were possible issues of denial, Norman was quick to say this was very much a problem because of the way people are made to feel by their faith. In addition, by making these issues taboo they only increase secrecy and problems of denial, denial to yourself and others, which in turn makes their situation more isolating and perilous. Employing Goffman's (1959) concept of 'presentation of self' it would suggest that individuals in this instance are engaging in performance management techniques. There are rules around social behaviours, and the behaviours Norman mentions are marked as having negative moral overtones, consequently there is a need for individuals to deflect attention and offer the audience the performance of socially acceptable behaviours instead. It is important to note that during our chats Norman made me aware of his own religious followings and he similarly made it clear that he was not against other faiths he merely wants to see a change in attitudes towards these topics, so organisations like Waverley Care can reach the community and assist in its social and health problems. In summary, fear and anxiety exist in relation to certain illnesses, especially with regards to sexual health. This undoubtedly creates obstacles in health information activities, activities between friends and family but also between the African community and organisations such as Waverley Care, organisations at the centre of health information access and dissemination. It can be argued that this barrier is maintained and reaffirmed by the actions and attitudes of possible health information leaders such as faith leaders, as presented above by Maggie and Norman. Matters of stigma in relation to Chatman's (1996) information poverty framework will be discussed in greater detail in chapter 7.

Finally privacy was an issue raised frequently by both Chinese and African interviewees, especially in relation to the use of interpreters in healthcare settings (this issue will be discussed in-depth in chapter 5). However, it is important to also examine how ideas of privacy impact upon health information activities. Zizi is an African woman in her forties who undertakes voluntary work. In her comments below, Zizi suggests her family are the only other people she can openly discuss health with because she understands health as secret. Subsequently, the idea of health as a secret raises the issue of exposure; in this case Zizi talks to close family members because only they can be trusted outwith of a medical setting, this clearly lessens the risk of exposure in her eyes.

> *Kirsty: Okay so close family*
>
> *Zizi (African female in her forties): Yes, I don't like to talk about myself to other people.*

> *Kirsty: And why do you feel you would go to them for health information rather than other people?*
>
> *Zizi: Because it is secret*

Distinguishing health as a secret may also be driven by concerns of stigma. During an exercise with the Barton women's group called the 'My Life Story Board' the women were asked to talk about their family (a full discussion of this group exercise and further analysis of Rosaline's conversation is offered in chapter 7). Rosaline, a group member, did not want to talk about her family's history for fear of what others in her community would say or do, this was primarily because she had family members who had died of a stigmatised illness.

> *Rosaline (African female in her thirties): ...but I don't want to speak about my family problem in the public…*
> *…for the type of sickness, in Africa if you say maybe the sickness killed my dad. Nobody wants to touch you because you have that problem.*

Rosaline is seeing herself in the minds of others, she is concerned with how she presents herself to others in the group, Scheff (2003) explains this is where for Goffman (1963) shame begins. Rosaline is also fearful of what Goffman (1963) labels as "courtesy stigma' (essentially stigma by association for those who offer support rather than rejection and judgement to stigmatised individuals). Rosaline wanted to conceal her family's history for fear of assumptions about her own health status and all the stigmatisation that would bring for her and her loved ones. It is important to point out that in this research no participants directly informed me of their HIV status, whether positive or negative, it was not necessary, nevertheless there were conversations around the fear of simply being associated with the illness as outline in the statements above.

4.9 Chapter Summary

In addressing the social factors and cultural influences that shape health information activities, a number of themes emerged. Firstly, in order to put fieldwork findings into context it was essential to highlight participants' feelings and experiences of living in Scotland, their sense of social inclusion or isolation, as this has a bearing on their attitudes to health as well as their health information activities. Notably participants displayed feelings and discussed experiences of social isolation most prominently through incidents of racism, yet conversely, they presented strong community cohesion not only based upon ethnic lines, but more prominently through shared life experiences, this was particularly noticeable with the Barton women's group. Social networks were important to consider in respect to health information activities. All participants had strong social networks in the form of friends, family and neighbours as a means of obtaining informal health information both directly and indirectly. This form of support however tended to be with others who shared collective ethnic identities, a pattern also reflected in research conducted by Salway et al., (2007). Noticeably in this research participants seemed to lack social networks outside of their communities, although the impact of the internet may have played a factor in this.

Both Africana and Chinese participants displayed clear ideas about health and what it was to be healthy. Chinese participants in particular were very pro-active in maintaining a healthy lifestyle. Traditional medicine seemed to be used flexibly within the Chinese community, although this usage was surprisingly limited. However, it should be noted that although this practice was unexpectedly lower, established health beliefs remained based upon traditional philosophies.

Undoubtedly, NHS services were being utilised by both populations, this was evident from the self-completion questionnaire, as well as, interviews and certainly there were a number of individuals who conveyed positive involvement with NHS services and health professionals. However undeniably it was African participants who voiced the loudest dissatisfaction. They highlighted negative experiences and described barriers in accessing healthcare when access was through front-line NHS staff. Chinese participants spoke of their trust in the doctor simply because the doctor holds the professional status of being a doctor. This may be linked to Chinese cultural attitudes to doctors and medicine in general, however further investigation would be needed before this statement could be asserted. Within patient-doctor encounters Chinese participants did raise concerns over a lack of time as well as regard for patients. African participants expressed their frustration and concerns with doctor-patient encounters, and there was genuine concern about what was being done with health information (this was a particular anxiety for current and former asylum seekers). Issues of confidentiality and trust were therefore paramount to African participants. The influence of the country of origin in relation to attitudes towards healthcare provision in Scotland was an interesting and potentially important factor which emerged during interviews. However, within the scope of this research there was limited space and time to develop this line of enquire especially in relation to health information, but it is an area with potential for future researchers.

During discussions on health, both through interviewing and participant observation exercises three prominent cultural factors emerged; notions of health ownership, stigma and privacy. Health ownership certainly encourages preventative healthcare but equally has the ability to present an initial barrier to seeking outside medical help. Undisputedly stigma played a crucial role in negotiating social norms around health as well as direct barriers to health information and support within the African community. Finally, privacy was the last factor to be considered in this chapter and certainly ideas around health remaining a secret or holding back on disclosing health information, has the potential to limit health information pathways, undoubtedly though, it also has the possibility to offer protection to participants in what are perceived as risky situations, this is a theme which is returned to in later discussions of information poverty in chapter 7.

It can be argued that for both communities heritage and culture has a far-reaching influence upon attitudes, behaviours and practices to health. How health is interpreted, opinions on what is needed to live healthily, ideas about where to seek health information and support and the need in some instances to present yourself in a socially acceptable manner when it comes to health disclosure all shape health information activities. Analysis and discussions will now focus on the second research question of this thesis.

Chapter Five – Socio-Economic Influences

5.1 Chapter Introduction

This chapter will consider the socio-economic factors which create barriers for both communities when engaging in health information activities. The chapter begins with commentary on the mechanisms of obtaining health information as well as the various sources of health information that participants evidenced. Discussions then move on to consider the different networks of health information that participants tap into. Attention will then turn to the consequences of educational background including limited literacy and language skills. Undoubtedly of the three, poor English language skills play a central feature in preventing and altering health information activities in this study. Hence, language is explored further with in-depth analysis of the role of language in participant observations, as well as the employment of interpreters in healthcare encounters. Discussions will then be brought to a close with a brief exploration of the digital divide, with particular focus on how the digital divide might influence the use of the internet in health information activities.

5.2 Health Information Sources

Now looking specifically at the different sources of health information utilised by participants, it was somewhat predictable that data from the questionnaire sample and interviews would indicate doctors as the most popular source of health information. This was followed by friends/family and neighbours and to a lesser extent television and the internet with finally community organisations and local libraries cited as sources. If interviewees did use the library for information it was to get recipe books in their first language as Paul suggests or to use the internet as Lady Hay mentions.

> *Paul (Chinese male in his twenties): Books in Chinese about eating… I read cookery books so I can eat to keep me healthy.*

> *Lady Hay (African female in her twenties): I just come to the library computer…*

Interviewees and questionnaire participants differed when it came to the prospect of the local community centre as a source of health information. It is important however to acknowledge that wording in the questionnaire may account for this difference. Please refer to appendix B to review a copy of the questionnaire pack. Interviewees often talked about CCDP, rather than the physical space they went to in order to attain health information. In offering the label 'local community centre' rather than 'local community organisation' or simply 'CCDP' this may have caused confusion. Interviewees frequently talked of the Barton women's group, CCDP and Wah Lok as sources of health information with most saying they visited to attend health talks or to share health information informally between friends. Gail and Grace T, an African lady in her thirties and a full-time mum were two such examples.

> *Gail (Chinese female in her sixties): Well they have health talks… sometimes I interpret for them, so prepare the material for interpretation I get more information from that otherwise if it is interesting then yeah I come with my husband usually.*

> *Grace T (African female in her thirties): Yes good, very good because learning something like health is important for us every day in our lives we might learn new things because sometimes we can be wrong and other can be right. It can give you information; it is good for me.*

Significantly, Ying mentioned the closing of one local centre which concentrated on disseminating health information specifically for the Chinese community.

> *Ying (Chinese female in her forties): I use to go to lots of activities run by the healthy living centre… So this is the only organisation still doing anything.*

Ying's statement underlines the vital role local organisations such as CCDP have in community health promotion and the gap left behind when this facility is no longer available.

In everyday information seeking, Savolainen & Kari (2004) highlight the role of printed media, arguing that people tend to draw on only a few respected familiar sources. In this research Chinese newspapers seemed to play an important role in health information dissemination, especially for older Chinese interviewees, who often explained how they picked up free copies in their local supermarkets.

> *Ying (Chinese female in her forties): Because I don't go to Library but I always get some health information from Chinese newspapers, books, television.*
>
> *Dan (Chinese male in his thirties): Every week I read Chinese magazine and they always have a column for health.*
>
> *Kai (Chinese male in his sixties): I usually get some free Chinese newspapers from Chinese supermarket and they always have a health column and I suppose if you put leaflet in the Chinese newspapers in the Chinese supermarkets because lots of people go there shopping… it's very convenient.*

From Ying's, Dan's and Kai's statements above it is evident that wider sources of health information are limited to Chinese newspapers (popular because they are written in their first language) and community groups specifically representing the needs of the Chinese community. Zach et al., (2011) suggests medically underserved populations tend to gravitate towards health sources with which they are familiar but also have established relationships with. In this study such relationships were built upon shared ethnic identities. Organisations such as CCDP and Wah Lok offer an information portal whereby language and cultural barriers are temporarily overcome this makes them valuable sources of health information. Conversely, as in the case of Rosealine and her self-protecting behaviours at the Barton women's group (previously discussed in chapter 4), such settings can also become arenas whereby the risk of exposure and stigmatisation can prevent health information activities from occurring.

In short, health information activities in the company of others can offer advantages: supportive environments where cultural and language barriers can be overcome. Yet, communal spaces also have the capacity to be environments laden with risk, which inevitably encourage self-protecting behaviours. Health information sources such as the internet and newspapers provide a vehicle to overcome the obstacles of language, they also offer privacy and lessen the risk of exposure.

5.3 Education, Literacy & Language

During interviews with African participants it became evident that education posed another obstacle; as a lack of primary level schooling prevented some participants from fully engaging in healthcare encounters. Limited English skills can make everyday health information exchanges problematic; Mrs G provides a useful insight into some of the issues African populations face.

> *Mrs G (African female in her thirties): No, no because most of them are not schooled…*
>
> *Kirsty: Reading and writing?*
>
> *Mrs G: Yeah reading and writing they don't do all of that it's like a big barrier for them so they just… when they are forced to go to the GP that is when they go but… they can't even go to the internet by themselves, most times when you talk to them they find it difficult to understand you know what you are saying in the English language without it being their own local language so it's… very hard for them.*

One interviewee, Isa spoke directly about her own struggles to learn English because of her lack of education. Isa informed me of her gendered life chances; she told me that although her brothers had all gone to school back in her country of origin, she had not been able to because of the financial cost to her family. She then described how she struggled to interact on a day-to-day basis in Scotland. Her main concern was for her son, although she was happy in the knowledge that he would go to school here and so become fluent in English. In the meantime she had to rely heavily on a neighbour and interpreters to get health information, especially about her son's health condition.

> *Kirsty: Isa does the doctor ever give you leaflets or posters in the GP's, do you find it difficult to read that?*
>
> *Isa (African female in her twenties): Yes but they… I ask about my son problem and then they give me a book to read then I said I could not read and they got someone to read it to me.*

Curiously, schooling and basic literacy was not something that was brought up in interviews with Chinese participants. Instead, language was noted as a particular barrier for Chinese participants. It has long been understood that language barriers compound health inequalities for BME populations, language barriers include an inability to communicate effectively with health professionals, which in turn can prevent access and ultimately the use of appropriate healthcare services (Dowler & Spencer, 2007). Language continues to be not just an obstacle for newly arrived Chinese immigrants, but remains an isolating factor for those who have lived in Scotland for many years. Participants frequently spoke of the isolation faced by the community's older population because of the language barrier. Karl a second generation Chinese individual, highlighted the weaknesses and strengths of this close knit community.

> *Karl (Chinese-British male in his twenties): I think everybody is isolated if they have a language barrier, every community that struggles to communicate in the native language struggles and then*

> *they are going to be a wee bit isolated. But like I say everyone's different, I am sure those who are isolated are not really that isolated they have their own wee group.*

Participants and development workers described two Chinese centres for older persons along with CCDP, as places where senior members of the community met, socialised and supported each another. However, as previously mentioned the closure of the local Chinese Healthy Living Centre a few years ago was still being felt by the community. Again, talking to local community workers, as well as, research participants, a picture starts to emerge of the reasons as to why and how parts of the Chinese population have struggled to gain English skills. Many Chinese participants spoke of the long hours associated with working in the catering industry; for it to be customary to work six days a week, for long hours each day.

Chau & Yu (2001) conclude that Chinese people in the UK face difficulties in social integration not because of cultural differences but because of their participation and status in the capitalist economy. In relation to social integration, participants talked of a lack of facilities (such as limited English Language classes) and how they have continually struggled to engage outside of their own community because of the language barrier which gradually cements their isolation over time. Macy and Ka offer further understandings into these obstacles.

> *Macy (Chinese, female in her fifties): Yes, usually older people, because most Chinese came here to work in the kitchen and they don't know what is wrong with them, so it would be good if… some topic or something about their health.*
>
> *Kirsty: You know people to talk to in Glasgow?*
>
> *Ka (Chinese male in his sixties): A little because I don't speak much English.*

For Betty a Chinese lady in her thirties working with CCDP, the biggest challenge facing the Chinese population was undoubtedly the language barrier, hence why organisations like CCDP offered popular health talks in first languages. Dan also thought health had its own particular language problems as he expressed the importance of being understood in healthcare situations.

> *Betty (Chinese female in her thirties): I think the language barrier is the main problem because if they have a health problem they have to go to consultant or hospital they don't have a clue.*
>
> *Betty: Yeah so that is why CCDP also provide different talks in health, health talks are the most welcoming talks they like health much more than other information.*
>
> *Dan (Chinese male in his thirties): There are lots people like us who can speak daily English but when going to the doctors there are technical terms and others, filling forms that we have difficulty with.*
>
> *Dan: It's hard, talking okay but forms hard and it's your health, that's the problem.*

Hence, understanding that medical terminology presents another hurdle in the patient-doctor relationship is an important point highlighted by Dan's comments. From a Foucauldian perspective power is being generated within the medical encounter, since medical terminology itself is a cog in the machine of medical knowledge, knowledge built on a belief system, a system shaped by social and political relations (Lupton, 2005). During my attendance at CCDP health talks the difficulties in communicating health related information to an audience whose first language is not English became very apparent. Although health workers from the NHS used local and trusted interpreters they often had difficulties with the practicalities of using an interpreter. They frequently talked for long periods of time, leaving interpreters struggling to remember details and having to ask health workers to repeat themselves, unfortunately this made many health talks extremely long and drawn out with the audience struggling to engage. Health workers presented health information through presentational slides which were always in English, as was other health information material such as promotional leaflets. When health websites were discussed at the end of one particular health talk on healthy skin, surprisingly the health worker did not mention 'Health in my Language' an NHS website which provides health information in many different languages including standard written Chinese. Chau et al., (2011) suggests that service providers must consider the ever changing health requirements of Chinese populations, whilst encouraging favourable conditions for the delivery of health services to continuously improve. In many ways it could be argued that the information channel for health promotion and education in this example is being unintentionally blocked and in so doing the prospect of community empowerment is being hampered.

Returning now to the barrier of language, Rebekah provides an interesting description of the frustrations related to not being able to express one-self fully, and the inner turmoil this can cause.

> *Rebekah (African female in her forties): …If black people are suffering that in this community, the people that are really suffering are the people that can't express themselves. Because if you have pain and you can't express yourself that person will feel worse.*
>
> *Kirsty: So language is a barrier?*
>
> *Rebekah: You die in you, because you can't express yourself, so it's really good to express yourself you know. Just say to someone, just tell someone could help.*
>
> *Kirsty: When I say a language barrier do you think it is a language barrier or just some people can't talk?*
>
> *Rebekah: Yes some people can't talk they can't open up because they feel their English is not good. I keep saying to people just say it out*

> *and you will feel more comfortable in saying it outside. But if you keep it to yourself you are not helping yourself.*

Obviously, with the diversity of the African population in Scotland there are a growing range of language needs, with some individuals having very limited English skills and communicating mostly in their local languages. During observations at the Barton women's group, members that only spoke their local African language were naturally the most isolated, and often had to rely on women from their country of origin to speak for them, a point commented upon by Mrs G.

> *Mrs G (African female in her thirties): Yes, yes they are quite isolated on their own. Like you notice them in the group most times they just come together and speak their local language and you have to say no local language so that they you know come back and speak to everybody you know.*

French speakers were able to participate well in the group, as were those obviously educated in English at school, such as the Nigerian and Malawian ladies in the group. Somewhat predictably these women with their advanced English language skills became informal interpreters and information leaders to others. Having informal interpreters allowed the otherwise excluded women access to group discussions and activities, however using someone who is from your own community as an interpreter can bring potentially risky settings for health information activities. Interestingly, Maggie emphasised some of the additional complexities facing the African population, even for those who have been brought up developing their English language skills.

> *Maggie (African female in her forties): its more so for people who have come from different and they are here… and it's the Scottish accent and it is not the English that you were taught by your teacher, it's now another you know… to understand as much, you know the communication itself, talking understanding what the next person is saying abstracting what that person is saying…*

This point was played out during one afternoon meeting at the Barton women's group when Rebekah translated from English to English. Sally an NHS Health Promotion Officer was explaining to the group different types of NHS checks relating to women's health but Jo a young mum living in the Barton area with limited English was struggling to understand. Rebekah intervened, translating this information, but she did not speak Swahili, to my astonishment Rebekah translated still in English. Perhaps with her accent, the vocabulary she used, or her body language, Jo seemed to comprehend the points when vocalised by Rebekah. This wasn't just an example of sharing of health information between two group members it was the exchange of health information through a dialogue that they could both understand. Since the English language continues to be a major barrier for both communities, it is now important to consider the availability of health information in first languages. Responses from the questionnaire suggest the Chinese community believe there is not enough health information provided in their first language, a point also echoed across interviews with Chinese participants.

> *Kirsty: Do you think there is enough written health information in your first language?*
>
> *Paul (Chinese male in his twenties): I have rarely seen any of it.*
>
> *Fang (Chinese female in her twenties): No*
>
> *Ying (Chinese female in her forties): I don't know English so I just read the Chinese health information.... Sometimes I get the information from the Chinese internet.*

Vera's and Sarah's comments below suggest that once individuals obtain English skills then their world not only opens up, but their channels of information too; Sarah emphasises that now she can speak English and that her doctor can now understand her during consultations.

> *Kirsty: Okay do you think there is enough written health information in your first language available?*
>
> *Vera (Chinese female in her sixties): It is okay for me because I know English*
>
> *Kirsty: Do you think there is enough written in French let's say? In your first language, like posters, leaflets when you go to the doctor…*
>
> *Sarah (African female in her forties): Before it was hard because when we came here, we didn't speak English but now it's okay because I can speak and my doctor can understand what I am saying and I can go out and meet people and talk.*

For individuals sourcing health information in their first language, resources can be limited (Wong, 2006). Chinese participants often talked about, as Ying previously remarked, using Chinese webpages or as Dan suggests free Chinese newspapers which have health columns and are available at local Chinese supermarkets.

> *Dan (Chinese male in his thirties): …I refer to the health column when they talk about illnesses.*

Very few Chinese participants mentioned NHS promotional material, and perhaps Betty the community worker outlines why this might be.

> *Betty (Chinese female in her thirties): I think the main problem is the NHS promotional materials they cannot provide in their own language, most of them are English, that's why even the Chinese people they have the query but they don't know much about it.*

As previously mentioned, CCDP and its health talks in Cantonese seem to offer a vital access point for health information, a point stressed by Fang and Ying in their statements below. Wong (2006) also found health talks to be popular amongst older Chinese people primarily because the setting allows attendees to engage with speakers at the end of health talks, a practice I was also witness to during my own participant observations.

> *Fang (Chinese female in her twenties): Yes from CCDP but not from doctor.*
>
> *Ying (Chinese female in her forties): ….there is quite a lot of health talks run by the community and I attend them quite often.*

Intriguingly, in the exchange below, Dan focusses not on the need for more materials in Cantonese but the types of material, suggesting it was more important to highlight health issues faced by the community and the community itself in big advertising posters. This may be in reaction to a recent NHS poster campaign highlighting health problems faced by other BME groups, such as diabetes and the South-Asian population in Scotland.

> *Dan (Chinese male in his thirties): I don't think health talks or leaflets are very useful I think it is better to have really big posters to promote locally so Chinese will realise it is important, big poster.*
>
> *Kirsty: Why do you think big poster is important?*
>
> *Dan: Because the more Scotch people know about us, in Glasgow in Scotland so it promote the community itself.*
>
> *Kirsty: So do you think when it comes to health and promoting health it would be better to promote some of the specific health problems the Chinese community face?*
>
> *Dan: Yes, that be better… yes*

During participant observation sessions at the Barton women's group I noticed some particular problems with language and health information. As previously stated some of the women who attended the group spoke limited English, and unfortunately this became a real problem when health workers tried to engage with them. The women's group was always held in English and the women encouraged to communicate in English to improve their language skills. In reality a pattern emerged where often small groups of women who spoke the same national or local languages such as Swahili would sit and speak together. During group sessions and the dissemination of health information the women would try and speak in English. In one session Sally handed out leaflets to the women on smoking and cervical cancer, a couple of the women struggled to understand what Sally was trying to say and a comical retort of pointing to pictures and slowly saying words in English occurred. After the session I spoke to Sally about the leaflets and she admitted that for the Health in the Community (HIC) course they had no culturally sensitive material, instead they were using leaflets developed for individuals with learning difficulties. The provision for BME communities in this instance is being significantly overlooked. Furthermore this is one small example which reflects van Dijk's (1993) claim (as discussed in Chapter 2) that inequalities between majority and minority groups can be covertly reinforced through discourse. Sally confessed that she was not sure everyone in the group understood what was being said, a concern later repeated by Mrs G during an interview.

> *Mrs G (African female in her thirties): That's why I don't say anything, because we don't know if they are actually get anything in, there is no communication they just come and its yes, no write name… so we don't really know if they are getting? Of course the sewing is a more practical thing so they can have, so they can cut… but the health is something that you hear and it goes in but you don't speak out so you just… so we don't know what exactly…*

Here Mrs G stresses the one way channelling of health information in this group situation and although in later sessions other women acted as informal interpreters the practical difficulties of translating during these conversations and without any health information in Swahili or French these women were often left isolated from group discussions. Finally Maggie offers an additional element which might impede language provisions for Africans living in Scotland.

> *Kirsty: okay do you think there is enough health information out there in languages like Swahili or French or…*
>
> *Maggie (African female in her forties): Not Swahili… maybe French but some of the Asian languages like Urdu you see them around quite a lot but the African languages I think more to do with how people were colonised so to speak in terms of the languages they were associated with in their home countries, so for instance the Southern parts of Africa it was more English and so I suppose sometimes there is an assumption or maybe through experience they have seen that people from that bit don't really need as much you know things made up in their own languages here so…. because they have come from English speaking countries…*

In summary, participants highlighted a lack of primary education, literacy and language problems as continuing barriers to health information activities. Language in particular was described as a major barrier to health information activities, especially for Chinese populations. During participant observations I was clearly aware of limited health resources available in other languages, especially a lack of written health information in first languages. To compound this, health information was often not culturally sensitive or relevant to BME communities. Participants underlined this point with their own comments regarding the need to promote the communities as well as the health problems they continue to face. Consequently, these findings concur with existing research and recommendations that maintain the need for the development of culturally sensitive healthcare systems including: healthcare access, health promotion and policy development considerations (World Health Organisation, 2009; Jones & Tilford, 2001; Bhopal, 2012, Bhopal & Donaldson 1988).

5.4 Using Interpreters

The need for better interpreting services in Scotland was initially highlighted by The Scottish Government's, Asylum Seekers in Scotland Report (2003) which determined that service provision in this area was poor (Scottish Executive, 2003a). This is somewhat unsurprising as the NHS as a whole has had a poor record on interpreting provisions for its non-English speaking patients (Bradby, 2001). Jones & Gill (1998: 1476) suggest

> "… it is far from clear that the NHS as a whole has changed rapidly enough, especially in inner cities, to meet the challenge posed by patients whose English may not be good enough to communicate adequately with health professionals."

Dowler & Spencer (2007) maintain professional interpreting services remain a low priority for the NHS possibly because of the widespread belief of the need to encourage assimilation into British society by BME populations. During this research the use of translators in healthcare situations figured prominently, especially with Chinese participants. Interviewees like Ying and Macy spoke of the need to be fully understood when undertaking a conversation involving the need to describe poor health as well as use medical terminology. Maggie meanwhile highlighted frustrations involved in communicating through a third person.

> *Ying (Chinese female in her forties): A while ago I did not need an interpreter my health problem was not as many as I have now but because I have depression sometimes I do not know how to tell the GP what I experience and also some of the medical terms I don't know what they are so I need an interpreter to translate for me.*

> *Macy (Chinese, female in her fifties): If I go to see the GP I need an interpreter but did not want to tell him the wrong thing, he can prescribe the wrong medicine*

> *Maggie (African female in her forties): Yes I remember one person talking about 'I was in an interview and I could tell the interpreter wasn't saying the right thing, but I couldn't you know… they kept saying no, no!' and the interpreter was saying something else so there are challenges where someone might feel what they want to say they can't or what they want to ask they can't ask because they are going through a third person who is not really relying what they really want to say…*

Repeatedly Chinese participants acknowledged employing the assistance of family members as interpreters in healthcare settings rather than formal interpreters. This pattern mirrors previous research carried out by Wong (2006) which proposed 90% of questionnaire respondents in her study relied on friends and family as interpreters. Unsurprisingly then Ka asked his daughter to carry out the task of interpreting, while Dan took his wife along to translator for him at his doctor's appointments. Gervais & Jovchelovitch (1998) believe this use of family members as interpreters in healthcare settings is due to cultural convictions about not wanting to bother outsiders to the community with their problems, this relates back to concepts of health ownership discussed in chapter 4 and was also echoed in Wong's (2006) findings .

> *Kirsty: Okay, and do you use translator when you use the GP here in Glasgow?*
>
> *Ka (Chinese male in his sixties): Yes my daughter*
>
> *Dan (Chinese male in his thirties): Yes, yes (Dan speaks himself here) you can't guarantee they understand you… usually I just go to GP and have my wife to translate for me.*

Certainly Chinese participants were aware of the barrier language presents in healthcare settings. Moreover they accept it as part of daily life and believed it their responsibility to change their own circumstances. May is a Chinese lady in her sixties who is retired, had strong views on learning

English although as discussed previously, certain barriers to learning English for the community remain.

> *May (Chinese female in her sixties): Its quiet convenient because usually I got a female interpreter but even if it is a male interpreter he is talking through a curtain… so the therapist would tell me what to do and then the interpreter would tell me.*
>
> *May: I feel it is quite natural he cannot speak my language because we are ethnic minority… I cannot speak the physio's language then he will feel quite strange because I have been in the country for so long.*
>
> *Kirsty: Okay so you feel it's your responsibility in some way? Then?*
>
> *May: Yes I think it is some of our responsibility because English speaking country we are coming to but those times when there were not so much English classes for us and I was busy looking after my children...*

Intriguingly for both populations when I asked male interviewees about any issues relating to the use of interpreters in a medical setting they answered no, but female interviewees frequently spoke of the difficulties of telling a stranger personal medical details.

> *Macy (Chinese, female in her fifties): No, no but if I'm going for some kind of gynaecological problem I wouldn't like a male interpreter that's what I got last time.*
>
> *Isa (African female in her twenties): Yes but I think… yerm… I don't know how to call it… but when somebody come they know everything about you, you don't have your secret life…*
>
> *Kirsty: So that not nice?*
>
> *Isa: No… for me, for me…but no choice*

The issue of talking to someone who is thought of as a stranger was also highlighted by Maggie when she described the story of a service-user who is HIV positive and is conducting their visits to the clinic with an interpreter. She describes how that single interpreter must know the whole medical history of the service-user and so Maggie questions how this must make the service-user feel.

> *Maggie (African female in her forties): a stranger… someone else... you know what you are saying I have been speaking with someone who has been coming with interpreter to the clinic and this has been a year on now and I am think 'oh my goodness' how must that feel? This person is in their working capacity and they also know all the medical details about this women and… what sort of relationship is that now because this man who is an interpreter has been coming to every appointment…*

This example underlines the important role of interpreters in healthcare setting, just like frontline staff, formal interpreters have an important role in building confidence and trust between the NHS and BME populations as outlined in chapter 4. This observation is supported by the conversations I had with African participants who vented their concerns over privacy and confidentiality when engaging with interpreters. Worryingly, there does not seem to be trust in the practices conducted by interpreters, instead there seems to be real anxiety and suspicion. In the excerpt below Grace T expresses her fears of speaking through an interpreter. When Grace T says "*he go tell outside"* she means the interpreter will go and tell people outside of the healthcare setting, and in particular tell people from her community.

> *Grace T (African female in her thirties): Stranger! I don't like! I don't like... I don't like because you know health, individual health you can't tell anyone, anybody… there are things… so he can, see you another day and you know people talk, talk too much.*

> *Kirsty: Okay so you were worried about interpreter talking about things outside?*
>
> *Grace T: outside, outside yes*
>
> *Kirsty: Okay you ever not tell the interpreter something because you worried about them talking outside?*
>
> *Grace T: Sometimes because you can't trust anybody. You can't trust anybody because perhaps you tell your problem and he go tell outside… not good.*

This fear, of the interpreter speaking to your own community, stems from the practical fact that many African communities are small and close-knit in Scotland. When academics and government officials speak of the African population living in Scotland they frequently consider them as one constant population, which fails to see the enormous diversity within the population. Thus, as Maggie says below, if the interpreter is speaking your language then they are from the same small community and this makes patients uncomfortable, there is a perceived risk of exposure. Moreover, stigmas associated with some illnesses such as HIV amplify this fear of 'telling outside' and creates an environment where sharing health information is seen as risky.

> *Maggie (African female in her forties): …people get inhibited because they feel because you know if somebody speaks your language then they are in the same community as you somewhere so you think okay so how much of this remains in… of course people are bound by confidentiality but it doesn't stop…*
>
> *Kirsty: People talking….*
>
> *Maggie (African female in her forties): Yes and it is worrying….*

One possible consequence of this fear of revelation is the potential for patients to hold information back, a concern that Maggie affirms in the statement below.

> *Kirsty: I wonder if sometimes people wouldn't express fully what is going on with their health because they wouldn't want an interpreter to know…*
>
> *Maggie (African female in her forties): That does happen and I am sure it is… for anyone if it is a sexual health thing I mean, even to talk to your own doctor about it and to go through someone else and to tell them 'yes I have some pain down where ever…'*

Reflecting on earlier discussions in the previous chapter, McKinney (2002) proposes close-knit communities produce environments where social stigmatisation becomes an extremely strong obstacle in obtaining HIV related healthcare.

Returning now to the point on diversity within populations, the Chinese population undoubtedly displayed levels of diversity: with a long established Hong Kong community and then new immigrants coming from mainland China and Taiwan, Gail expresses her concern that NHS interpreters cannot always speak the right dialect, which can lead to misunderstandings and in Gail's words "*be really disastrous*".

> *Gail (Chinese female in her sixties): I don't know. But I am concerned about one thing I know there are many Chinese people in Glasgow who don't speak English and need an interpreter and it will be difficult for the NHS to choose really good interpreters. On one hand if you don't know where they speak the same dialect because I have done interpretation on occasions and I have come across people whose dialect is say putonghua which is mandarin which is the main language in China but people here they speak Cantonese which are two different dialects and sometimes they are really not that confident in the interpretation and….*

> *Kirsty: Things can get lost in translation…*
>
> *Gail (Chinese female in her sixties): They can make it not only a loss but it can be really disastrous and of course the Scottish people the doctors they have no way of telling.*

Anxiety over the abilities of NHS interpreters was also expressed by the Chinese community worker Betty. In the statement below, Betty expresses how she is particularly worried about the quality of written translations for health information.

> *Betty (Chinese female in her thirties): You know, I really don't know! I need to complain around two or three times but it is not much better. Actually I tell the NHS people what the difference is with Mandarin and what the difference with Cantonese but all writing out is the same but they are still misunderstanding and asking the people who do the translation into Cantonese writing… I say 'why?' the writing is the same, but what they doing is translating Cantonese verbal into written they put what they say on the writing.*

It is clear from the voices above that interpreters play a very active part in health information activities. However, just as importantly their work reflects the professionalism and empathy of the NHS towards BME populations, a lack of trust in NHS interpreters equates to a lack of trust in the health service itself. Moreover, it can mean an impermeable barrier between patients and health professionals.

5.5 The Digital Divide

The final socio-economic factor to be considered in this chapter focuses on the digital divide. Chapter 2 of this thesis showcased the scholarly debates surrounding the digital divide, which until recently had been explored along material divisions and between differing socio-economic groups. van Dijk, (2005, 2013) and Warschauer (2003) have called for a re-examination of the divide to explore educational, social as well as the traditional economic factors, while Mehra et al., (2004) calls for the internet to act as a genuine tool for the empowerment of BME groups. The scope of this research is not to examine the character or indeed the impact of the digital divide in Scottish society. Nevertheless, it is still crucial to understand some of the obstacles in accessing and using the internet for health information activities. New figures from Ofcom highlight a surprising and recent trend in internet access across Scotland. In the space of a year, Scotland's up-take of broadband has risen fastest of all UK home nations, jumping 7% (Ofcom, 2012:1). In addition, the number of adults in Scotland using smartphones has also increased dramatically, up from 21% in 2011 to 32% in 2012, although this is still a little below the UK average (Ofcom, 2012: 7). It should be noted that these figures are reflective of the Scottish population as a whole and are not broken down by ethnicity. When it came to Chinese participants and their use of computers, questionnaire results indicated 66% of respondents used a computer, along with 26 Chinese interviewees (please see appendix J for SPSS output regarding computer usage for questionnaire respondents). In most cases, older Chinese participants I spoke with took pride in detailing their attendance at computer classes, which was run by CCDP.

> *Kirsty: So are you learning how to use the computer at home or are you going to classes?*
>
> *May (Chinese female in her sixties): I go to CCDP, class run by CCDP.*
>
> *May: I'm learning.*

Again results from the questionnaire data were echoed by interviewees with most saying they used the internet regularly, just as Gail, Fang and Kai stated in their answers below.

> *Gail (Chinese female in her sixties): [laughs]... too much. In terms of hours probably half the day!*

Fang (Chinese female in her twenties): Everyday…

Kai (Chinese male in his sixties): Not every day, but whenever I got time.

Of course there were those who did not have access to a computer or smartphone, but instead simply did not want to use the internet or did not have the skills to use a computer. Zizi was particularly uncomfortable about using a computer and spoke of her anxiety in using a computer, possibly because she felt embarrassed about her lack of eHealth literacy skills.

Kirsty: Why don't you like computer?

Zizi (African female in her forties): I hate computer.

Kirsty: Do you?

Zizi: I don't know how to use computer, I don't want to learn computer to be honest because when I use I feel nervous... I like to switch off computer.

For those that did use the internet, African interviewees spoke of having internet access at home or on mobile phones, while questionnaire results indicated a range of physical spaces used by the Chinese community to access the internet. These included most commonly their own homes, followed by the unusual response given by 26 individuals of a pub. I can only speculate that respondents in this case are meaning that they are using their mobile phone to connect to the internet whilst at the pub, and this would therefore explain its popularity as an answer in questionnaire responses. Other places included family, friends and neighbours houses and the local library/community centre. Please refer to appendix B to review the questionnaire pack. The mobile phone was an answer heard frequently in participant interviews.

> *Ying (Chinese female in her forties): I not very good at the internet I usually just check information from my phone.*
>
> *Robert (African male in his forties): Yes I have this… (points to his blackberry).*
>
> *Karen (Chinese female in her forties): Everyday, especially now it's on there… (Karen points to her mobile phone).*

Interviewees from both populations reveal the mobile phone as a popular source for internet connection; this reflects similar patterns in the US where BME populations led the way in mobile internet usage (Smith, 2010). Isa who spoke about her limited schooling and English skills earlier in this chapter, stating that she did not know how to use a computer however she informed me that she used the internet on her mobile phone instead. A practice shown during the interview when she played music via YouTube on her mobile phone to keep her young son entertained. Betty a community worker at CCDP also talked briefly about internet access and the opening up of communication possibilities through mobile phones.

> *Betty (Chinese female in her thirties): Yeah because now days the mobile phones they are newly, new issue they can communicate in their own language that's why they great… That's why they use the most updated phone like iphone or smartphone because they… I saw them many use the iphone because it can be set in the Chinese language…*
>
> *Kirsty: Right okay so everything in the phone comes up in Chinese. So from your experience the Chinese community isn't shy about using technology then?*
>
> *Betty: No, no they like to learn and even the older people!*

For those that did use the internet as a source of information displayed resourcefulness in utilising the benefits of the internet for daily living.

> *Grace T (African female in her thirties): In English sometimes if I didn't understand I can just pick dictionary or translate in the computer… Google translate.*

> *Rosaline (African female in her thirties): sometimes if I hear any information and I don't understand I will go to, back to the internet and check it and see what is going on…*

Internet users in this study predominantly employed the internet for communicating (mostly via email, Skype or facebook) as well as for news and entertainment. Chinese participants talked of watching Chinese films or checking Hong Kong news, whilst African participants described how they kept in contact with loved ones back in their countries of origin.

> *Dan (Chinese male in his thirties): Sometimes sports, sometimes facebook…*

> *Doudou (African female in her twenties): Internet I use for checking emails, facebook, chatting…*

> *Tasha (African female in her thirties): Facebook first of all, that is the first thing I do when I wake up… it's the main way I communicate with my family as well so I know what is going on with them.*

From interviews and questionnaire results the internet is clearly being utilised by both communities, and it is fair to say this research did not uncovered a digital wilderness. Nevertheless, there were a few noteworthy concerns raised by interviewees in relation to cost and broadband connection. Kai was willing to use an internet enabled phone but he was concerned as to the cost and saw this as a barrier which prevented him from using such a device.

> *Kirsty: Would you ever consider using your phone to access the internet?*
>
> *Kai (Chinese male in his sixties): No because it's very expensive.*

Betty also highlighted some of the practical difficulties faced by the Chinese community in getting broadband installed at home.

> *Betty (Chinese female in her thirties): There is a barrier here with the broadband, because lots of people not sure how to get a broadband service even they know they got the wrong service or…*
>
> *Betty: …Sometimes they think they can afford it but they get the wrong service or the expensive service or they get it wrong…*

Other research studies indicate internet access and usage remain tied to socioeconomic status and educational attainment, and that this continues to work against disadvantaged communities (White & Selwyn, 2013). Clearly wider research is needed if the lingering shadow of the digital divide is to be fully understood. However, this research contends that smartphones in particular have the potential to act as a vehicle upon which marginalised communities can access and utilise the internet. The declining costs of mobile phones, cheaper phone tariffs and data contracts, language translation facilities as well as the basic benefits of greater flexibility and mobility are increasingly making mobile phones a valuable platform for internet connection. Zickuhur & Smith argue that, in the case of mobile phones there is a change in the story of the digital divide,

> "Groups that have traditionally been on the other side of the digital divide in basic internet access are using wireless connections to go online." (Zickuhur & Smith, 2012: 2)

Moreover they suggest that minority populations in the US such as African-Americans and Latinos were more likely to use their phones for a wider range of activities than other groups. Although the digital divide is frequently associated with a generational gap (White & Selwyn, 2013;

Millward, 2003). This study failed to uncover such a trend, instead many senior Chinese interviewees remarked on their attendance at computer classes and their positive views on technology. Meanwhile, African participants of all age groups were using mobile phones for internet access. Undoubtedly technology is continuing to open up access for these two communities, even with underlining educational and economic barriers. The question of empowerment, as Mehra et al., (2004) denotes is however questionable.

5.6 Chapter Summary

The socio-economic factors which influence health information activities have been varied and at times surprising. Results from questionnaire data and interviews indicate that participants mainly use the doctor as their core source of health information, perhaps more unexpected was the importance of community organisations and community information points such as health talks and community newspapers, these seemed to be central access points for health promotion and education because they had the potential to offer an escape from language and cultural barriers. Conversely, community settings also provided spaces which could present risk; they had the prospect to become front stages whereby performers had to act out socially acceptable behaviour.

Undoubtedly language was the most prominent socio-economic barrier to health information within this research as it presented an obstacle on a number of levels. Limited primary education coupled with literacy problems certainly compounded participant's abilities to quickly develop English language skills and as such participants highlighted everyday difficulties in accessing healthcare and more specifically health information. Accordingly, the healthcare encounter was of particular concern to participants, they were anxious that healthcare professionals understood them fully, but they also noted that the medical language which necessitates such an encounter can compound difficulties. During participant observations the impact of the language barrier once again became apparent, a lack of health information in first languages and the use of inappropriate, irrelevant material exposed the layers to which language offers an obstacle to both communities in this study. The final point to be raised on the issue of language was with the use of interpreters. Chinese participants routinely used family members as informal interpreters harping back to the notion of health ownership, first described in chapter 4. African participants meanwhile discussed issues of mistrust, linking interpreters with the risk of exposure; that personal health information might be fedback into close-knit communities. Just like the previous discussion on frontline staff in chapter 4, interpreters seem to play a key role in developing levels of trust associated not only with their own tasks but with the NHS as a whole.

The final socio-economic factor to be explored in this chapter was that of the digital divide. Unexpectedly the digital divide did not figure as prominently as expected, at least in the traditional understanding of the digital divide. As discussed in the literature review of the digital divide debate, attention now needs to move onto how e-literacy and empowerment opportunities in relation to the internet are now developing within marginalised groups. Certainly mobile internet technology is opening up access to these two communities, even with underlining educational and economic barriers. The use of the internet to overcome language barriers and keep vital commination channels open was undoubtedly evident, although the use of the internet as a health information tool is still questionable and will be discussed in greater depth in chapter 6.

Chapter 6 - The Role of Technology

6.1 Chapter Introduction

> "Technological change is leading to new ways of delivering and improving public services. It allows greater opportunity for people to contribute their views, access information and interact with others." (The Scottish Government, 2011a: 17)

This chapter will examine the role of technology in health information activities. Attention will be given to the role of the internet, as well as, different forms of eHealth. Unexpectedly, participants in this research were very positive about the potential of technology to provide health information in the manner of eHealth, especially with regards to the possibilities of language provision. The only negative comments provided were directed at NHS 24, the national telehealth service in Scotland. The term eHealth covers a multitude of new technologies to assist patients and practitioners alike, these ITC solutions are often referred to as public health informatics, telehealth or telecare. In this investigation of health information activities I concentrated on health technologies and their abilities to aid communication channels to engage with both populations. In this chapter deliberation will also focus on NHS policy, including discussions on online provisions of health information under the umbrella of NHS Scotland online, telehealth, in this case NHS 24, mHealth, and finally health information kiosks. Although my research was with African and Chinese communities, I believe some of the conclusions drawn from this study can be transferable, offering insights to other BME populations. Although I would equally stress that the heterogeneity of each BME community must not be overlooked, and that further research is needed to aid policy makers and eHealth developers alike.

6.2 The Internet

Consideration has already been given in previous chapters as to how these two BME populations access and utilise the internet, now attention must be given over to, how the internet is used as a tool for health information activities. From questionnaire responses to question 13, “Do you ever look at information about health and well-being on the internet?” answers were equally split with 48% of respondents saying yes and 46% answering no (6% of respondents did not provide an answer, please see appendix K for a SPSS output). Interviewees likewise provided mixed responses to questioning about the internet; interviewees like Gail talked of embracing the internet while others like Fang seemed less enthusiastic.

> *Gail (Chinese female in her sixties): Well sometimes actually I get sent some very good websites that you can practically get everything on…*

> *my Chinese friend seemed to have cough that she could not control so I had a look up and find a couple of recipes because like ginger is good for when you are coughing mostly at night they say ginger is hot and if your body is cold then it helps you get rid of the coldness but if your coughing mostly in the day time then your body is hot, it is in the hot state, then ginger does not help with it then there is another recipe with orange and that helps and then there is another recipe with onion soup and I recently sent that to a Chinese friend. These are things that we look up.*
>
> *Fang (Chinese female in her twenties): Very rarely…*

Mr Lee used the internet as a means of keeping up to date and double checking health information. In this sense the internet was often referred to as a tool whereby 'you could check health information'. Fascinatingly, Karl, employed the internet as a kind of triage nurse, as described in his comments regarding self-diagnosis.

> *Mr Lee (Chinese male in his sixties): They have some news about Chinese medicine I will… Sometimes maybe I find some new things, and I look them up so I know more about them.*
>
> *Karl (Chinese-British male in his twenties): You search your symptoms and look does that match mine and self-diagnose! [laughs] you take that to the doctor and the doctor will tell me if I am right. Then he will say if google agrees that must be right! [laughs]*

Meanwhile, African interviewees like Mrs G and Doudou described how they used the internet as a tool in gathering information about women's health and wellbeing, since the majority of African participants included in this research were women it is not surprising that these health topics were frequently discussed.

> *Mrs G (African female in her thirties): Look it up and read the net and sometime when I go for ante-natal services I go back on the internet…*

> *like in Barton my experience I not know anybody the first experience really helped.*

> *Doudou (African female in her twenties): …When I started to do exercises I was reading on internet how it can get you slim.*

For Isa however, she had never used the internet to look up health information, and during our chat it became evident that it had never struck her to use the internet for such a purpose. Isa's brief reply below makes a bold statement, it emphasises her determination to learn as well as her recognition of the value of the internet.

> *Isa (African female in her twenties): I never try*

> *Kirsty: You never tried?*

> *Isa: I have to try…*

After a further chat it was obvious that Isa's difficulties with reading prevent her from using the internet fully as a health information source yet when I proposed the possibility of health videos that she could watch or more health information in her own language she was enthusiastic.

> *Isa (African female in her twenties): If I go to the YouTube? I translate in my language… Yeah, yeah I would try that…*

Isa was not the only participant who did not utilise the internet for health information. Sarah simply employed the internet to communicate, while Ying did not have a computer at home, only her phone had access to the internet and she preferred to read a book for health information.

> *Kirsty: Do you know how to use the internet? or have you ever used the internet?*

> *Sarah (African female in her forties): Yes but internet to be honest I just use for Facebook.*
>
> *Kirsty: Would you ever use the internet to look up information about your health?*
>
> *Ying (Chinese female in her forties): No I usually read a book about it..*
>
> *Kirsty: Do you prefer using a book because its physical or…*
>
> *Ying: Because I don't have a computer at home so I would rather read a book.*

For those who did use the internet as a source of health information a range of advantages as well as disadvantages were expressed. For participants below, the internet offered quick access to health information but more importantly, it offered reassurance about unresolved health queries.

> *Tasha (African female in her thirties): I think the good thing about it is like, well if you got the access you got the information when you want it, when you need it like, at your fingertips, wrong or right, it's right there for you.*
>
> *Cheng (Chinese male in his sixties): After I got information from the internet I can follow the instructions.*
>
> *Fang (Chinese female in her twenties): Sometimes if we don't understand about an illness we can get more information.*
>
> *Rosaline (African female in her thirties): The doctor one day say your pressure is very high, so we decided to go and look for what causes that pressure, so we sit on the computer.*

Other facilities that participants valued included google translate or a dictionary tool. Iree, an African lady newly arrived in Scotland, who was desperately trying to improve her English talked about googling words to learn their meaning. Nadia meanwhile explained the benefit of availability, that the internet offers health material in other languages.

> *Fang (Chinese female in her twenties): Chinese websites, I google, I type in the illness but I want this information in Chinese so I use google translator to then translate it.*

> *Iree (African female in her twenties): Like health things is also there… the things you are not going to use… like the things you are not suppose to take to be healthy… Yeah it's nice I mean to learn more, you can learn more on internet. Also reading sometimes you don't know the word then you google and it tell you… you the meaning of that word.*

> *Nadia (African female in her thirties): If you got the internet at home it means you can get all the information and like I said in different languages.*

In spite of this active use of the internet and its potential as a language tool, health forums as spaces where health information can be sourced, were not exploited. Questionnaire data suggests of the 117 individuals who completed and returned the questionnaire, only 20 people indicated that they would use health forums. Whilst, during interviews no Chinese participants acknowledged their use of health forums and in the case of African participants only 3 interviewees said they had ever used a health forum, explaining it was usually a one-off occurrence and that they did not post anything online; as Sheena describes below. The absence or passive use of health forums on the internet is therefore unexpected but may be linked to issues of eHealth literacy or possible concerns surrounding online security and exposure; further research would be needed to identify possible explanations.

> *Sheena (White female in her thirties): hum… I have looked through once, somebody said he had a swollen big foot and somebody said it*

> *was gout so I said well I have never really known much about gout so I on the internet and I bumped into this forum and I was just looking through what people were saying I never really got involved.*

A key finding from this inquiry is that African and Chinese participants were both very positive about using the internet in general terms. Yet, when it came to using the internet as a possible tool for sourcing health information opinion was split. When the internet was used by participants the benefits in terms of language abilities and culturally sensitive material were emphasised. Moreover, when employed the internet was mostly used in a checking capacity. To gain a fuller understanding of the internet habits of participants it was necessary to explore the types of health information utilised and investigate if trust impacted online activities.

6.3 Online Health Information & NHS online

When online health information activities were employed, they were driven by slightly different needs, as the statements below suggest. Chinese participants spoke predominantly of searching for information regarding illness, usually specific illnesses such as diabetes and high blood pressure, (please refer to chapter 1 for discussions on the health of African and Chinese populations in Scotland). Although African participants also mentioned illnesses such as diabetes and high blood pressure, there was much more emphasis on diet and exercise as a means of weight control.

> *Macy (Chinese, female in her fifties): I look up things about menopause…*
>
> *Mrs G (African female in her thirties): Women's health*
>
> *Doudou (African female in her twenties): I was reading some people saying you have to do more exercise, and other people saying no you have to eat proper.*

> *Grace T (African female in her thirties): Usually I use, I check hum…diet given course to people who is fat and they wana lose the weight… I want to know which foods they eating and how to cook it and I check it and sometimes I look up about health which things can I eat, fruits, vegetables…*

When asked if there were any bad things about using the internet as a source of health information, issues of reliability and trust were considered as were the practical disadvantages compared to face-to-face contact.

> *Fang (Chinese female in her twenties): Sometimes I feel the information given is exaggerated.*

> *Mr Lee (Chinese male in his sixties): …but a lot of the information on the internet is rubbish!*

> *Nadia (African female in her thirties): Yeah… we should not trust everything.*

> *Dan (Chinese male in his thirties): If I got any questions, I got nobody to ask! [laughs]*

It is interesting to note on the matter of trust, not all interviewees mistrusted health information on the internet there was an even response. Macy suggested that simply by being on the internet she felt the health information she was getting would be reliable. Dan also raised the point that health information from the Hong Kong authorities would be trustworthy, possibly because of the status he affords the Hong Kong health authorities.

> *Tasha (African female in her thirties): I think I am one of people, if it's on the internet it must be right.*

> *Ying (Chinese female in her forties): I think you can trust it.*

> *Dan (Chinese male in his thirties): Yes, sometimes it is provided by Hong Kong authorities*

> *Macy (Chinese, female in her fifties): I think if it's put on the net it should be reliable… about seventy or eighty percent… that I trust.*

During exchanges about trust and online health information, I asked what sources participants used to locate health information, sources including NHS websites. Findings indicated Chinese participants routinely accessed health pages which were provided by Hong Kong health authorities. When asked about using NHS websites, very few had ever looked up NHS websites and the main reason given was because information was only provided in English. When I mentioned the website 'Health in My Language' and how it offers health leaflets in standard written Chinese, no interviewees had heard of the website. Data from the questionnaires reiterates this point with only 7% of questionnaire participants stating that they use NHS websites for health information (please refer to appendix L for SPSS output regarding the use of health websites). Interviewees such as Mr Lee and Fang did talk about using google however as a starting place to search for Chinese websites.

> *Mr Lee (Chinese male in his sixties): Put things in google but in Chinese sometimes I find google has more knowledge.*

> *Fang (Chinese female in her twenties): Chinese websites, I google…*

Although African interviewees also used google for health information they did express greater use with NHS websites, as the excerpts below illustrate.

> *Robert (African male in his forties): I use the NHS website last year when I was looking for information an operation and the type of service they provide… I clicked on a link and it took me to the department and it told me more about it.…*

> *Ozzy (African female in her twenties): Even if I do google then it is a general website that comes up... if I am not satisfied then I can use the NHS website*

> *Grace T (African female in her thirties): Yes swine flu I was checking the NHS website.*

Ozzy also commented as did Doudou on the trust they have for health information on NHS websites. As Doudou emphasises, there was a strong feeling that if information was on an NHS website then it was to be believed.

> *Ozzy (African female in her twenties): I would say I trust the information on the NHS website more…*

> *Doudou (African female in her twenties): Yeah I trust them, I trust NHS because I know they… what they are putting on their website is… can help you, they can't put wrong things... I trust them.*

Yet, most African interviewees said they simply used both options and at times employed a checking practice against different information. Robert in his assertion below acknowledges using NHS information as the basis for such a checking exercise.

> *Grace T (African female in her thirties): Google sometimes, NHS sometimes…*

> *Karen (Chinese female in her forties): I just google it but if an NHS website comes up I think I pay more attention to it, probably go into it a bit more.*

> *Robert (African male in his forties): I would look around at other websites but the one I come back to is NHS website and I compare the information, it better to go on the NHS website.*

However, Robert also illustrates his frustration with NHS websites signifying that the information they carry is very generic, and that not enough is specifically for African populations. Academics are aware that certain BME groups suffer disproportionately with specific health concerns (Bhopal, 2007; Ingleby et al., 2012) and so Robert is stressing a vital point relating to engagement opportunities on NHS websites.

> *Kirsty: …and do you think there is enough health information for the African community online?*
>
> *Robert (African male in his forties): No, there is a gap, there is a huge gap of information… I mean NHS, they are just try have it for general… they have information on cancer and people getting checked…*

During my time at the Barton women's group there was no discussion of NHS websites; NHS workers never mentioned websites as a source of health information. Neither did they inform the group about the 'Health in My Language' website which may have been of particular use to some of the women with limited English skills. Unfortunately due to time constraints I was unable to attain NHS ethical approval to interview NHS staff, therefore I was not able to formally interview health workers running the HIC course to ask why this was the case. It was possibly not seen as part of the courses remit and instead emphasis was given to encourage the women to see the group as being a primary source of health information. However, I did witness an NHS worker refer to health websites was during the Healthy Skin health talk at CCDP, at the very end of the presentation Sam (a dermatology nurse) offered a slide with a list of health websites in English, notably the 'Health in My Language' website was absent.

Hence, results from this study indicate two main challenges to eHealth in the form of NHS Scotland online; awareness and relevance. Chinese participants did not use NHS websites because they do not know about them, (none had heard of Health in My Language website) they were not aware of the information that might be on such websites and importantly they did not perceive such sites to be relevant to their health information needs. African participants did use NHS websites but concerns were raised as to a lack of information specifically for African populations.

6.4 The GP or Google?

Interestingly, the rise of person-centred approaches in medical provision has led to a grown in the questioning of medical power. Nevertheless, research participants in this study overwhelmingly preferred to see their GP compared with sourcing health information on the internet. Although there were a few interesting responses to this line of inquiry, for example, Fang stated that communication was such a barrier, she actually preferred to use the internet, while others like Rebekah talked about using the internet as a means of seeking health information before visiting the doctor; background preparation before taking to the front stage for social interaction.

> *Fang (Chinese female in her twenties): Go on the internet because can't directly communicate with doctor. If it is not necessary I will not go to the GP.*

> *Rebekah (African female in her forties): I prefer going to my doctor if I have any problems before I want to check on the internet first.... So if I see the internet is not helping me with that then I can see the doctor. So I combine, both from the doctor and what I saw on the internet. The internet will not give me tablets!*

Undoubtedly from this research it is clear that when individuals engage with technology and use the internet for health information activities they are not looking to replace health professionals but for the internet to act as a supplementary source. When I discussed the role of technology in delivering health information with Kerry, a Scottish woman in her forties and an eHealth Policy Analyst from the Scottish Government, she gave the following insight.

> *Kerry (White female in her forties): I think the thing is you will never replace face to face, I think if people want to use technology have the*

> *opportunity and in terms of the NHS that's good because giving people the opportunity removes a lot of these people for costs sake, for resourcing sake and not just that but for the convenience for people …I think we are trying to design services that are a lot more flexible and give more choice you know in theory you could press a button and get you prescription, you could be on facebook and remember oh I need to get that….*

The aforementioned tells us that face-to-face interaction will remain central to NHS care and health information delivery which may even in some cases include video conferencing. Yet as evidenced in earlier discussions NHS health professionals, on occasions, did not function as active providers of health information; often health information was irrelevant to the audience, lacking cultural relevance. Technology has, as Kerry says, the potential not just to save the NHS vast sums of money but to provide flexibility and reassurance to its service users who are actively seeking health information.

6.5 Telehealth: NHS 24 & BME Engagement

As an important source of health information for the general public, I took the decision from the outset of this research to explore the role of NHS 24. NHS 24 is a telehealth service which provides health information and self-care advice for the Scottish public, its main function is to provide a phone service where service users can speak to health professionals about their symptoms after doctors' surgeries are closed. At the time of writing this thesis, the NHS 24 telephone service charged callers at a local rate for landline calls and mobile networks charged a range of prices, the cost of calls along with issues of mistrust and awareness emerged during interviews. The uptake of telephone health services by BME populations has customarily been low, according to Byrne et al., (2007) with only 6% of callers to the English NHS Direct service (now the 111 service) were from BME populations. In this study many interviewees especially Chinese interviewees, had simply never used the service. During one conversation with the Chinese community worker Betty, she outlined some of the community's activities in engaging with NHS 24, patterns also reflected within other BME groups across Scotland (REACH Community Health Project, 2012).

> *Betty (Chinese female in her thirties): They think it is useless. Because they think 24…. they won't use it and also they ask too many questions on 24…. but they lack the confidence over the phone…and communication is another problem…*
>
> *Kirsty: But they can get a translator?*
>
> *Betty: I heard they can get a translator for you but I heard it was…*
>
> *Kirsty: Not very good?*
>
> *Betty: Yes and….they would like a GP or nurse at least to look at it they have more confidence in this.*

Betty, has worked with the local Chinese community for over 10 years and was vital to locals in signposting them onto other services and organisations who could assist them. The aforementioned tells us that Betty believes once again that language serves as a major barrier for the Chinese community in using a service such as NHS 24, even with an interpreting service available, the community still suffers a lack of confidence to speak about health over the phone. Issues of trust also surfaced, with Betty's statement "they think it is useless". During this discussion Betty went on to give me examples of how individuals have used NHS 24 and felt let down by the service. Since this is a close-knit community such stories may have spread and compounded negative opinions of the service. Betty's emphasis on wanting to see a nurse or doctor face-to-face was also an issue echoed by several Chinese participants and possibly links back to previous discussions on the legitimatisation of health information when presented by a doctor face-to-face.

African participants meanwhile raised slightly different issues, they certainly had heard of the service and used it more than their Chinese counterparts however issues of trust and cost were raised. I became aware that for African participants the fact that many of them rely on using mobile phones rather than having a land lines meant high call costs when using the service, this issue has also been raised by research conducted by the REACH Community Health Project (2012). Please note that at the time of writing, the NHS 24 service is being revised, appeals from MSP's and charities to consider a free phone number were being considered by the Scottish Government, this would put the service in line with its English equivalent, the 111 freephone service. During Karen's interview she noted that there is confusion over the role of the service with some seeing it as a service you can call anytime for anything and others saying it should only be used in an emergency. Her own personal experience of the service was not very positive. She talked of being made to feel as if she was wasting the health professional's time. Finally Zizi mentioned the language barrier but as a fluent English speaker she spoke of how she found the Scottish accent difficult to cope with.

> *Rosaline (African female in her thirties): only the problem sometimes, they keep you on the line, it costs a lot of money.*
>
> *Karen (Chinese female in her forties): She made me feel as if I had wasted her time. 'you not having any pains?' 'no' 'you can raise the arm?' 'no tingling in the fingers?'*
>
> *Zizi (African female in her forties): Sometimes I can't understand voice…*
>
> *Kirsty: The accent?*
>
> *Zizi: Yeah…oh my god Scottish accent! [laughs]*

It is important to highlight that one participant, Sarah did talk to me about a positive experience she had with NHS 24 and acknowledged that she would use the service again.

> *Sarah (African female in her forties): That service they are very help, yes I have used that service because of my baby, I've got a young boy he is two years now and he had a problem, he had a problem and we used that service and they help me, they took me with my son to the hospital but they were really helpful.*
>
> *Sarah: Yes I would phone them again.*

Key conclusions from this study endorse existing research Byrne, (2007) regarding BME populations and their usage of telehealth services. Research conducted by the REACH Community Health Project (2012) in Scotland regarding NHS 24 and BME engagement stressed major concerns that language, mistrust and a basic lack of knowledge about such services exists within BME communities, findings which have also been uncovered in this research with Chinese and African participants. Recently, NHS 24 has published its Equality Outcomes Report (2013) themes which also evidenced the poor up-take of NHS 24 services by BME populations the report provides a number of suggestions to rectify this (NHS 24, 2013). Since this research study coincided with the Equality Outcomes Report (2013) it seemed appropriate to analyse research findings within this context. The following action points were offered for consideration through a public consultation held during 2013 (NHS 24, 2013).

- Engage and continue to develop partnerships with BME communities to promote services offered by NHS 24.
- Scope the feasibility of providing information on NHS 24 to asylum seekers at point of entry to Scotland.
- Raise more awareness among BME communities about benefits of preventative care.
- Raise awareness of Language Line among BME community.
- Recognise that different cultural groups exist within the BME community and take cognisance of this during contact.
- Improve staff understanding of cultural factors unique to BME community members and thus appreciation of health and illness behaviours among minority groups.

Many of the themes raised in the points above have been echoed in the findings of this research. The first topic regarding community engagement stood out from interviews and participant observations. Robert comments below emphasise the need for health services to build trust with the African community.

> *Robert (African male in his forties): The most important thing is to build trust, some of them…. in the Black community, in the African community people are so suspicious…*

In addition, this research has highlighted the role of community organisations like CCDP, and small grass-root factions, like the Barton women's group in health information activities. Although community organisations can be potential settings of risk and stigmatisation, their status as important places for health information activities should not be overlooked. BME community organisations offer access to health information whereby language and cultural barriers can be temporarily bypassed. For NHS 24 to fully connect with BME communities, it needs the endorsement of community organisations and information leaders. Individuals like Audrey (from the Barton group) and Betty (from CCDP) hold the key in overcoming mistrust and notions of irrelevance to accommodate changes in health information practices within both communities (the concept of information practices is discussed in detail in chapter 7). The backing of informal community information leaders like Robert (prominent community campaigner) and Rebekah (informal leader at the Barton women's group) are essential. If they can become champions of eHealth, encouraging engagement and facilitate understandings of the range of health services available including NHS 24, then potentially others in the community will follow. In order to get eHealth champions on-board there needs to be direct consultation with community groups, representatives need to visit communities to network; building vital working relationships. Time and again participants and gatekeepers in this research told me that they wanted their voices to be heard by health service providers. The second action point would obviously be welcomed by organisations working with asylum seekers. Recent social research carried out by the Scottish Refugee Council suggests,

> “*The main gap in terms of knowledge concerned out of hours GP services and the subsequent use of accident and emergency when GP surgeries are closed.*” (Scottish Refugee Council, 2013a: 8)

During discussions with members of the Scottish Refugee Council, Sheena and Zara both emphasised that when entering the UK it can be a confusing and scary time and often asylum seekers suffer with information overload, so at what stage during the asylum process mental health support is accessed is very important.

> *Sheena (White female in her thirties): In terms of when they first arrive….it’s really about getting people registered with a GP, it’s really getting them used to… …these are the steps that you will need to use… …these are where things are located, this is you know getting them up to speed with the asylum process itself and what will be expected…*

> *Zara (White female in her thirties): They are very vulnerable and it is information overload for the majority of people…. people are pushed through the asylum process very fast within a couple of weeks you might have your asylum interview which is your one chance to tell your story… you can tell your story and tell very traumatic things that might have health issues you know arising out of them, certainly for women I know and I am sure it is the same for men and families but mental health arising from trauma and things like that with symptoms of PTS are really big problems and we’ve got research that has shown that particularly for women so it’s managing that conflict between having to tell your story and disclose sensitive personal information really early on but managing that in a way that isn’t going to cause re-traumatisation you know that might lead to a breakdown eventually…*

Interview analysis in previous chapters also focussed on feelings of fear that many undertaking the asylum process associate with the disclosure of health information. Once again it was Robert who explained why health disclosure is regarded as a risky business for refugees or asylum seekers.

> *Robert (African male in his forties): …refugee or asylum seeker the pressure of the system, all the mental torture they receive in that system creates fear.*

Accordingly, the lack of face-to-face contact through telehealth may prove an additional barrier to this particular group, requiring greater reassurance about what happens to health information disclosed via NHS 24. It would be advantageous for NHS 24 to undertake consultation with organisations who specifically work with asylum seekers to establish mechanisms for reaching this group. The next action point is an interesting assertion and perhaps is relevant to some BME groups more than others. This research uncovered a solid understanding of preventative care especially in relation to diet and exercise within the African community, as the statements from Doudou and Grace T below spotlight. Furthermore, the Chinese community have deeply embedded attitudes towards preventative healthcare measures associated with lifestyle choices, as Mr Lee and Cheng explained.

> *Doudou (African female in her twenties): No too much fat, fish, wheat's, more veg, more fruits… and other food, proper food… Yeah, exercise, I like exercise… I am doing exercise in my home…*

> *Grace T (African female in her thirties): Yes, yes I stayed to go Zumba… Now it's one month and… I don't want to eat so unhealthily! Like butter or many sugar, like many salt and oil.*

> *Mr Lee (Chinese male in his sixties): Yes I think everyone Chinese do more… they more aware, they know more about their health.*

> *Cheng (Chinese male in his sixties): The western people do not do as many exercises as Chinese do because there are a lot of Tai Chi class, Ku Foo class and a lot of people walking.*

Previous analysis in this study has suggested that language is a physical as well as a social barrier to health information exchange; Grace T sums up the risks and feelings of mistrust when using an interpreter.

> *Grace T (African female in her thirties): Sometimes because you can't trust anybody. You can't trust anybody because perhaps you tell your problem and he go tell outside… not good.*

Accordingly there needs to be greater emphasis on the confidentiality that the Language Line service can offer users. Confidentiality policies by which health professionals and interpreters are bound and the professional qualifications held by interpreters need to be stressed in order to overcome negative perceptions around using interpreters during medical encounters. Point five of this action plan is something that policy makers, service delivers and researchers like myself need to always keep in mind. Undeniably this research uncovered heterogeneous populations within both African and Chinese communities. Complex relationships between these culturally, and at times, linguistically different groups need to be considered when trying to build stronger relationships with BME communities. Maggie underlined the diversity within the African community living in Scotland in her comments.

> *Maggie (African female in her forties): Yes communities… you find the Zimbabwean community has you know its own way of doing things, the Nigerian community the same, the Ugandan community, Malawian's, Zambian's, so they are communities within themselves, so within those communities you also find that access to different things is different, according to how those communities interact. So you might find the earlier communities that were built up like the Nigerian communities and the Ugandan communities they are more settled and probably know more about access to stuff…. then we have the newer communities like the Zimbabwean communities they are trying to get themselves around, link into things, but you know that is*

> *the newer communities, people are at different stages in terms of how well they know Scotland, or Glasgow, or the services in Glasgow...*

Maggie's point about communities within communities is a critical point, as is the fact that these different communities within the African population will access health information differently. Community and charity workers like Maggie, Audrey and Betty know their communities, they recognise the complexities and the different ways in which they will access health information, share health information and perhaps reject health information sources. They undoubtedly can be the first point of contact in advising how best to encourage service use. The final point regarding training of NHS 24 staff to understand the cultural influences in BME communities and health behaviours is a positive step. Accordingly when BME populations start to engage with the service, call operators and health professionals will be better prepared to deal with health queries and concerns. Additional considerations regarding the use of NHS 24 as a health information and support service can be concluded from these research findings. Firstly, NHS 24 has the opportunity to connect with individuals who use self-protecting behaviours to bypass the risk of health disclose in face-to-face encounters. By focusing on particular illnesses that are stigmatised, such as HIV or mental health this would allow NHS 24 to pitch their service as a safe clinical setting where health information and medical assistance can be obtained. Hence, the benefits of speaking directly to a health professional and the level of confidentiality that the service and Language Line can offer need to be promoted.

Another consideration would be to undertake an advertisement campaign to acknowledge a link with BME communities. Dan makes the point that he believes it is important to promote the Chinese community itself and their health needs, which obviously could be done in conjunction with the promotion of the NHS 24 service. Similar health campaigns have already been undertaken with NHS Scotland and South-Asian populations.

> *Dan (Chinese male in his thirties): I don't think health talks or leaflets are very useful I think it is better to have really big posters to promote locally so Chinese will realise it is important, big poster.*
>
> *Kirsty: Why do you think big poster is important?*
>
> *Dan: Because the more Scotch people know about us, in Glasgow in Scotland so it promote the community itself.*

Finally call costs were of primary concern for African participants as many did not have land lines and relied solely on using mobile phones, however it should be noted that call costs to the service are currently under investigation by the Scottish government.

6.6 mHealth

> "More recently, mobile technologies have exploded in popularity, unlocking a unique vehicle for eliciting behaviour change… mobile phones are being used for every stage of disease – from health knowledge and promotion to disease prevention, diagnosis, and treatment, including appointment reminders and medication compliance…" (Kwan & Kaonga, 2013: 15)

Positive associations with mobile phones and their potential for health information activities emerged whilst in the field. Since mHealth is in the early stages of development in Scotland and although there was not the scope to further investigate mHealth and its possibilities in greater depth, it should nonetheless be briefly considered within this discussion of eHealth. It quickly became apparent during my visits to the Barton women's group and health talks at CCDP that mobile phones were an established and popular communicative device. The use of mobile phones within BME populations is popular because it is seen as a convenient and increasingly cheap method of staying in touch with loved ones at home and abroad and without the financial restrictions of a landline contract. Betty outlines why smartphones in particular have become popular with the Chinese community, while Ozzy from the African community confesses that he no longer has a computer instead he simply uses his phone to connect to the internet. Although Doudou does not use the internet on the move, she still uses the wireless function on her mobile phone so both she and her husband can use the internet when they are at home.

> *Betty (Chinese female in her thirties): They use mobile phones as well even the new migrants its very updatable… now days the mobile phones they are newly, new issue they can communicate in their own language that's why they great… I saw them many use the iphone because it can be set in the Chinese language.*
>
> *Ozzy (African female in her twenties): Definitely, yes…I haven't even got my laptop at home any more I just use this… (Ozzy points to his mobile phone)*
>
> *Doudou (African female in her twenties): …I got wireless, just wireless you can't use it when you leave home. When my husband is using computer I am able to use my phone.*

Users like Isa with language and literacy problems can access the internet, call and use text to gain information and communicate with others, highlighting the possibilities for health information access through this medium. mHealth as a potential setting for health information activities therefore is an area that this research has briefly uncovered, if not fully explored. Nevertheless the positive reactions of participants and acknowledgements that mobile phones are an established trusted and relevant medium hints at the possibilities to filter health information to BME communities via this platform.

6.7 Health Information Kiosks

While the first touch screen health information system was developed twenty four years ago, the actual up-take and implementation of health information kiosks by the NHS has been a long and protracted process

(Nicholas et al., 2003). Health information kiosks are starting to appear in doctor's surgeries across Scotland however apart from a pilot in 2012 in Dumfries Infirmary, there is yet to be implemented across Scottish hospitals (NHS Dumfries & Galloway, 2012). Health information kiosk work like any self-help touch screen kiosk now commonplace in supermarkets and airports. The kiosk can be set-up in different languages, used for patient check-in, as well as offering health information and promotion. Most often they are located in spaces such as doctor's surgeries, pharmacies and hospitals, although there is capacity to locate these devices in non-healthcare settings (NHS Institute for Innovation and Improvement, 2013; Jones 2009). Talking about this new world of possibilities for health information access, interviewee's reactions were surprisingly positive, as Cheng and Ying suggest, while certainly language facilities were welcomed by Chinese participants such as Dan. Introductory sessions and publicity in collaboration with BME community organisations and health services before their introduction to places such as doctor's surgeries or hospitals could be a considered as a means of better engagement.

> *Cheng (Chinese male in his sixties): I would use it!*
>
> *Ying (Chinese female in her forties): Because it is really difficult going to big hospital there are so many departments and you have lots of people and it can get very hectic...*
> *If the kiosk was established it would be helpful... just like a Sat Nav! [we all laugh]*
>
> *Dan (Chinese male in his thirties): uh huh, Chinese language would be much better.*

Rosaline makes the point that some simple training would be good and that if someone was on hand to show her how to use the kiosk then she would be willing to give it a go.

> *Rosaline (African female in her thirties): maybe I don't have to use it, but I try if you don't try… you don't know, so you have to try, training is a good thing to try.*
>
> *Kirsty: if there was someone to show you?*
>
> *Rosaline: this is okay for me, I'll try.*

Kerry underlines the need for trainers and individuals who can encourage the use of such technology within BME communities. However Kerry's last statement suggesting "BME communities tend to be quite slow on the up take with these things" emphasises her lack of understanding on the full range of obstacles faced by BME communities when adopting health information activities through new types of technologies.

> *Kerry (White female in her forties): And I think it kind of needs as well that pioneer or champion in GP practices, in the community part of the success of a community initiative is you need someone to recruit people and for someone to say 'are you using it?' you know, 'here let me help you' some people will just pick it up and run with it but many more people need to be not quite cajoled but encouraged, and for some it wouldn't appeal and that's fine, I think it's difficult because BME communities are always a vulnerable communities… what usually happens with them … other people came… you know you get your pioneers who tend to go off and do things but the BME communities tend to be quite slow on the up take with these with things and the problem with the work we are doing is no one has done it before…*

From this analysis it can be argued that both Chinese and African participants were positive to the ideas of the health information kiosk and its possible functions. Nevertheless, there are important points for consideration, firstly these positive reactions might be spurred by what Nicholas et al., (2003) calls the curiosity or novelty factor of health information kiosks. If health information kiosks are to complement patient services and offer additional sources of health information then there needs to be on site assistance and encouragement to use the device (Williams et al., 2003). Nicholas et al., (2003) discovered that to boost pro-active engagement and for developing practical skills in using the kiosk, face-to-face interactions were needed. This would be especially important for BME populations who have come to Scotland as economic migrants or through the asylum process, as the healthcare system in their country of origin could impact on their understanding and confidence in using a health information kiosk.

Like other eHealth resources there is the possibility for kiosk users to become disengaged, especially after the novelty period of initial use. Kiosk users will undoubtedly disengage if they believe the information is of no relevance to them; becomes difficult to understand, too detailed or too brief (Nicholas et al., 2003). In the case of BME users, if health information was not provided in first languages, if the health information was not culturally relevant, then this would further compound disengagement. The proposal to promote NHS 24 services in informal information grounds such as Chinese supermarkets and barbershops may also have potential for health information kiosks. Undeniably there are many advantages in using health information kiosks they can provide bespoke, accurate, quick and convenient health information to users. They can simply offer information dissemination or become an interactive part of the patient experience. Nevertheless, a crucial drawback is their public character for health information seekers who are looking up sensitive health information or information regarding stigmatised illnesses the public nature of accessing a health information kiosk potentially limits its use. Just as public community settings (such as the Barton women's group or CCDP health talks) can be considered risky environments for health information activities so could a health information kiosk being accessed in a public place. Hence, there are advantages and disadvantages of using health information kiosks for BME populations, but as with all other aspects of eHealth already considered, themes of promotion, engagement, relevance and trust all need to be considered when implementing this eHealth format for BME communities.

6.8 Chapter Summary

Overall, participants were positive about the role of technology. In the case of the internet, participants viewed it as a useful tool in day-to-day life however they did not always perceive it to be for health information activities. When participants did use the internet for health information activities they tended to employ it as a means of checking existing knowledge or to compare sources, they appreciated the language capabilities as well as the accessibility of material in other languages online. Surprisingly health forums were not utilised as a place where health information and advice could be sourced. When it came to the types of health information being sourced on the internet, African participants were interested in searching for general health and wellbeing information, especially on diet and exercise, whilst Chinese participants wanted information on specific illnesses. Participant observation exercises spotlighted a gap in promoting NHS websites, especially the Health in My Language site which offers health information leaflets in different languages. Thus, further publicity of NHS online with particular focus on eHealth literacy could foster changes in health information practices prompting greater use of the internet as a tool for health information activities within BME communities.

NHS 24 was a key area of investigation during my time in the field. A large number of participants had negative perceptions as well as poor experiences of the service. The Chinese community had limited engagement with the service, whilst African participants were prevented greater up-take of the service by high call costs via mobile phones. At the time of writing NHS 24 had published its Equality Outcomes Report (2013) and was undertaking a public consultation exercise, this provided the perfect platform upon which to further analyse research outcomes. Through this exercise NHS 24 has a huge opportunity to reach out to underserved communities across the country and to begin to build better connections with BME communities.

From my time in the field, mHealth as a possible vehicle for health information emerged, its' potential capacity in overcoming language barriers, as well as, providing culturally appropriate health information is exciting and although its capabilities are just starting to be developed, the possibilities for engagement with BME communities should not be overlooked. Finally, health information kiosks offer similar facilities to mHealth, but perhaps need more formal promotion and training to secure success. The positive reactions of participants in this research showed a glimpse of the possibilities going forward, but lessons can be learned from the experiences of implementing NHS 24. Moving onto the final findings chapter now, chapter 7 will probe the final research question of this thesis, asking: is information poverty evident in this study?

Chapter 7 Information Poverty

7.1 Chapter Introduction

The objective of this chapter is to further examine research findings within the theoretical construct of information poverty. Each of the theory's propositions will be examined in combination with interview data as well as conclusions drawn from participant observations. Interwoven into this discussion is academic commentary including relevant research from those inspired by social constructivist perspectives, including Fisher (Pettigrew, 1999; Fisher et al., 2004a) and Savolainen (2008). Fisher's (Pettigrew, 1999; Fisher et al., 2004a) theory of information grounds will be utilised to expose the information grounds of research settings and to assess how health information exchange needs to be understood in context as well as how health information seeking can occur as a by-product of social interaction. Meanwhile Savolainen's (2008) theory of everyday information practices approaches the actions of information seeking, using and sharing through the context of furthering everyday projects. Inspired by Bourdieu's (1990) habitus the concept acknowledges the process of a social and cultural system internalised by individuals through which information practices manifest. Thus, Savolainen's (2008) information practices allows for succinct new insights which have potential for future information scientists. Finally, the chapter will be reviewed in preparation for the concluding thoughts and recommendations chapter, the final chapter of this thesis. The chapter begins with some commentary on the concept of insider and outsider roles which is central to the theory of information poverty.

7.2 Evidence of Information Poverty?

Chatman's (1996) theory of information poverty acknowledges insider/outsider statuses can be fluid. During my attendance at the group I often found I had switched between status groups. When the group was first formed, I was certainly viewed as an outsider, and was usually associated with the NHS staff in attendance. My ethnicity and perceived class identity certainly played a role in defining this outsider status. No matter the passage of time, at certain intervals, I would always be considered an outsider. Intriguingly though after several weeks I started to become a member of an insider group, primarily because the women got to know and trust me, my social identities started to become subdued and somewhat replaced by my membership to the group, (especially as a founding member). This insider status was apparent when new members joined the group, the exchange of information between myself and other established members was founded on previous conversations and knowledge of each other. During these conversations new members would be members of an outsider group, not privy to the history and information exchanged between the established insider group. Subsequently during my time spent with the Barton women, I held different sets of social statuses dependent upon the social and cultural values attached to the situation, (for reflexive discussions my role in the field please see chapter 3). It could be argued that in certain contexts my researcher role maintained a third space, whereby I was an insider and an outsider able to switch my status with relative ease especially compared to NHS staff or the formal group leader. I was an insider to the group because as a founding member I was able to connect with the members but I was also known as an independent researcher, a woman with a different ethnic background, someone who was therefore an outsider to both the community and the group's function as a women's support group. Some members of the group confided in me because I had built up trusting relationships with them over the months, so the insider status was productive in building rapport, yet the outsider status meant there was little risk I would know others in their community, and so I was someone who the women could open up to during interviews with little fear of exposure.

Other insider groups within the Barton women's group were created through ethnic associations. There are obvious reasons for these ties, as discussed in Chapter 4, some of the women in the group had poor English language skills and relied on other women to act as informal translators. In addition, women from the same geographical areas in Africa shared cultural customs, religious beliefs and social norms. These small insider groups exchanged information but also created barriers to information exchange between these different insider groups. I witnessed this most prominently when the women were discussing what types of dresses should be made for an up and coming fashion show. Much discussion took place between the different insider groups around the various styles, fabric, and symbolic representations associated with different national dress. Although these insider groups seemed strong and close-knit, I later discovered that they could also (as Chatman's (1996) theory proposes) become settings where self-protecting behaviours are adopted to minimise risk of exposure. In order to fully apply information poverty as a conceptual framework in this research, it is necessary to compare fieldwork findings with each proposition of the information poverty theory.

7.3 Six Propositions of Information Poverty

Proposition 1: Participant Perceptions

Proposition one of Chatman's theory identifies the information poor as individuals who perceive themselves devoid of useful sources of information. After careful analysis of interviews and participant observations it can be concluded that participants in this study did not recognise themselves devoid of sources of health information, primarily because the doctor was seen as a sufficient source. Answers offered by Mrs G and Grace were typical of interviewees.

> *Mrs G (African female in her thirties): I go to the GP straight.*

> *Grace T (African female in her thirties): Well I go to the GP.*

Although many participants from both BME communities did have limited knowledge of where and how to access additional health information (as discussed in previous chapters) few distinguished themselves as devoid of additional health sources. However, when questioned about written health information available in Chinese, participants confirmed a lack of health resources available to them. In the case of African participants, a lack of culturally appropriate material was also acknowledged. Yet, when asked directly, participants did not perceive themselves to be devoid of health information. This pattern of reliance on a single source, the GP, may harp back to the previous discussion on medical authority and legitimacy outlined briefly in chapter 6. In addition, the traditional nature of health information provision at a single point of access possibly encourages people to view one source as adequate for their needs. However, NHS Scotland is beginning to move away from emphasising the doctor at the centre of medical care, adopting instead what is termed as a person-centred approach, providing services responsive to individual preferences (The Scottish Government, 2010c). Spink & Cole (2001) identified in their study of information seeking channels used by African American low-income households that participants also used a single source for health information. Moreover, unlike other types of information, health information was usually sourced outside of participant's immediate social environment in the form of a GP or other health professional. While Chatman's model takes stock of the relevance of information being sought, and the disadvantages for information seekers, she does not account for the character of the information itself and how this impacts upon information activities. Lingel & Boyd maintain,

> "It is inadequate to consider information poverty solely in terms of whether people themselves are significantly disadvantaged; it is also

> necessary to consider whether information itself constitutes a kind of stigma, and how that stigma shapes information practices.” (2013: 34)

In addition, when participants in this study did wish to pursue other sources of health information they did perceived them to be readily available. Veinot’s (2009) research on people living with HIV/AIDs presented a scenario where participants were reliant on professionals to offer them HIV/AIDs related information, because as outsiders and professionals they were viewed as trusted individuals or as Goffman (1963) would have labelled them, the ‘wise’. Consequently participants were not completely cut off from information access as depicted by Chatman’s (1996) theory. In this research, community based sources such as local community organisations and Chinese newspapers were typically discussed by Chinese participants whilst Africans spoke of using the internet for additional health information. Dan and Mrs G both outline these patterns of health information retrieval below.

> *Dan (Chinese male in his thirties): Every week I read Chinese magazine and they always have a column for health.*
>
> *Mrs G (African female in her thirties): Look it up and read the net…*

Overall, these research findings suggest access to health information is shaped primarily by social norms and cultural understandings of health, as discussed in the previous chapter. Contrary to Chatman’s (1996) first proposition participants did not perceive themselves helpless of health information sources, possibly changes in the character of the digital divide may account for the impression of accessibility. Nettleton & Burrows (2003) suggest the internet contributes to the construction of a new medical cosmology, although it continues to exist in a world of established structural inequalities (a fuller discussion on the digital divide was provided in chapter 5).

Proposition 2: Privilege Access

Chatman's (1996) concept then moves onto ideas of power and class distinction, suggesting information poverty is influenced by outsiders (information leaders) who withhold privileged access to information. This type of behaviour was most evident at the Barton women's group and the monthly CCDP health talks. Outsiders in these settings included: NHS health professionals/promotional workers, and third sector workers, in these situations they were often performing the role of information leaders. Rather than understanding class positions as Chatman (1996) suggests, outsiders in this context have been understood as potential information leaders with distinctions based upon differences in race and ethnicity as well as cultural knowledge (a discussion on the use of race and ethnicity as constructive concepts in this research was provided in chapter 2).

The first example of this behaviour, mimicking proposition 2, occurred during a health talk with the Chinese community. Sam an NHS Health Promotions worker began the healthy eating talk by explaining the 'Eatwell Plate', outlining the different food groups people should be eating on a daily basis. It quickly became apparent that this generic presentation had not been adapted for the Chinese community. During her presentation Sam did not use any examples of Chinese diet when giving out nutritional advice. Instead she used examples such as "a ham sandwich for lunch", one look at the lunch of noodles, rice and vegetables on offer at the talk would have told Sam that ham sandwiches are not a regular staple for the audience. In addition, Sam spoke about illnesses such as heart disease and the dangers of being overweight, a health issue not usually associated with Chinese populations in the UK. It soon became evident that the audience was disinterested in the presentation; people started to whisper to each other while others left to make phone calls and returned once the talk was over. Towards the end of the health talk Sam did apologise for not having any examples of food that the audience might eat and consequently not providing advice that would complement such examples. This illustration of a generic health talk on healthy eating indicates Sam unintentionally withheld health information relating to diet and nutrition for the Chinese community. Sam holds power in this situation as she has specialist knowledge and has at her disposal the resources of the NHS. van Dijk's (1997) consideration of discourse and the reproduction of inequalities in societies through covert and subtle messages interwoven into public and social practices is evident here. To guard against this, Bhopal (2006) argues for mainstream initiatives to integrate evidence based modifications to ensure the health needs of BME groups are meet. Netto et al., (2010) also argues that to increase appropriateness of health engagement, minority status, disadvantaged social statuses, cultural and religious beliefs as well as cultural affiliations all need to be considered. Of course this illustration of unintentionally withholding health information reflects the use proposition 2 in its broadest of sense. Nevertheless, it does focus on power distinctions between health information seekers and information leaders, where in this case a lack of shared identity and cultural understanding hampered the information leader in realising the needs of the audience.

The purpose of groups such as the Barton women's group is to build bridges across settings of isolation and poverty, to encourage the women to support each other but to also become more confident and independent. Without doubt the group provided this on many levels. Even during the short months that I attended the group, I was witness to the birth of new friendships and the sharing of cultural customs. However, when it came to information dissemination there were times when this was limited. In respect to general information it quickly became apparent that the formal group leader Audrey was very selective about the type and amount of information disclosed to the group. On a few occasions when I begin talking about other African organisations or events such as Black History month, I was quickly dismissed by Audrey. This may have been because I was viewed as an outsider by Audrey herself. Although, this is not to say new information was not introduced to the group at all, because it was, it was just always filtered through Audrey or NHS staff. For Goffman (1959) the group leader Audrey is performing her part on the stage of the women's group, executing the norms of her social status. Thus, as group leader, deciding what information to deliver to the group and when this should occur is anticipated by group members. From the perspective of Chatman's

(1996) theory, Audrey as the group leader switches between insider and outsider statuses, as a fellow African who came to Scotland over ten years ago, Audrey is viewed in high esteem and definitely considered an insider, but as the formal group leader and someone who does not live locally Audrey was also viewed as an outsider. The example of Audrey withholding and filtering information into the group challenges proposition 2 since Audrey shares social and cultural identities with the women in the group, Audrey and the group members would often refer to themselves as 'we Africans….', this would suggest power in this situation was based upon an element other than ethnicity, arguably it was based upon the performance of social norms expectant of a group leader.

When it came to NHS information leaders, they too sought to control and filter information into the group whilst also creating a dependency on the group as a primary source of health information. During one health talk, Sally an NHS promotional worker, made a suggestion that by seeking health information from friends and family group members were relying on sources that would not always be correct, interestingly this behaviour seemed to be encouraging the legitimatisation of health information provided at the group. At no point did formal information leaders encourage independent health information activities. If the point of the women's group was to empower its members (a point relayed by Audrey and Sally) then perhaps there needed to be greater emphasis on the variety of health sources available to the women outside of the group. Formal information leaders, such as NHS health promotions officers never spoke of the local library, NHS 24 or any NHS websites as possible places where the women could source more health information themselves. The only other source of health information that was mentioned at any point during my time at the group was that of the GP. Obviously there were benefits in gaining health information from the Barton women's group, yet there was no encouragement for alternative forms of information access, encouraging the women to embrace a variety of information points and learning to assess their possible relevance. I propose therefore that information leaders (outsiders) have privileged access to information, information which is not always shared because it is believed it is in the insider's best interests not to, it is not viewed as socially acceptable to do so or because the impact of withholding such information is not fully realised. In the examples of Sam and Sally differences of race and ethnicity may have influenced the access of health information to insiders, yet in the case of Audrey (who shared these social identities with insider members) the limiting of information could have been founded on her social status as an information leader.

Proposition 3: Self-Protecting Behaviours

Proposition 3 focuses on the expected social norms within a group, and the performance of self-protecting behaviours by group members. This research found principles and opinions of health and especially illness which were heavily shaped by cultural influences (as discussed in chapter 4). The embeddedness of health beliefs within the Chinese community has led to the development of social norms around healthcare and health disclosure. Karl a second generation Chinese man explains some of the social norms relating to health ownership and how this impacts healthcare engagement.

> *Karl (Chinese-British male in his twenties): …the older generation try and fix everything themselves because of their own knowledge and what they have learned back home all the traditional stuff… I don't know if that could be an issue.*
>
> *Karl: Aye I suppose a lot of the older generation don't want to go to the doctor, they are quiet tough and they don't want to go see the doctor until they are really ill.*

The aforementioned hints to underlying reasons why engagement with NHS services is low within Chinese populations but it also displays some of the social norms and expectations around health within the community and how self-protecting behaviours may be adopted to comply with social norms. It is important to note however, as I was unable to undertake in-depth participant observation with the Chinese community, I acknowledge that I was not actually privy to directly witnessing self-protecting behaviours amongst Chinese participants which is therefore a limitation to this research.

Conversely, African participants did throughout the course of participant observations and interviews, talk or display self-protecting behaviours, behaviours necessitated because of expectations based upon social norms. Similar to Veinot (2009) this research found this was especially true of illnesses perceived to be associated with anomalous behaviour and therefore stigmatised. In chapter 4 I outlined the influence of faith and faith leaders in establishing social norms, especially in relation to expected modes of behaviour around the disclosure of health. In the comments below Maggie emphasises the social norm of not disclosing illnesses such as HIV, even to faith leaders.

> *Maggie (African female in her forties): …a few said we don't have HIV in our churches which is obviously…. If someone is saying that obviously they are not knowing their congregation, and no one in their congregation would have the confidence to go up to them and say….*

Hence, social norms around health disclosure and stigmatised illnesses encourage self-protecting behaviours for health information seekers within African communities. Certainly in both communities social norms and cultural beliefs influence how health is perceived, which equally influences how health information is sought and shared. The example of Rosaline from the Barton women's group in chapter 4 and the discussions around courtesy stigma are also relevant here since it evidences the need Rosaline felt to engage in self-protecting behaviours. In the statement below Rosaline is referring to the 'My Life Story Board' exercise at the Barton women's group. One afternoon the women were asked to draw a time line of their lives and to include family members. This exercise did not go to plan as many members became visibly upset. Rosaline acknowledged to me during our interview that she did not truthfully disclose what had really happened in her life and to that of her family and their health during this exercise for fear of the repercussions, thus she used the behaviours of secrecy and deception (proposition 4) to lie and ultimately protect herself.

> *Rosaline (African female in her thirties): That's why that day I couldn't express myself, because if it's white people. I'm okay for that, but we blacks… if the person know that you say something…*

Iree another member of the Barton women's group also engaged in self-protecting behaviour, and although in this example Iree did not lie to protect herself, she nevertheless acknowledging that there is some information, in this scenario health information about herself that she deliberately does not wish to share with the group in order to protect herself.

> *Iree: But there is some of the thing that you can share with group and some other thing you can't share with group…*

Proposition 4: Secrecy & Deception

Proposition 4 obviously links with the previous proposition and identifies self-protecting behaviours created from mistrust involving the interest or ability of others to provide useful information. It was evident that there was a mistrust concerning the interests of others to provide useful information and support in the 'My Life Story Board' example in proposition 3. Although the women's group offered a place for African women to share cultural customs and build friendships, it also became a space where potential dangers were perceived. After the 'My Life Story Board' exercise Sally (an NHS Health Promotion Officer) explained to me the objective of the exercise was to get the women to open up to one another, in order to create a safe space where they could come each week and talk about their health as well as life events. The exercise was initially supposed to get members thinking about health and how life events can impact their physical and mental health. Far from becoming a 'safe space' the exercise illustrated that for many members, the group can be a risky setting, whereby you need to protect yourself from possible exposure. Rosaline's experience was just one example of a group member feeling threatened by this exercise. I was very much aware however that during that afternoon the atmosphere quickly changed from being informal and friendly to awkward and discouraging. A number of the women excused themselves and left with a few seeming visibly uncomfortable (one lady left in tears). This exercise not only got the members to think of their past and perhaps traumatic experiences (which was obviously very upsetting for some) but it also showed that members needed to engage in behaviours to protect themselves. I only know of Rosaline lying to other group members, but it was quiet obvious that many of the women purposely withheld information, simply giving details of where they had lived in Africa or how many family members they had, NHS staff were disappointed that this exercise had not served its purpose to create a save setting for the women.

Being untruthful about the past or in particular health problems was not the only self-protecting behaviour I witnessed during my fieldwork. In the course of interviewing it became clear that utilising the services of an interpreter on occasion necessitate the need to self-protect, to use in this example secrecy. The use of interpreters to communicate with health professionals highlighted challenging and risky settings for participants. As presented earlier in chapter 5, Grace T's excerpt below illustrates the possible risk in employing an interpreter to discuss individual health.

> *Grace T (African female in her thirties): I don't like because you know health, individual health you can't tell anyone, anybody… there are things… so he can, see you another day and you know people talk, talk too much….* sometimes because you can't trust anybody. *You can't trust anybody because perhaps you tell your problem and he go tell outside… not good.*

Analysis in chapter 5 exposed two key issues associated with the fear of disclosure in African communities, one that the African population is very diverse within Scotland and subsequently comprises of close-knit small communities where there are strong bonds and associations, individuals fear the ease with which information can be spread in a community where everyone knows everyone. Secondly, certain illnesses, connected with what are perceived as anomalous or deviant behaviour, held the risk of stigmatisation. Hence, there is an apparent need for health information seekers to adopt self-protecting behaviours such as secrecy and deception to lessen the risk of exposure.

In the Chinese community there was evidence of the second part of proposition 4; mistrust in relation to the ability of others to provide useful health information. Although Chinese participants trusted their GP's and other health professionals they did not have faith in the abilities of NHS 24 to assist them in their health information needs. Betty's reply to my questioning underlines the mistrust associated with the telephone service by the community.

> *Betty (Chinese female in her thirties): They think it is useless!*
>
> *Kirsty: Why do you think, they think that?*
>
> *Betty: Because they think 24 only help… a case okay… I say 'why you not call the NHS 24?' He said 'No NHS 24 they just for advice you blah, blah, blah, but not emergency or take you to the hospital or help you instantly' so that's why they think 24 is useless.*

My analysis of proposition 1 indicated that Chinese participants did not perceive themselves to be devoid of health information, yet there is a lack of engagement with NHS 24, and mistrust of this health information provider, aligning with Chatman's notion of mistrust regarding the capacity of others to deliver valuable information. A limitation to this research analysis is that secrecy and deception as self-protecting behaviours were not directly witnessed with Chinese participants, most probably because of the absence of in-depth participant observations with the Chinese community.

Proposition 5: Negative Consequences

The use of self-protecting behaviours is adopted by information seekers because of the anticipated negative consequences associated with exposure. This forms Chatman's (1996) fifth proposition and suggests individuals who are information poor take decisions not to risk disclosure because the supposed negative consequences often outweigh probable benefits. Here it is useful to return to Rosaline from the Barton women's group and her self-protecting behaviours of deception and secrecy. Rosaline believed that if she had been truthful that afternoon about her life and her family's past then she would have faced social consequences, consequences she outlined to me during our interview.

> *Rosaline (African female in her thirties): … for the type of sickness, in Africa if you say maybe the sickness killed my dad. Nobody wants to touch you because you have that problem.*

Rosaline is fearful that by disclosing information about herself she will face stigma and rejection by her community, therefore she feels it necessary to employ self-protecting behaviours. On reflection she could have disclosed her family history in order to get advice from NHS staff or support from group members but this would have been at huge risk to her and her immediate family living in the area. In this situation Rosaline has made the decision that negative consequences outweigh potentially positive consequences.

From earlier analysis of Maggie and Robert interviews, it is known that both remarked on the behaviour of Africans in terms of withholding information about personal health for fear of negative consequences. Maggie relayed during our conversation her fear that Africans suppress information when using an interpreter to communicate; the fear of others in the community finding out is often too great. Hence, a decision is made by patients not to risk exposure. In addition, Robert believes there is anxiety within the community that health information is shared between government establishments and ultimately may help to decide asylum claims.

> *Robert (African male in his forties): Things cannot be easily said or easily shared, they will keep it because…..someone will come maybe someone will take that….information and do something with it.*

In Robert’s comments above he emphasises the consequences of exposure: that by disclosing health information someone might share that information and use it to take action against you. Consequently, knowledge about people’s activities or in this case past histories informs and produces new knowledge which could be used to reinforce existing power. Sheena from the Scottish Refugee Council confirmed (in the chapter 4) Robert’s fears that for some asylum seekers health information may have been used in an unauthorised manner during the asylum process. Certainly when health information seekers are looking for and sharing health information they must weigh up the potential benefits versus any negative consequences. I would argue the factors that influence such a decision depend upon social norms towards health and illness, the channels through which information is sought (if a third person is used) as well as the social settings in which the health information seeking occurs.

Proposition 6: New Knowledge

Now stepping away from self-protecting behaviours and returning to the issue of access, Chatman (1996) argues new knowledge is selectively introduced based upon relevance, relevance of that information to everyday concerns. During my fieldwork I uncovered differences between the two BME populations in terms of health interests. Generally Chinese participants were anxious to find health information on specific illnesses such as diabetes or high blood pressure. Meanwhile African participants wanted health information in relation to diet and exercise in order to lose or control weight. Health information was sought that would answer such interests, consequently, when deciding what health talks to organise Betty at CCDP thought about the current health concerns of the community. This made the health talks popular but it could be argued that this new health knowledge was selectively introduced in response to the everyday health concerns of the Chinese community. Adopting Dervin’s (1977) model of sense making, Chatman, (1996) suggests individuals can relate more to information being received by them if it is particularly useful in addressing current concerns or a problem. However, this behaviour generates a situation whereby individuals may bypass sources of information or information itself which is not deemed useful in solving a concern. As a result, Chatman (1996) proposes a need to appreciate the relevance of information to truly understand why potentially helpful sources of information are sometimes ignored by information seekers. This discussion is not about judging new knowledge itself, accurate or not, rather it is about the mechanisms by which health information seekers attain new knowledge or overlook potential health information sources. The lack of NHS online or NHS 24 usage by the Chinese community was founded on assumptions that this source was not relevant, primarily because health information was not seen as culturally specific and only offered in English. Chatman's (1996) relevance of information is critical in understanding why potentially useful health information sources are not utilised.

As you would expect, the ladies at the Barton group were happy to attend the HIC course in the knowledge that they would be learning something new in terms of health but also have the opportunity to socialise. Grace T described to me during an interview why she attended the group.

> *Grace T (African female in her thirties): Yes good, very good because learning something like health is important for us every day in our lives we might learn new things because sometimes we can be wrong and others can be right. It can give you information it is good for me.*

Health information disseminated at the group was often bound together with instilling ideas of empowerment and confidence. Thus, health information was not always passively fed, sometimes group members were asked to partake in exercises and games to get them thinking about their positions in society and their abilities as a group of women to support each other. As a result, participants did not always considered this information to be relevant to their needs. There were times this approach caused confusion, some of the ladies struggled to grasp the link between group activities embracing ideas of empowerment and confidence building, and the topics of health and wellbeing. In one instance group members were each given a card with details of a character they were to play in a game; a character such as an unemployed disabled women living on her own.

Members were then asked to discuss some of the health and social issues this woman might face during her life. Members enjoyed such activities but they did not always feel it was relevant to them and their health needs.

In summary, Chatman's information poverty undoubtedly provided a valuable conceptual framework which offered further analysis of qualitative data in this study. With regards to the first proposition of information poverty participants in this research did not perceive themselves devoid of health sources, in many cases participants indicated their doctor as a single sufficient source of health information. The accessibility of a vast information resource in the form of the internet may have also encouraged this view. When it came to the second proposition, participant observations in this research uncovered the unintentional withholding of health information by health information leaders through the delivery of generic health information to Chinese participants. For African participants there were examples of information control through leadership filtering of general as well as health information, although this was not governed by differences in ethnicity. Social norms attached to health and the disclosure of health issues influenced health information activities in both African and Chinese participants and therefore reflected behaviours associated with the third proposition of information poverty. Next, self-protecting behaviours associated with proposition four were evidenced with African participants, as secrecy and deception were used to protect against exposure. Mistrust in the ability of others to provide useful health information also weakened health information access and delivery channels for Chinese participants. Proposition five was showcased in health information activities which necessitated a need to weigh up potential consequences especially for African participants, where the risk of exposure versed the possible benefits of accessing health information. The final proposition can be linked with Chinese participants who offered examples of sourcing health information appropriate to outstanding health concerns through access points they deemed as relevant, potentially limiting other likely beneficial sources, such as NHS 24 or NHS websites.

I became increasingly aware that the internet might play a greater role in overcoming the barriers of information poverty, especially in relation to propositions 4 and 5. Research analysis will now therefore consider the advantages as well as disadvantages of using the internet for health information seeking in order to mitigate the effects of information poverty.

7.4 Overcoming Information Poverty via the Internet?

As discussions regarding proposition 1 outlined, participants in this research did not believe themselves devoid of health information, this perception was possibly fortified with frequent use of the internet by some participants. Interviewees spoke of using the internet for health information at times when they felt they had no one else to share experiences of health with or seek information from. Mrs G's statement below indicates that when she was first living in Barton she did not have anyone to share health experiences with so she turned to the internet. Likewise Rebekah felt the internet was a good source if she was in a situation where she could not speak to someone else.

> *Mrs G (African female in her thirties): Look it up and read the net and sometime when I go for anti-natal services I go back on the internet... like in Barton my experience I not know anybody the first experience really helped.*
>
> *Rebekah (African female in her forties): If I am on my own sometimes I get some information from the internet.*

In addition, by using the internet for health information seeking, participants bypass formal and informal health information leaders. Instead they independently decided which information to accept or reject, what Kivits (2009) describes as a personalisation of health information. Internet users judged the source and type of health information they would utilise, meaning they could select relevant health information avoiding the limitations health information leaders may impose. They could also use sources which they knew and trusted as well as sources of information in their own languages. In using the internet to seek out health information it allowed participants in this research to avoid the need for self-protecting behaviours. The internet provided health information seekers a portal through which health information could be sought independently. This is especially important for individuals who saw themselves at risk when undertaking health information seeking. In her excerpt below Zizi agrees that the internet is an important source for her.

> *Kirsty: You said earlier that health information is secret… is personal… do you think looking at health information on the internet is a good way to get around…problems of privacy?*
>
> *Zizi (African female in her forties): Of course I think yes…*

In using the internet to look for health information there is less need for Zizi (a participant who previously referred to health as a 'secret' in earlier discussions) to adopt self-protecting behaviours, she can break with social norms, since there is a lower risk of exposure, in using this method Zizi breaks free from information poverty. For those whom the risk of revelation is greatest, the internet provides a vital anonymous alternative (Hasler & Ruthven, 2011). Hamer's (2003) study of young gay men, gay identity and information seeking spotlighted the internet as a central source which supports the concealment of information seeking. As discussed in the previous chapter Maggie offers an example of the risks involved in health information seeking for a HIV positive African, and how the internet offers an escape from such risk.

> *Maggie (African female in her forties): …we do recommend certain websites, especially in support groups, because people want to come…. You know when someone is diagnosed with HIV it is not that they are knowledgeable around issues with HIV so one of the things we try and do is in your own time, if you don't want to carry a leaflet or carry a booklet then have questions about 'why are you carrying this?' try this website or this one, in your own time, look it up and get to know what other people are saying, other people who are living with*

> *HIV as well, what information is out there you know about living healthily or living a healthy life so we do signpost people to websites.*

The internet offers a unique tool for health information seeking as well as a real chance to escape information poverty. The full extent to which the internet allows for the by-passing of self-protecting behaviours compared with health information seeking in face-to-face encounters, specifically for BME populations could be an area of consideration by future researchers. Although on the surface it appears to offer greater anonymity; online security and privacy concerns continue to shape user engagement with the internet. As Maggie, the African community worker highlights in chapter 5, just liking an HIV charity on Facebook can bring assumptions and stigma, so the internet has its limitations too. Nevertheless, it remains an interesting vehicle for health information with a range of possibilities when it comes to over-coming information poverty.

7.5 Fisher's Information Grounds

Influenced by Chatman's fieldwork and conceptual frameworks Fisher, née Pettigrew (1999) develops an understanding of information seeking behaviour emphasising the role of context (a detailed discussion of Fisher's work is offered in Chapter 2). Fisher (Pettigrew, 1999; Fisher et al., 2004a) proposes a social context model in which physical space and social types influence formal and informal information exchanges. Information grounds are physical spaces where information is consequently exchanged as a by-product to a specific given task which individuals have gather to undertake. Fisher defines information grounds as,

> "synergistic 'environment(s) temporarily created by the behaviour of people who have come together to perform a given task, but from which emerges a social atmosphere that fosters the spontaneous and serendipitous sharing of information." (Fisher née Pettigrew, 1999: 811)

Like Chatman, Fisher et al., (2004a) provides proposition statements derived from her fieldwork which then offers a theoretical framework for her information grounds theory. Fisher et al., (2004a) propositions have been deliberated in Chapter 2 but it is useful to summarise them here to allow for comparison. Fisher et al., (2004a) suggests the following key concepts to her information grounds theory: that the information ground is temporal, that people gather for an instrumental purpose, that different social types attend, while social interaction is the core activity and that informal and formal information sharing occurs. Finally Fisher et al., (2004a) concludes that sub-contexts influenced by individual's perceptions and physical environments exist within an information ground, making it context rich. In terms of the places and people I met during my fieldwork, there are certainly links to be made with the conceptual premise of information grounds. Fisher begins by outlining information grounds as temporal, explaining:

> "Clinics were typically set up in a large room that was usually used for another purpose, such as arts and crafts in seniors' centers or as an auditorium or meeting room in churches and hospitals." (Fisher née Pettigrew, 1999: 804)

In discussing Fisher's (Pettigrew, 1999; Fisher et al., 2004a) information grounds I will assess the impact of context on the flow of general as well as health information at CCDP talks as well as the Barton women's group. Monthly talks at CCDP were held at a local community centre in the main community hall, the space was adapted for the talks and the hot lunch that was served afterwards. Once the audience left the room it was cleared and ready for its next purpose so in this respect the environment was temporal, used once a month as a space where the local Chinese community could meet and listen to talks about anything, from how to recycle to changing to digital TV service, but relevant to this research, were talks on health topics, which were always included in the talks programme. For the Barton women's group their home was a small community centre in the middle of Barton's housing estate. The centre consisted of just three small rooms for which all community activities occurred. These activities ranged from computer classes to weekly church meetings. This space was booked out for the group every Wednesday afternoon and chairs and tables assembled for health and sewing activities, again making this a temporal information ground.

Fisher's et al., (2004a) second proposition suggests people gather at information grounds for an instrumental purpose other than information sharing. In this study the information grounds were chosen specifically because they would be places where health information dissemination would be taking place. Thus, the purpose of both gatherings was to disseminate information and socialise. However, my expectation was that health information would flow from group member to group member or from information leader to the audience, in reality there were instances where information flowed back and forth in a variety of patterns and over time some group members even became informal information leaders themselves. Fisher et al., (2004a) then suggests information grounds are attended by identifiable social types who have set roles in the flow of information. The social types within these research settings included African women who were group members, health workers, community/charity workers, and members of the local Chinese community. Group and community members were in attendance at information grounds to access health information, whilst health workers (such as health promotional staff) were in attendance to offer health information. Fisher explains,

> "…although people gather for a primary, instrumental purpose… their interaction, from the moment they arrive at the information ground's temporal setting is always social in nature. As people "visit" and engage in social interaction in the information ground setting, their conversation about life in general and about specific situations leads to the formal and informal sharing on a range of topics and in a multitude of directions." (Fisher née Pettigrew, 1999: 757)

This type of behaviour was frequently witnessed at both information grounds. In the case of the Barton group conversations about life in general and about specific situations always led to exchanges between the women and the health/community workers from which it could be derived formal and informal sharing of information on a range of topics in a multitude of directions, sometimes information exchanges were focussed on cultural attitudes. One afternoon I arrived early for the group who were meeting up to do sewing activities, Mrs G and Audrey (the group leader) started to have a conversation about women in the group who had had multiple pregnancies and the health problems accompanying pregnancy. They then talked about family sizes and the role of African women in Scotland compared to Africa. Mrs G talked about how women were stuck with their husbands who always want a lot of children because that is the "African way"; to have a large family. She said African men needed to understand that they are now living in a foreign country with different attitudes to family. Mrs G says she is different because she was the sixth child in her family of nine and she does not want to struggle like her family did. She explained that she wanted her own family to be different, wanting just two children. Beth, a community worker said she thought the key to emancipation was by empowering women to be more independent to show that they can say no to their husbands. Mrs G disagreed saying it was not that easy and that re-education should be directed at African men, not just at women. The discussion then moved onto men's roles in the community and the impact of having large families, as group members arrived they too entered into the conversation. This conversation between Mrs G and community workers highlights Mrs G's concern for African women and her attitudes to the re-education of African men in order to change current social norms around multiple pregnancies and family sizes. This informal exchange of attitudes and experiences about a health/social issue; where experiences of having children and issues of patriarchy were discussed, clearly shows that although the women had come along to partake in sewing activities informal exchanges about social attitudes and health experiences occurred between all social types in attendance.

In the case of Chinese health talks it was much more difficult for me to witness informal exchanges because of the language barrier. Nevertheless, during a question and answer session after a health talk on cancer a member of the audience told the story of her sister who had died very suddenly from cancer after being diagnosed, she spoke of her sister's illness and the effect it has had on her and her family members. In this example the lady was a provider of information (offering her personal experience of cancer in her family to the audience) and sparking informal discussion within the crowd, but also simultaneously engaging in a two person exchange between herself and the presenter, a cancer nurse. In information grounds Fisher maintains,

> "…people use these causal interactions purposefully as a segue to questioning someone about his/her knowledge of a particular area in which the person may be experiencing difficulty…" (Fisher née Pettigrew, 1999: 757)

An example of this at the Barton women's group occurred one lunch time when two of the members, Tasha and Doudo asked me what I thought they should do to lose weight. Although this was a somewhat usual conversation for the women in their weekly conversations at the group it was interesting that they used the informal space and time (lunch time) to question me, and that they saw me as someone who would have knowledge on the topic of diet and weight control. These fieldwork examples of informal and formal exchanges of information and more specifically health information flowing in all directions matches Fisher et al., (2004a) proposition 5. To say people used the information obtained in information grounds in alternative ways and ultimately benefited socially, as proposition 6 contends, is certainly true. Attending the Barton women's group brought the ladies not only new information about a range of health and social issues but crucially it also became as place where supportive bonds could be formed. NHS workers also learned a lot about the women of Barton, overcoming previously held notions (as they informed me at their last attendance). As for the CCDP health talks certainly the talks were beneficial on a social level, with lots of noisy discussion over lunch (I was told by Betty). However, in terms of the physical and mental value of information grounds, I would suggest that more research would be needed before such an assertion could be made. The re-questioning of participants from both BME communities over time could possibly indicate positive lifestyle changes or changes in terms of mental health but at present there was no evidence within this research to base a claim on the possible physical or mental consequences of information grounds.

Undoubtedly the last proposition of information grounds, that there are many subtexts within an information ground is evidenced in this research. Cultural influences as well as socio-economic factors discussed in chapter 5 indeed play out in these collective spaces. Fisher's (née Pettigrew, 1999) work was conducted in a formal health setting but she maintains that information grounds might occur in informal places such as a hairdressers. Earlier analysis of interviews with African and Chinese participants as well as community workers pinpointed possible informal information grounds through which health information may be disseminated. During my interview with Kai he started to talk about the local Chinese supermarket and how it is an important source of information for the community with an information board and Chinese newspapers. The local supermarket may therefore already be an information ground where formal and informal information flows occur, a place where some of information seeking and sharing behaviours, may be evident. Kai's excerpt below also highlights the difficulties many Chinese locals have in finding the time to seek out information because of long working hours, so making health information more accessible in a convenient information grounds may generate greater engagement.

> *Kai (Chinese male in his sixties): I usually get some free Chinese newspapers from Chinese supermarket and they always have a health column and I suppose if you put leaflet in the Chinese newspapers in the Chinese supermarkets because lots of people go there shopping.*
>
> *Kirsty: Okay so this is a good place to engage with the community*
>
> *Kai: Yes it's very convenient*
>
> *Kirsty: If you had to get health information would you prefer to get it that way or through CCDP or would you prefer to see someone from NHS?*

Kai: It is more convenient to go to Chinese supermarket because I go shopping regularly

Kirsty: Okay do you work 6 days a week?

Kai: Yes 6 days a week

Kirsty: So not a lot of free time?

Kai: No

Whilst talking with a charity worker for the African community she informed me that promoting health information, especially information on safe sex, which is crucial in protecting and educating people about HIV. Interestingly she told me about some of the informal and non-health related places they put condom packs and sexual health booklets, places including African barber's shops, hairdressers and African food shops.

7.6 Everyday Information Practices

Savolainen's (2008) discussion of information practices frequently refers back to Chatman (1996) as well as Fisher et al., (2004a) spotlighting the sociological inquires made during their work. Although Savolainen's (2008) concept of information practices was not considered prior to or during the fieldwork stage of this research it nevertheless presents an opportunity to offer further insight to research findings. The model of everyday information practices suggests information seeking, use and sharing become meaningful in the context of furthering everyday projects (Savolainen's, 2008). In essence it is a model for exploring the ways in which people make sense of their information worlds, their daily information habits and routines. However research explorations in this study were driven by the topic of health and health information specifically, rather than a variety of daily information activities. Therefore, the purpose of this section is not to re-evaluate all research findings using the theory of information practices in the fashion undertaken previously to evaluate information poverty. Rather it is to take several significant findings and explore them briefly using Savolainen's sociologically rooted concept. Savolainen explains,

> "Information practice may be understood as a set of socially and culturally established ways to identify, seek, use and share the information available in various sources such as television, newspapers, and the Internet." (Savolainen, 2008: 2)

Savolainen (2008) theory of information practices unlike information poverty places less emphasis on norms and rule bound forces described in Chatman's work and explores instead the role of routines and habits; how reflexivity and routines pave the way for changes in practices albeit slow changes.

This process is self-perpetuating and stable, preserving practices through the process of information selection, thus everyday choices are shaped by what is perceived as desirable by an individual's social class or cultural group (Savolainen, 2008). An example of a health information practice in this research can be observed in the use by Chinese participants of online health information provided by Hong Kong health services. As stated earlier this practice is driven primarily because this health information, as well as, the provider is recognised as relevant for the needs of the Chinese community. Using the concept of information practices, this action can be viewed as habitualised as well as culturally acceptable by the community. Another health information practice exercised by Chinese participants would be the use of close family members to act as interpreters during health consultations. This method of seeking health information through the pathway of a close relative could be viewed as an information practice since it is again a socially acceptable and established way through which to gather health information within the community. Another health information practice can be seen in the actions associated with health ownership, health ownership as previously detailed includes a reliance on one's self to source health information, usually from informal sources such as friends and family, always within the community. This practice of self-reliance and community dependency can have both positive and negative consequences as previously outlined in chapter 4. Significantly it is a way Chinese participants make sense of the social world when engaging in health information activities. These sources of informal health information were also evident within the African community, thus using family and friends was an established way of attaining health information since it was a practice which was socially and culturally acceptable and made sense to African participants

Finally, employing Savolainen's (2008) perspective to explore findings regarding eHealth in this study is valuable as it indicates a need to encourage changes in health information practices for implementation and up-take to be successful. Accordingly a social and cultural system of acceptance regarding eHealth would need to be established within BME communities. eHealth in the form of NHS 24, NHS online, mHealth or health information kiosks would need to make sense to BME populations and be accepted as part of the process of interaction with health information. As Savolainen's (2008) points out the role of routines and habits is important here, practices can undergo change, albeit slowly. eHealth would ultimately be seen as another meaningful way to engage with health information but to achieve this relates back to previous discussions regarding trust, relevance, and culturally appropriate health information. To conclude, understanding the social structures that shape ways of interacting during health information activities has been central to this investigation hence using the concept of information practices even in this brief discussion is important since it allows for greater insight into the social actions uncovered in this research. It also affords future researchers within the discipline of information science scope for further investigations.

7.7 Chapter 7 – Chapter Summary

In summary, to answer the final research question: is there evidence of information poverty? Undoubtedly there was evidence of different aspects of information poverty in both communities. In situations where health information seekers associate risk with disclosure, they switched statuses becoming outsiders so they can utilise outsider channels of information and support. For the most part participants in this study did not follow Chatman's first proposition, they did not perceive themselves to be devoid of health information since they judged their GP to be a sufficient source. Chinese participants did acknowledge a lack of health information available to them in standard written Chinese and mentioned the difficulties they had with communication, as detailed in chapter 6. In addition, African participants complained of the lack of culturally specific health information available through NHS websites again discussed in chapter 6.

Chatman's self-protecting behaviours were evident in both communities but notably stood out with African participants, although this may be a reflection of the in-depth participant observation work conducted with the African community at the Barton women's group. Health information sourced by participants was usually driven by outstanding queries relating to current health problems or concerns. Accordingly health information seeking was based upon the supposed relevance of the source and information itself. An example of this was the absence of NHS websites usage by Chinese participants. It is important to note that other factors may also influence the dismissal of potential information sources. Brashers et al., (2002) suggests avoidance behaviours allow individuals to maintain control over their health knowledge as well as their established health beliefs. Some people therefore utilise health information to subdue ambiguity or to increase uncertainty and subsequently allow for the possibility of positive outcomes, but health information also has the ability to intensify distress and uncertainty, and so is purposefully avoided. The influence of culture and social norms associated with health has been presented in previous chapters, but here Brashiers et al., (2002) links the importance of maintaining control over established health knowledge and social norms associated with health in the form of avoidance behaviours.

Writing at a time when the impact of the internet on everyday life was yet to be fully felt, it is subsequently important to consider Chatman's (1996) information poverty in the context of today's information saturated society. Participants in this study, who used the internet to engage in health information seeking, did not distinguish themselves devoid of information sources. Moreover, the use of the internet allowed them to bypass information leaders when wishing to source specific health information. The absence of face-to-face interaction also has the potential to supersede the need for self-protecting behaviours, since the internet offered greater privacy and anonymity, although I would add a note of caution and suggest further exploration of this area, especially with BME users. Findings from this investigation along with present-day commentators (Pettigrew, 1999; Hamer, 2003; Hasler & Ruthven, 2011) continue to update the theory of information poverty in ever shifting and increasingly connected information societies.

In addition to Chatman's information poverty, the findings from this research led me to consider the work of Fisher (Pettigrew, 1999; Fisher et al., 2004a) and information grounds. The two sites in which I undertook participant observation can be viewed as information grounds. CCDP monthly talks and the Barton women's group were both held in temporal settings with the instrumental purpose of information dissemination. During my time at both sites I was witness to the exchanging of information both formally and informally. This exchange occurred in a multitude of different directions with information leaders learning about information seekers and their health concerns as well information seekers gaining relevant health information. Information was usually delivered in a passive presentational style (although at the Barton group games and activities were undertaken) but this yielded multiple flows of information between social types in attendance. These information exchanges sometimes included purposeful questioning to gain knowledge of others. These information exchanges undoubtedly had social benefits for those involved however due to the limitations of this research it was not possible to assert the possible physical or mental benefits.

Fisher (Pettigrew, 1999; Fisher et al., 2004a) makes the conclusion that information grounds can be found in places such as hairdressers and tattoo parlours, informal temporal setting where the purpose of the visitor is to undertake an instrumental act. Information is exchanged by social types expected in such temporal settings and this information is exchanged formally and informally in a multitude of different directions between social types. Places of possible information grounds highlighted in this research included local Chinese supermarkets and African barbers or hairdressers as well as African food shops. The point therefore remains, if health information is to reach underserved populations including BME communities, then there needs to be a consideration of the dissemination of health information in information grounds.

Using Savolainen's (2008) sociologically inspired theory allowed for further analysis of research findings. The concept of information practices and its foundations rooted in Bourdieu's (1990) theory of habitus suggest health information activities occur within socially and culturally determined systems, internalised by individuals. Significantly, these activities became practices, repeated actions as a means of interacting with health information in a way that made sense to participants. In the previous chapter the role of technology was evaluated and the implementation of eHealth for BME populations discussed. With regards to eHealth issues of trust, relevance, and culturally appropriate health information have the potential to influence health information practices within BME populations. Thus, Savolainen's (2008) theory of information practices brought findings analysis to a close, attention will now turn to summarising key research findings whilst also offering recommendations to future researchers, policy makers and eHealth developers.

Chapter 8 – Concluding Discussions

8.1 Chapter Introduction

This chapter will bring together all the different dimensions of this research to provide a key summary of findings chapters ultimately providing fundamental insights to the original research questions set out in chapter 1. The applicable theories of Goffman (1959, 1963) and Chatman (1996) will then be reviewed, offering distinctive conclusions in relation to this research and both theories. Limitations of the research will then be addressed followed by an outline of the study's strengths coupled with discussions on further opportunities for future researchers. From key conclusions research recommendations will then be proposed, including recommendations specifically for health information providers who seek to engage with African and Chinese populations. Finally a concluding statement will be imparted, bringing this research investigation to a close.

8.2 Key Findings Summary & Future Research

The first findings chapter was structured around answering the first research question; what social and cultural influences shape health information activities for participants? To allow findings to be put into context it was necessary to understand a little more about participants' experiences of living in Scotland. Participants describe positive life events whilst living in their communities. However, they also described experiences of social exclusion, either due to the language barrier or because of racist attitudes endured by participants. Interestingly, although some participants experienced isolation, they also encountered social support in the form of community cohesion. Ethnographic research at the Barton women's group and CCDP health talks showcased the benefits of community support. Crucially both sets of participants had clear ideas about what health was and what is was to live a healthy life. African participants described health with the inclusion of mental health and with the understanding that in living a healthy life you needed to have good physical and mental wellbeing. This may be a reflection of the traumatic life experiences many African participants had sustained, as well as their continuing stress when undertaking the asylum process. Chinese participants detailed their pro-active and preventative healthcare measures through the lifestyle choices they make. Many Chinese participants spoke of eating a healthy diet mentioning the need for, in their words, 'clean food' equally they consumed little alcohol and frequently undertook gentle exercise. This healthy lifestyle and emphasis on living a healthy life to prevent illness may be a reflection of the aging Chinese population sampled in this study. Traditional medicine was an interesting area of investigation. Before undertaking fieldwork I expected the use of Chinese medicine to be high, I was therefore surprised to discover that it was not a prominent feature in Chinese healthcare measures amongst this sample. Nevertheless, the philosophy of traditional Chinese medicine still underpinned Chinese attitudes to health.

Chinese participants were generally registered with a doctor and many were happy with their care, saying they trusted their doctor simply because of the professional status they held. Those Chinese participants that did voice concern; voiced it over the lack of time doctors had during appointment sessions and regard for their health conditions during these encounters. Many African participants expressed frustration and anxiety over the patient-doctor encounter. African participants perceived a lack of regard as well as genuine concern about what was being done with health information disclosed to health professionals. This concern was once again linked to issues of mistrust; mistrust stemming from previous experiences in their countries of origin, but also as fallout from the asylum process. Clearly coming to the UK and undertaking the asylum process continues to impact how health information seekers engage with health services and providers. Emerging from the field I discovered that those Chinese participants who could afford to, returned to their country of origin, in this case Hong Kong for medical treatment. The way in which African and Chinese participants therefore engaged with health services in Scotland may be influenced by experiences of healthcare in their countries of origin, although I would warn that further investigation is needed before more robust statements can be made about this potential impact.

Research findings from chapter 4 indicated three prominent social and cultural features of health information activities. Firstly was the notion of health ownership; prominent in discussions with Chinese participants who referred to health as their own responsibility but equality has the potential to encourage heavy reliance on insiders within the Chinese community and a lack of engagement with more formal health services. This finding may go some way to explaining the traditionally low up-take of NHS services by Chinese populations. Stigma became an issue associated with health and in particular HIV status during my time in the field with African participants, and so to analyse this trend further, Goffman's (1963) concept of the spoiled identity was explored. The perceived deviant behaviours allied with HIV and the subsequent need for individuals to distance themselves from this stigma and instead be seen to follow social norms acts as a barrier in health information activities. Consequently this narrows pathways to information and support. The final cultural association linked to health was that of privacy; privacy was a major concern for African participants. Concerns for privacy fuelled the potential to withhold personal health information, especially whilst in public settings. Equally it could be argued that the strength of this need for privacy provides a tool which protects participants from what are perceived as possibly risky situations.

The next findings chapter to explore research findings, chapter 5 was defined by the second research question; what socio-economic factors impact upon health information activities for participants? There were some interesting and surprising outcomes in the examination of socio-economic factors. Social networks were evident amongst all participants as they detailed tapping into friends, family and neighbours to source health information. However they lacked social networks out with their own ethnic communities. When asked directly about health information sources participants spoke of their GP as the primary source but also of the importance of community access points such as CCDP or the Barton women's group, other sources mentioned included Chinese newspapers and the internet. Community settings such as the Barton women's group and the health talks at CCDP present communal settings whereby language barriers can be overcome and where the potential for culturally sensitive material could be utilised. Yet, these environments also present risk for health information seekers since their public nature offers no anonymity and the possibility for unintentional health disclosure if only by association. Language, literacy and education were then areas of discussion in chapter 5. Not being able to read and write or having limited primary education made learning English a daunting task and offered real barriers to the use of healthcare services for many participants. Poor literacy and limited education may compound the development of eHealth literacy skills, although again this particular off-shoot of this research inquiry would need further investigation before definitive statements could be made. Undoubtedly, language was a major barrier for participants in this research, especially for Chinese participants. It would be far to say that the language barrier shaped every aspect of their health information activities, including patient-doctor encounters and online health information sourcing. During participant observation exercises with both African and Chinese participants it was noted that a lack of health information in first languages, as well as, the use of inappropriate and generic material provided yet more layers to the language barrier. When asked about the use of NHS services and dealings with frontline staff, African participants voiced loud and clear their frustrations, often citing miscommunication and misunderstandings which led to the denial of access to healthcare professionals, as well as, a rise in mistrust by participants.

Another interesting finding in Chapter 5 was the role of formal and informal interpreters for participants and their views on privacy and interpreters during health information activities. Chinese participants routinely used family and friends as interpreters in healthcare situations, again the idea of health ownership is apparent here with emphasise on the need to rely on insiders rather than external sources, so as not to be perceived as a nuisance. African participants voiced significant concerns in using formal interpreters in healthcare situations as they feared their personal health information might be shared with others, individuals within their own communities. This fear was driven by the fact that interpreters usually came from the same small close-knit communities here in Scotland. Subsequently, there is potential for health information seekers to withhold health information in healthcare settings when using an interpreter. This discovery would benefit further investigation, especially to assist NHS Scotland in developing ways to build trust and encourage better engagement with interpreters and services such as Language Line. Since the internet figured prominently in this research it was essential to explore the role of the digital divide on health information activities. Again there were some surprising outcomes; the debate around the digital divide now emphasises social influences on the divide, rather than purely material characteristics. Accordingly with respects to issues around eHealth literacy and NHS online this divide is still visible. Korp (2006) argues that to capitalise on the positive opportunities that health information on the internet offers, health promotion and empowering strategies need to encourage individuals to strengthen their abilities to evaluate different information sources as well as health information itself. In terms of overcoming the material divide, participants had some interesting observations; mobile phone technology with its ability to connect to the internet in more flexible and cheaper ways seemed to appeal to both African and Chinese participants. Using the internet in this way allows for the collection of information in first languages as well as health information which is relevant to users. It also provides an opportunity to overcome traditional limitations instilled by a lack of computer skills. As participants explained they could use their phones rather than needing to learn how to use a computer in order to connect to the internet.

Chapter 6 considered research findings alongside the third research question; what role does technology have in shaping health information activities for participants? Participants were generally very positive about the use of technology to obtain information as part of their daily lives, but it became apparent that they did not always consider the internet as a tool in sourcing health information. For those that did utilise the internet for health information activities, it was employed as a tool for checking information against existing knowledge, as well as, different sources online. The positive functions offered by the internet, in terms of language tools and the provision of information in different languages were emphasised by participants. Unexpectedly however, very few participants had ever used an online health forum to gain health information, and for those who employed this resource they did so in a passive manner. There may be a number of possibilities as to why this this online resource was not used by participants, lack of familiarity, limited eHealth literacy skills further research would be needed to explore this theme.

eHealth in chapter 6 spotlighted the role of NHS information provision, focussing specifically on NHS websites, NHS 24, mHealth and health information kiosks. Significantly Chinese participants did not use NHS websites citing the language barrier and a lack of relevance as their main motives. African participants meanwhile did use NHS websites and placed trust in the information provided on these sites, however there was acknowledgement in the lack of health material catering specifically for African populations living in Scotland. Participant observation exercises highlighted a gap in the promotion of NHS websites, especially potentially relevant sites such as the Health in My Language site. When it came to using the NHS 24 service, once again Chinese participants did not, citing the same motives as previously stated. African participants meanwhile did use the service but were anxious about the cost of the service as few had land telephone lines and instead relied on mobile phones for which call costs were much higher. NHS 24 has acknowledged its poor engagement with BME groups across Scotland and was at the time of writing conducting a public consultation exercise. This offered the perfect opportunity to provide feedback from these research findings to the service. For NHS 24 to increase uptake, better engagement strategies need to be implemented. Creating partnerships with community organisations including central figures in the community like Betty and Audrey as well as informal information leaders, such as Robert, Rebekah and Mrs G is imperative. Emphasising the confidentiality of using a service such as Language Line is important. Moreover, working closely with refugee and asylum seeker organisations to know when to promote the service is necessary. Tailoring preventative healthcare messages to different BME groups (since they have different cultural associations and social norms relating to health and consequently make different lifestyle choices) is important to consider.

mHealth was a surprising, and in many ways an exciting discovery, in the field. The use of mobile phones by both groups was very noticeable. Furthermore the growing use of smartphones to connect to the internet was unexpected. Its potential to offer flexible and ever cheaper means of connecting to the internet as well language translation was realised by both African and Chinese participants. Undoubtedly there is potential engagement through text messaging services, phone apps as well as the use of established online health information services. It certainly is an area for future social research which has the potential to inform healthcare providers. Health information kiosks as possible vehicles for health information delivery were welcomed by Chinese and African participants. Chinese participants were particularly interested in its abilities to provide information in other languages. Jones (2009) suggests kiosks can complement other health promotion media as well as having the distinct possibility to be used by BME for audio-visual interviewing or to provide culturally tailored health information. Using Fisher's (2004a) information ground theory, health information kiosks could be located in flexible locations such as local supermarkets or hairdressers. Health information kiosks need to be implemented in the community with the endorsement of community organisations and informal information leaders. Their public character means not everyone will engage with a health information kiosk and perhaps the information they provide would need to be non-sensitive. Nevertheless there once again is potential for future research on the possibilities of health information kiosks and their abilities to offer healthcare provision to marginalised communities.

The final findings chapter of this thesis employed the conceptual framework of Chatman (1999) to investigate the fourth research question; is Chatman's (1996) theory of information poverty evident amongst participants? Undeniably aspects of the theory were evident in research findings. Somewhat unexpectedly, participants did not follow Chatman's notion that those who are information poor perceive themselves to be devoid of any information sources. Instead, participants observed that if they needed information on health then their GP was an adequate source. Chinese participants did want more health information provided in standard Chinese while African participants desired more culturally specific health information, but they did not in this instance perceive themselves to be devoid of information sources. In relation to the second theme of information poverty, I made the observation that both African and Chinese participants were subjected to the filtration and even the unintentional denial of health information through information leaders. Consequently access to health information via a health information leader can be shaped by expected normative behaviours akin to the social status of a group leader.

One of the most interesting aspects of Chatman's (1996) theory is the idea that individuals deliberately hide information about themself or simply refrain from asking for information because of the perceived need to protect against risk. Notably, both Chinese and African participants exercised self-protecting behaviours when engaged in health information seeking behaviours. Chinese participants employed self-protecting behaviours encouraged by the social norms of health ownership and secrecy. Meanwhile African participants used performances of deception and secrecy spurred on by social norms about health disclosure and by fears of direct or courtesy stigma. The decision to employ self-protecting behaviours is often, Chatman (1996) argues driven by the perception of negative consequences if this action is not taken. This decision making was evident in African participants who were driven by the fear and the associated shame of stigma. In this situation participants described a switching of statuses, moving from being an insider to an outsider permitting the use of outsider channels of information and support. These are significant findings which could help practitioners understand why some individuals from African or Chinese populations struggle to engage with NHS services and instead adopt self-protecting behaviours. Finally returning once more to the idea of access and how new knowledge is introduced and accepted by the information poor, Chatman (1996) maintained that information would only be accepted if it was seen to be relevant. Although the method of delivery was important to African participants, it was Chinese participants in this research that displayed concerns over information relevance. Chinese participants did not use NHS 24 or NHS websites because they did not perceive them to be relevant to their outstanding health information needs, this action limits a potentially useful source of health information for the Chinese community.

Using Chatman's information poverty theory in chapter 7 provided a constructive framework for research finding comparisons. During the analysis of findings I also found it valuable to explore the context in which communal information exchanges occurred and for this I looked to a contemporary of Chatman, Fishers et al., (2004a) and her theory of information grounds. The theory of information grounds highlights the informal exchanges of information that can occur as a by-product in information grounds. It encouraged me to think about how conversations flowed between information leaders and information seekers in all directions during communal discussions. It was particularly interesting to witness informing leaders learning about the lives and health information needs of information seekers. Hence, although members usually meet for given tasks I was witness to health information being shared amongst members as a by-product of more formal activities. Possible information grounds highlighted by participants and community workers included the Chinese supermarket and the African barbershop or hairdressers. As a final reflection of fieldwork findings I decided to include a brief discussion on information practices, using Savolainen's (2008) concept. This definition of information practices, rooted in sociological understandings, not only brought analysis up-to-date within scholar debates around information seeking, but more significantly brought different perspectives to research findings. Undoubtedly there have been interesting individual behaviours of information seeking on show in this study. Nevertheless there has also been the discovery of practices related to health information activities, practices that have added to the complex picture emerging of health information activities in both communities.

Finally, it is necessary to reflect on the central theories which have underpinned the analysis of research findings and ultimately offered new perspectives. If there is one narrative in this concluding section, it is that the health information activities of participants were described and acted out as performances; as social actions. When participants sought health information they did so in social contexts with an audience be that audience health professionals or individuals who shared collective ethnic identities. In sections 4.6, 4.8 and 7.2 of this thesis, participants spoke of their fear of disclosure and of being stigmatised during these interactions and utilised self-protecting or avoidance behaviours to mitigate perceived negative consequences. Conversely, participants also talked about the supportive environments of community groups such as CCDP or the Barton women's' group, especially in order to overcome language barriers. Health information activities therefore do not occur in a void, they occur in the social world, and have social meaning (Goffman, 1959). Performers (health information seekers) are directed by social norms and cultural norms; behaviour is controlled by the perception and expectations of others. In section 4.8 of this thesis Norman and Maggie from Waverley Care emphasis this point with their discussions on the expectations from faith leaders and members of the African community in relation to attitudes to lifestyle choices and health. Taking to the front stage for a health information seeker can have its risks and as previously evidenced in sections 4.8 and 7.2 it can mean the performer needs to take action to protect themselves in a situation deemed risky. Goffman's (1959) concept of the personal front was hinted at in the face-to-face encounters described by participants. For example, African participants' expressions of frustration and miscommunication with frontline staff and health professionals could be explained by Goffman's (1959) idea, that the personal front influences social interaction between performer and audience. Although I would strongly maintain that further research, using Goffman's personal front concept would be required before an absolute statement connecting the concept and the reality of patient encounters could be provided. Goffman's notion of the backstage and front stage also played out in health information activities. The concept of the front stage was evident in the Barton women's group especially for individuals like Rebekah and Mrs G who both performed the roles of informal information leaders with Audrey taking the led as formal leader. The internet when used passively, was portrayed by some as a backstage, a place where performers could prepare, where they could gain knowledge before taking to the stage in a setting such as the doctors surgery. Essentially the only online setting where there was reference to the front stage was in connection to Facebook. The presentation of the self in front of an audience was highlighted by Maggie's statement that even to 'like' the Waverley Care Facebook page, was to associate yourself with an HIV charity and for many in the community this was seen as risky. Speaking with community workers like Maggie and then with African interviewees led to the adoption of Goffman's (1963) theory of the spoiled identity. Of the three stigmas that Goffman (1963) outlines the most prominent in this study was spoiled identity related to illness, so stigma of the body as well as spoiled identity related to immigration status, stigma of the social collective. Spoiled identity and HIV status were issues discussed with African community workers and participants. The anxiety of courtesy stigma was apparent in conversations with African interviewees, where notions of fear and shame were associated with perceived cultural norms and expectations around sexual behaviour. Once again, it was African participants who spoke about stigma in the sense of social stereotypes associated with refugee and asylum seeker statuses. Experiences of racism and fears over what would be done with personal health information by health professionals all stemmed from the notion that their identities were spoiled by their immigration status; that social interactions and in some cases social interactions with health professionals would be altered because of their spoiled identity. Thus, Goffman's (1959, 1963) theoretical tools helped me in understanding the social dynamics at play during health information activities, whether face-to-face or online. Goffman's (1959, 1963) work allowed me to peel back the surface layer of health information activities to begin to understand the social meanings that participants gave to their interactions.

Chatman's (1996) theory of information poverty was immensely productive in considering the behaviour of health information seekers, especially in relation to self-protecting behaviours. Without the concept of relevance, self-protection and risk many of the health information seeking behaviours witnessed may have on the surface seem impractical or irrational. Yet, seen through Chatman's (1996) lens you begin to understand why some health information pathways simply will not be useful or practical, especially for those who confront the risk of stigma. Accordingly, for Waverley Care to facilitate community groups in the provision of health information, is at one level very productive, it encourages the establishment of community cohesion and is a setting where some health information behaviours can occur but for health information exchange seen as risky, a public setting is just too dangerous to be utilised by health information seekers. Online facilitation or one-to-one health information provision may be alternative pathways. Undoubtedly, the relevance of health information and the relevance in its delivery defined its perception within the communities and ultimately its uptake. If the delivery system is not perceived as relevant then it is not utilised; if the provider of that health information is not seen to provide for the needs of the community then another provider is used instead (as was the case in online health information and telecare for the Chinese community). Instead of using NHS online or NHS 24 information services, Chinese participants used the services of the Hong Kong health services because this information as well as the provider was recognised as suitable for the needs of the Chinese community. The unintentional withholding of health information by those who have an expert status was particularly interesting and links again to relevance. If Chinese and African populations believe there is a barrier between themselves and health information access then there is greater potential for alternative informal sources to be used, with greater reliance on insiders rather than outsiders. Information poverty as a concept reiterates that health information is a prize, that not all in society have equal access to, use of, or have the ability to share, thus compounding health inequalities and continuing the cycle of information poverty.

The impact of the internet especially through the use of mobile phone technology and its saturation into society is I believe, beginning to reshape aspects of Chatman's (1996) information poverty. Health information poverty online has the ability to offer ways in which to bypass the need for self-protecting behaviours. Online health information services offering passive as well as interactive engagement allow the potential for health information behaviours to occur out-with perceived risks. For African and Chinese populations there is the possibility to overcome language barriers, to attain culturally appropriate health information. However the internet as a resource can still yield information poverty. Online health information especially through traditional health information providers such as the NHS currently echoes issues of relevance evidenced in face-to-face encounters. While a lack of eHealth skills conceivably shackle users to a new digital divide. The belief behind the provision of health information online such as the Health in My Language website is simply, get the information out there and it will provide equality for all. I would argue that information poverty in the guise of health information poverty does not simply disappear online;

online provision can offers some advantages over face-to-face encounters for those who need to protect themselves in a social setting, but the internet also replicates many social and socio-economic barriers established offline. Thus, the theory of information poverty remains an instructive and flexible conceptual framework for social researchers exploring a world in which information can equate to power.

8.3 Research Limitations

There are some important limitations to be considered when putting this research into perspective. Firstly considering the sample of participants involved, it must be noted that most participants took part in community activities or had membership of a community organisation such as CCDP, as this was the means of accessing participants. Therefore findings represent a majority of individuals who operate in their respective communities even if this meant simply being signed up to a community organisation such as CCDP. Accordingly, this research does not effectively represent individuals who might therefore be more isolated and who subsequently might be more vulnerable to information poverty. Another limitation relates to the point of contact for conducting participant observations and interviews, where I was attending community groups where individuals with shared ethnic identities were meeting. During these encounters I was witness to only a brief glimpse of their lives, within the context of a community group setting. As a result, this will have led to the potential to overstress aspects of intra-ethnic social interactions without the framework of other dimensions of participants' lives, such as their home and work lives.

The interview sample in this study represented more women (26) than men (10). Moreover, participant observation exercises were conducted with a women specific group, and so obviously showcased the voices of women more than men. This narrows our knowledge of the health information activities of men from African and Chinese communities in this study. Findings from this research have the potential to offer insight into the health information activities of other BME populations living in the west of Scotland, however the diversity of BME populations makes this possibility precarious and particularly in relation to findings on social and cultural influences, these will be specific to African and Chinese communities and therefore the possibility of transferability along these lines is limited.

The limitation with greatest impact on this research however applies in the differences in research methodology between the two BME groups. Not being able to conduct questionnaires with a large African sample was disappointing but I believe the reasons for this limitation, as outlined in the methodology chapter, are interesting in themselves. Secondly, the inability to conduct in-depth participant observations certainly limits the richness of understanding within the health information activities of Chinese participants. Nonetheless, my participant observations at the CCDP health talks did yield some interesting findings and did add another dimension to understandings. As with any social research it is important to remember this is a snapshot in time and that outcomes reflect individuals living in a Scottish society which is undergoing continual social and political change and in which its public services are under considerable strain due to austerity measures. Thus the context in which outcomes were collected and the limitations of its scope are recognised.

8.4 Research Recommendations

Arguably the biggest strength of this work is its interdisciplinary style and its' potential for impact. The interdisciplinary character of this research brought prominent sociological perspectives together with information seeking behaviour and practice theories. Accordingly, this research offers new sociological understandings of the health information activities of BME participants; opening up the potential for further lines of enquiry.

I would argue from this study that activities involving seeking, using and sharing health information need to firstly be recognised as part of the daily performance of self within social interactions. If this is appreciated then health information activities will be understood as occurring not in a vacuum but within social and cultural contexts, continually shaped by socio-economic factors, social norms and cultural expectations. Elements from all three areas of research inquiry: social, cultural and socio-economic affect health information activities, they shape how health information is attained, used and shared amongst African and Chinese populations.

NHS health information providers, especially doctors and health promotional staff (both were key access points for health information in this research) need to recognise issues of trust and confidentiality when engaging with African populations. Explaining what will happen to personal health information during doctor-patient encounters was particularly important for those who had gone through the asylum process. Another recommendation for health professionals is to understand that stigma within the African community plays a definitive role in health information activities, especially around certain illnesses such as HIV. When devising health promotional engagement, health professionals need to be mindful that certain information delivery methods will not always be effective in public settings, evidenced in this study with examples from the Barton women's group. To overcome this issue organisations such as Waverley Care could look at expanding their online delivery methods or explore engagement through mHealth initiatives. Interestingly this was an area of consideration highlighted by Waverley Care workers during the early stages of this study. This alternative route to health information allows those who fear risk and stigmatisation (both direct and courtesy stigma) the opportunity to escape information poverty and the subsequent need to utilise self-protecting behaviours. For healthcare providers working with Chinese populations understanding the influence of health ownership and how it impacts upon the up-take of health services is important. To encourage the community to use what is perceived as outsider services a promotional campaign similar to the diabetes campaign highlighting the South-Asian community by NHS Scotland, could be adopted to try and accommodate changes in health information practices. In this scenario members of the Chinese community would be associated with NHS services, especially NHS 24. These points were fed back to NHS 24 during a public consultation process in early 2013.

When disseminating health information in public settings health information providers such as NHS health promotional staff need to be aware that although such surroundings offer a means of escaping the barriers of language as well as the ability to provide more culturally relevant health information, they conversely can also be seen as risky spaces, places where self-protecting behaviours are used to shield against unwanted attention or suspicion. Hence, community settings like that of the Barton women's group offer spaces of potential benefit as well as risk. These points of interest were discussed with members of the Scottish Association for Mental Health during a meeting regarding how they can engage with BME communities for their 'know where to go' campaign. Language played a significant role in the health information activities of both African and Chinese participants but was unquestionably more prominent in discussions with Chinese participants. A lack of written health information in standard Chinese was initially highlighted in questionnaire returns and was then emphasised in interviews, especially with Betty the Chinese community worker. Interestingly, this has been an area of increased focus by NHS Scotland. The development of the Health in My Language website certainly shows a commitment to offer information about health and health services in other languages for those living in Scotland. However, it is vital that the next step is taken to get the word out there, for individuals from BME backgrounds, for community workers working with BME communities and for health care professionals in order that this resource is used to its full potential.

Interpreters within the NHS are qualified and the services they provide evaluated (as outlined in the NHS Health Scotland (2008) 'Now We're Talking' staff guidelines). However the perception of African participants was that employing the skills of an interpreter in healthcare encounters made them vulnerable. Therefore African users of interpreters in healthcare encounters require reassurance about the professionalism of the interpreting services they utilise. Literacy and education were also important in utilising health information, consequently for the African community there needs to be more consideration on the provision of culturally appropriate health information, using perhaps more visual methods for engagement. Frontline staff were pinpointed by African participants as obstacles in the process of accessing traditional healthcare services and consequently health information. The NHS 24 Equality Outcomes Report highlights a need for cultural training for its call handlers, as they are the first point of call for users of the service. Similar training could be rolled out for frontline NHS staff that work in areas where BME communities have settled. A similar training programme has been rolled out by Waverley Care offering cultural training to GP's whose patients include African populations.

The NHS 24 Equality Outcomes (2013) will undoubtedly be welcomed by BME organisations and campaigners alike, and certainly there is a huge opportunity to learn lessons about eHealth and BME engagement from this exercise. Research outcomes presented in this thesis have been forwarded to the NHS 24 public consultation exercise for consideration by the service. NHS Scotland has the opportunity to build stronger more medically productive relationships with its patients through eHealth services. I would argue that eHealth also affords an opportunity to lessen some of the health information gaps felt by BME populations. eHealth commentators believe eHealth has the ability to tackle underserved populations because it offers language tools, has adaptability and the capacity to be customised (Ahern, 2006; Gibbons, 2005; Cashen et al., 2004). Research findings in this study would argue eHealth in the guise of NHS 24, NHS online, mHealth and health information kiosks all have potential to offer greater access, relevance, privacy, language/literacy tools, as well as, convenience to health information seekers who experience barriers in accessing health information via traditional channels. Certainly, eHealth affords an opportunity to address wider health inequalities through preventative care measures and health promotion directed at BME populations. It can deliver health information through established means of communication such as mobile phones and the internet as well as introducing new forms such as health information kiosks. Relevant to this research, NHS 24, NHS websites and mobile phone services all offer health information seekers greater privacy and mechanisms which bypass the need for self-protecting behaviours when compared with traditional channels. Of all the eHealth formats considered in this review process, I would argue mHealth has the greatest potential. In terms of an established, cheap, popular, accessible health information tool for BME health information seekers, the mobile phone offers many possibilities. Health information provision via the mobile phone allows users health information through internet access, text-messaging as well as smart phone apps. Crucially, supporting changes in the health information practices of BME populations needs to occur if greater use of eHealth as a tool is to be achieved. Findings from this research argue that vital to accommodating such changes is the need to consider the following themes: eHealth literacy, building trust and confidence, showing relevance, recruiting community eHealth champions through formal and informal health information leaders whilst finally delivering culturally appropriate health material. All of the above points have been fed back to the eHealth Person Centred Strategy team at the Scottish Government. At the time of writing, the team were deciding on a timeframe for engagement with BME communities, undoubtedly this is a valuable development. It must also be acknowledged that development of eHealth provision in Scotland is occurring at a time of austerity and consequently the role of charities and community organisations as well as BME communities themselves, is vital to the successful implementation of eHealth. Finally, it is important to stress that eHealth will not always be the most appropriate means for health information delivery (Eysenbach, 2000). King et al., (2010) stresses the need for consultation with members of the public about future eHealth development. eHealth undoubtedly has many potential benefits, yet, on some level the philosophy of eHealth assumes everyone wishes to be a self-manager of their own health needs; a philosophy which derives from the notion of empowering patients to be the 'expert patient' or the 'involved patient' (Donnelly et al., 2008; Shaw & Baker, 2004). For some individuals, however, the idea of the individual being seen as a self-manager of health directly attacks the status of health professionals. Hence, face-to-face services should not suffer as a result of eHealth development, a point strongly supported by Kerry at the Scottish Government who was quick to stress that the core function of the NHS to provide friendly personalised face-to-face services would not replace or be diminished by eHealth. The following key policy recommendations are therefore proposed.

- Health information providers need to recognise the significance of trust and confidentiality when engaging with African populations.
- Stigma associated with certain illnesses such as HIV, shapes health information activities within African communities.
- When devising health promotion for BME groups health professionals need to consider methods of information delivery. Public settings offer escapism from language barriers as well as the ability to offer more culturally relevant material nevertheless they can present

environments which are perceived as too risky for health information activities.

- Organisations which offer health information and support like that of Waverley Care could consider using more online health information tools or mHealth to engage with health information seekers, especially with regards to stigmatised illnesses.
- The development of online tools such as 'Health in My Language' are welcomed by both communities however very few individuals or organisations in this study had heard of the website and therefore there needs to be greater emphasis on engagement with BME communities so this valuable tool is not overlooked.
- The African community in Scotland because of its small size and diversity needs reassurance regarding the NHS interpreting services they utilise. They require reassurance that personal health information will not be fed-back into their own communities.
- Literacy and education also shaped health information activities and consequently engagement with the African community would benefit from more culturally relevant material as well as other means of delivery such as visual aids.
- Cultural training for frontline staff who work in areas where BME communities have settled would be valuable, as it could offer the potential to create positive perceptions of access to the GP and NHS services for health information seekers.
- eHealth offers a great opportunity for better engagement and health information provision, although relevance, trust, confidence, eHealth literacy, community champions and formal/informal community leaders are all central aspects to be considered when contemplating eHealth engagement with BME communities.
- eHealth should not replace or diminish face-to-face services on offer by the NHS.

8.5 Concluding Statement

This research set out to offer a snapshot of the health information activities of African and Chinese participants living in the west of Scotland. Undeniably the information worlds in which we all live are complex, multi-layered and ever-changing. Yet, at its heart, this research strives to explore some of the multifaceted aspects of ethnicity which impact upon health information activities. The four core research questions of this study were driven by a desire to examine the often hidden barriers to health information activities. Trust unsurprisingly was central to health information activities, trusting health information, trusting the method of delivery, as well as the individuals with which health information is exchanged even the environment in which this exchange occurs all had a bearing on health information activities in this study. Cultural attitudes to health and concerns around how health information should be disclosed also shaped health information activities for participants. Significantly, health was often referred to as something private, something secret which at times necessitated self-protecting behaviours to safeguard against risk. Finally language, literacy, education and eHealth literary skills all affected potential access to health information sources for participants, while frontline staff and interpreters were perceived as barriers to more formal channels of health information. Unquestionably the prospect of technological involvement in health information activities was welcomed, especially with regards to the potential of mhealth. To conclude, health information activities are part of Goffman's (1959) presentation of self in everyday life; performances participants in this study used to make sense of and navigate their way through their social world. Ultimately, health information activities do not exist in a vacuum; they occur within social contexts and are bound by unwritten rules.

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Appendix A

University of Strathclyde
Humanities & Social Sciences

Confidentiality Agreement Transcription/Translation Services

Name of Translator: ____

Name of Organisation (if applicable): ____________________________________

Organisation Address: ____

Contact Telephone Number: ____

Date and time of interview and translator services: __________________________

____

The agreement confirms the following:

1. The translator will not disclose any identifiable information pertaining to the interviewee to any other person except the interviewer. In this case, the interviewer is Kirsty Henderson of the University of Strathclyde.

2. The translator may have access to the interviewee's personal experiences of health which may include confidential health information. Under no circumstances should this confidential health information be disclosed to anyone out-with the interview.

3. All participants in this health information research study are given a Health Services List, which includes a number of local and national health organisations and charities who can offer advice and assistance on health matters.

4. Data gained during the interview will be kept in secure facilities. All information will be keep secure, documents and files will be password protected and any paperwork will be filed away in lockable cabinets.

5. Interviewee's will have the opportunity to utilise pseudo –anonymity where they will choose a name which they will be referred to in any published work.

I ___________________________ hereby agree to maintain full confidentiality in regards to interview dialogue between the interviewee, the interviewer and myself.

Signature: ____
Date: ___________________________________

Appendix B

QUESTIONNAIRE

Searching & Sharing Health Information

We all need vital information about our health, wellbeing and local health services, but where do you go for it and how do you share health information with others?

My name is Kirsty Henderson and I am a social research student at the **University of Strathclyde**. I am interested in finding out how people from Black and Minority Ethnic groups search and share health information in Glasgow.

The Chinese Community Development Partnership have very kindly agreed to facilitate this research by sending this questionnaire out to you. I would be very grateful if you could complete it (It should only take *5 minutes* to fill in) and return it using **the self-addressed stamped envelope** or by handing it into the **Chinese Community Development Partnership, Napiershall Street Centre, 39 Napiershall Street, Glasgow G20 6EZ by the 2nd April 2012.**

No identifying or personal details will be taken in this questionnaire!

WHY TAKE PART?

This research gives ***YOU*** *an opportunity to voice your opinions and experiences!*

Outcomes will potentially help create better information services

Help highlight any problems you have when sourcing health information

Help **service providers & community organisations** understand some of the hidden barriers you face

This research will potentially highlight **gaps in ehealth provision** for BME groups across Scotland

There has been limited health research on BME groups & health information in Scotland.

Participant Information Sheet

School of Applied Social Sciences:
Sociology

Title of the study: Unwritten Rules: a sociological exploration of health information seeking via the internet within black and minority ethnic populations.

Introduction

My name is Kirsty Henderson and I am a PhD student from the University of Strathclyde.
If you wish to get in contact with me then please write to me at: Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. Alternatively you can call me on: 0141 548 4301.
Or email me at: kirsty.e.henderson@strath.ac.uk

What is the purpose of this investigation?

The purpose of this study is to explore the views, thoughts and experiences of black and minority ethnic individuals in regards to how they search for health information, and especially how the internet might be used.

Do you have to take part?

Taking part in this research is totally voluntary. If you do not want to take part then you do not have to. If you attend classes or groups at the Chinese Community Development Partnership then please be reassured that should you choose not to take part this will not affect the services that you receive at the Chinese Community Development Partnership.

What will you do if you take part?

You will read and complete the attached questionnaire. If you have any queries about the questionnaire then please do not hesitate to contact me using the contact details above. Locations for this research study will include the Chinese Community Development Partnership, Napiershall Street Centre, 39 Napiershall Street, Glasgow G20 6EZ, and the Garnethill Multicultural Centre, 21 Rose Street, Garnethill, Glasgow. G3 6RE. The anticipated duration of this investigation is 9 months.

Why have you been invited to take part?

I would like to know about the experiences and opinions of people from black and minority ethnic groups. I want to know how you search for health information, especially what you think about using the internet to search for health information. To take part in this study I ask that you are over 18 years of age and that you are from a Black or Minority Ethnic group.

What happens to the information in the project?
I will collect in all the questionnaires, take the information and code it and then look for common themes and patterns. Your answers remain completely private, and confidential, only me and my university supervisors will see the information I gather. When my work is made available to the public, no identifiable information about anybody in the questionnaire will be offered, all information will therefore remain anonymous.

All information will be keep secure, documents and files will be password protected and any paperwork will be filed away in lockable cabinets.

When completed, all participants will be able to get a copy of my research findings at the Chinese Community Development Partnership or the Garnethill Multicultural Centre or I am happy to send you a copy of my research findings directly, just email me at kirsty.e.henderson@strath.ac.uk or call me on 0141 548 4301.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?
If you are happy with the above answers and you do not have any other questions and you would still like to take part then **please turn over this page and start the questionnaire**. If you do not want to be involved in the project, thank you very much for your time and attention.

If you want me to send you a copy of my research findings directly then please just contact me, email me at kirsty.e.henderson@strath.ac.uk or call me on 0141 548 4301. The data from this research study will be published in my PhD.

This investigation was granted ethical approval by the ethics committee of the School of Applied Social Sciences at the University of Strathclyde.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Laura Steckley
Convener, Ethics Committee for the School of Applied Social Sciences
University of Strathclyde
76 Southbrae Drive
Glasgow
G13 1PP
Telephone: 0141 950 3122
Email: Laura.L.Steckley@strath.ac.uk

Researcher Contact Details: Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. Tel: 0141 548 4301. Email: kirsty.e.henderson@strath.ac.uk

Supervisor's Details: Dr Colin Clark, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. Tel: 0141 548 5789 Email: c.r.clark@strath.ac.uk

Searching & Sharing Health Information

Self-Completion Questionnaire

By completing this questionnaire you are consenting to your responses being used in my research study.

All information in this questionnaire is anonymous. Please see the attached information sheet for further details.

Please choose answers that represent your views by placing a tick ✓

1. Do you use any of the following NHS Services? (PLEASE TICK ALL THAT APPLY)

○ Doctor

○ Dentist

○ Hospital services

○ Other NHS services, please specify

____

○ Other, please specify

____

○ None

2. Over the last year, how often have you used NHS services? (PLEASE TICK ONE)

○ At least once a week

○ At least once a month

○ At least once every 6 months

○ At least once a year

○ Never

3. Do you use any alternative/traditional health and well-being practices or medicines? (PLEASE TICK ONE)

○ Yes

○ No

3. a) If Yes, do you use any of the following alternative/traditional health and well-being practices or medicines? (PLEASE TICK ALL THAT APPLY)

○ Herbal Medicine

○ Healing Practices

○ Acupuncture

○ Aromatherapy

○ Homeopathy

○ Other, please specify ____________________________________

4. Where do you get information about your health and well-being? (PLEASE TICK ALL THAT APPLY)

○ Local Doctor/Nurse

○ Other NHS services

○ Family

○ Friends & Neighbours

○ TV/Radio

○ Internet

○ Local Library/Local Community Centre

○ Other, please specify ____

5. Where do you <u>prefer</u> to get information about health and well-being?
(PLEASE TICK ALL THAT APPLY)

○ Local Doctor/Nurse

○ Other NHS Services

○ Family

○ Friends & Neighbours

○ TV/Radio

○ Internet

○ Local Library/Local Community Centre

○ Other, please specify ____

6. Are you satisfied with the amount of health information available to you? (PLEASE TICK ONE)

○ Yes

○ No

7. Is enough health information provided in your first spoken language?
(PLEASE TICK ONE)

○ Yes

○ No

8. Have you heard of or ever used any of the following NHS health information resources: (PLEASE TICK ALL THAT APPLY)

○ NHS 24 telephone service

○ NHS 24 digital TV channel

○ Greater Glasgow & Clyde NHS website

○ NHS Inform website

○ SHOW (Scotland's Health on the Web) website

9. Do you use or have you ever used a computer? (PLEASE TICK ONE)

○ Yes

○ No

9. a) If No, why not?

____

____

10. Typically, how often do you use the internet? (PLEASE TICK ALL THAT APPLY)

○ Everyday

○ Once or twice a week

○ Once or twice a month

○ Once or twice a year

○ Never

11. Do you use the internet at any of the following places?
(PLEASE TICK ALL THAT APPLY)

- ○ Home
- ○ Work
- ○ Local Library/Local Community Centre
- ○ Local School
- ○ College/University
- ○ Family member’s house
- ○ Friend or neighbour’s House
- ○ Other, please specify ____
- ○ None

12. What do you like to <u>use</u> or <u>look at</u> on the internet? (PLEASE TICK ALL THAT APPLY)

- ○ Email
- ○ Online communication (such as Skype)
- ○ Social networking sites (such as facebook and twitter)
- ○ News
- ○ Entertainment
- ○ Work/Education
- ○ Health/Lifestyle
- ○ Online Shopping
- ○ Other, please specify ____
- ○ None

13. Do you ever look at information about health and well-being on the internet? (PLEASE TICK ONE)

○ Yes

○ No

13. a) If yes, which webpages do you look at about health and well-being on the internet? (PLEASE TICK ALL THAT APPLY)

○ NHS websites (such as NHS 24/Greater Glasgow & Clyde NHS)

○ Health Charities (such as British Health Foundation/Cancer Research)

○ News websites (such as BBC or Sky News)

○ Advice pages (such as Netdoctor or WebMD)

○ Health forums (such as women or men's health forums)

○ Other, please specify ______________________________________

○ None

14. Are you: (PLEASE TICK ONE)

○ Male

○ Female

15. What age are you? (PLEASE TICK ONE)

○ 18-25

○ 26-30

○ 31-40

○ 41-50

○ 51-60

○ 61-70

○ 71-80

○ 80+

16. What is your ethnic group? (PLEASE TICK ONE)

○ Chinese	○ Caribbean
○ Chinese Scottish	○ Caribbean Scottish
○ Chinese British	○ Caribbean British
○ African	○ Black
○ African Scottish	○ Black Scottish
○ African British	○ Black British

○ Other, please specify ______________________________________

17. Are you a: (PLEASE TICK ONE)

○ British Citizen or EU citizen

○ A Refugee

○ An Asylum Seeker

○ Other, Please specify ______________________________________

<u>THANK YOU FOR PARTICIPATING IN THIS RESEARCH!</u>

If you require more information about this study or you have any questions please write to me at: Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. Alternatively you can call me on: 0141 548 4301. Or email me at: kirsty.e.henderson@strath.ac.uk

Appendix C

問卷

探索與分享
健康資訊

我們都需要知道保持身體健康及所屬地區的醫療服務的重要資料,但是,你是否知道在那裡尋找有關資料及你如何與其他人共享健康知識?

我是Kirsty Henderon,就讀於莎芙溪大學社會研究系。我很有興趣去探討格拉斯哥少數族裔的人士,如何探索與分享健康資訊。

華人社區發展計劃同意協助此研究,使問卷更有效地送到你手上。我非常感激,如果你能完成它(只需用五分鐘便可填妥它),**並於2012年4月2日前,用已貼上郵票的回郵信封寄回**或親自交回**華人社區發展計劃, Napiershall Street Centre, 39 Napiershall Street, Glasgow G20 6EZ。**

問卷內沒有要求與個人有關的資料!

為何要參與?

此研究給你發表意
見及經驗的機會!

研究結果可以有
助獲得更好的資
訊服務

格蘭,有關少數
族裔及健康資訊的

有助**提供服務者及**
社區團體明白
你面對的隱憂

此研究可以突出蘇格蘭少數
族裔**網上健康資訊服務不足**
之處

參與者資料!

應用社會科學學院:

社會學

研究名稱:不成文的規則:

少數族裔透過互聯網尋找健康資訊的社會研究探索。

University of Strathclyde
Humanities & Social Sciences

簡介

我的名字是Kirsty Henderson，就讀於莎芙溪大學博士研究。如果你想與我聯絡,請寫信給我:Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow G1 1QE。或者,你可以打電話給我:0141-548 4301。或給我發電子郵件:
kirsty.e.henderson@strath.ac.uk

這項調查的目的是甚麼?

本研究的目的是探索少數族裔如何尋找健康資訊,尤其是如何利用互聯網,從而探討他們的意見、想法和經驗。

你是否需要怎樣參與?

參與這項研究是完全自願的。如果你不想參與,那麼你便無須做任何行動。如果你日後出席華人社區發展計劃的小組討論,你應該選擇不參與,請放心,這是不會影響華人社區發展計劃向你提供的服務。

如果你參與,你需要做甚麼?

你需要閱覽和填寫內附的問卷。如果你對問卷有任何問題,請儘管用上述提供的方法與我聯絡。這項研究地點包括華人社區發展計劃 (The Chinese Community Development Partnership, Napiershall Street Centre, 39 Napiershall Street, Glasgow G20 6EZ,及山仔多元文化中心(The Garnethill Multicultural Centre, 21 Rose Street, Garnethill, Glasgow G3 6RE)。預計整個調查時間需要9個月完成。

你為何被邀請參與此研究?

我想了解少數族裔的經驗和意見。我想了解你怎樣尋找健康資訊,特別是你對於利用互聯網搜索健康信息有甚麼想法。如果你是18歲以上的少數族裔人士,我會邀請你參與此項研究。

如何處理此項目的資料?

我會收集所有問卷,提取所有資料和輸入密碼,然後將相同主題和模式配對。你的答案是絕對隱秘的和保密的,只有我和我的大學系主任才可以閱覽我所搜集到的資料。當我的調查可以對外公報時,調查問卷內是不會提及任何個人資料,所有資料將會不記名的。

所有資料將會被妥善保管,文件和檔案將用密碼保存,任何書面文件將鎖在文件櫃。

完成後,所有參與者均可以在華人社區發展計劃或山仔多元文化中心索取我研究所得的副本,又或以電郵方式或直接給打電話給我,我便寄一份報告給你。我的電郵地址:
kirsty.e.henderson@strath.ac.uk或我的聯絡電話:0141 548 4301。

莎芙溪大學已向資訊專員公署登記,確實執行1998年個人私隱條例。對所有參與者的個人資料,將按照1998年個人私隱條例的規定處理。

感謝你細閱此單張,如對上述所提供的資料有任何疑問,請與我聯絡。

接下來是甚麼?

如果你滿意上述的資料和沒有任何疑問,你仍感興趣參與,那麼,**請翻開下頁,調查問卷即開始**。若然你不想參與此項研究,非常感謝你的寶貴時間和關注。

完成後,所有參與者均可以在華人社區發展計劃或山仔多元文化中心索取我研究所得的副本,又或以電郵方式或直接給我打個電話,我便寄一份報告給你。我的電郵地址:
kirsty.e.henderson@strath.ac.uk或我的聯絡電話:0141 548 4301。

此調查被莎芙溪大學應用社會科學學院倫理委員會認可,合乎道德倫理。如果你在此調查期間或之後有任何疑問或關注,或可聯絡獨立召集人,她可以直接地協助你解決相關疑問或尋求其它資料,請聯絡:

Laura Steckley
Convener, Ethics Committee for the School of Applied Social Sciences
University of Strathclyde
76 Southbrae Drive
Glasgow
G13 1PP
Telephone: 0141 950 3122
Email: Laura.L.Steckley@strath.ac.uk

研究員聯絡詳情： Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow G1 1QE。電話:0141 548 4301。電郵信箱:kirsty.e.henderson@strath.ac.uk。

監察員詳情:Dr Colin Clark, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow G1 1QE。電話:0141 548 5789。電郵信箱:c.r.clark@strath.ac.uk。

探索與分享健康資訊

自我填報調查問卷

你同意本人使用你在問卷內所填寫的資料,作為我的研究。

此問卷內的所有資料都會不記名的。請閱覽附加文件作參考。

請在所選答案旁加上 ✓ ,以代表你的意見。

1. **你是否使用以下的國民保健局服務?** (請選擇任何與你有關的答案)

○ 醫生

○ 牙醫

○ 醫院服務

○ 其它國民保健局服務,請詳述 ______________________________

○ 其它,請詳述 ____

○ 沒有

2. **在去年，**你曾經使用國民保健局服務多少次? (請□所屬答案)

○ **一星期最少一次**

○ **一個月最少一次**

○ **六個月**內最少一次

○ **一年最少一次**

○ **沒有**

3. 你是否有用其他/傳統的保健治療方法或藥物? (請✓所屬答案)

○ 有

○ 無

3. b) 如果有的話, 你是否有用以下所述的其他/傳統的保健治療方法或藥物?
(請選擇任何與你有關的答案)

○ 中藥

○ 復康治療

○ 針灸

○ 香薰療法

○ 順勢療法

○ 其它,請詳述 ____

4.你從何獲取有關保持身體健康的資料? (請選擇任何與你有關的答案)

○ 所屬區域的醫生/護士

○ 其它國民保健局服務

○ 家人

○ 朋友及鄰居

○ 電視/電台

○ 互聯網

○ 所屬區域的圖書館/社區中心

○ 其它,請詳述 ____

5.你想在那處獲取有關保持身體健康的資料? (請選擇任何與你有關的答案)

○ 所屬區域的醫生/護士

○ 其它國民保健服務

○ 家人

○ 朋友及鄰居

○ 電視/電台

○ 互聯網

○ 所屬區域的圖書館/社區中心

○ 其它,請詳述 ____

6.你是否滿意目前提供的健康資訊服務? (請✓所屬答案)

○ 滿意

○ 不滿意

7.提供你母語的健康資訊是否足夠? (請✓所屬答案)

○ 是

○ 否

8.你曾否聽聞或曾經使用以下的國民保健服務的健康資料:(請選擇任何與你有關的
答案)

○ 國民保健局24小時電話服務

○ 國民保健局24小時數碼電視台

○ 大格拉斯哥及克萊德國民保健局網頁

○ 國民保健局資訊網站

○ 蘇格蘭健康互聯網站 (SHOW)

9.你是否使用或你是否曾經使用電腦? (請✓所屬答案)

○ 有

○ 沒有

9. a) 如果沒有使用,何解?

___

___

10.通常,你多久會瀏覽一次互聯網? (請選擇任何與你有關的答案)

○ 每天

○ 一星期瀏覽一或兩次

○ 一個月瀏覽一或兩次

○ 一年才瀏覽一或兩次

○ 從未嘗試上網

11. 你在下列所述的那些地點瀏覽互聯網? (請選擇任何與你有關的答案)

○ 家裡

○ 工作地點

○ 所屬區域的圖書館/社區中心

○ 所屬學校

○ 書院/大學

○ 家庭成員的家裡

○ 朋友或鄰居的家裡

○ 其它,請詳述 ____

○ 沒有

12. 你是否喜歡使用互聯網尋找資訊或其它用途?
(請選擇任何與你有關的答案)

○ 電郵

○ 網上通訊 (例如 Skype)

○ 社交網站 (例如 facebook and twitter)

○ 新聞

○ 娛樂
○ 工作/教育

○ 健康/生活方式

○ 網上購物

○ 其它,請詳述 ____

○ 沒有

13.你是否曾經利用互聯網搜索有關保持身體的資訊? (請✓所屬答案)

○ 有

○ 沒有

13. a)如果曾經試過,你在那個網頁搜索有關保持身體健康的資訊?
(請選擇任何與你
有關的答案)

○ 國民保健局網站(例如國民保健局24小時服務/大格拉斯哥及克萊德國民保健局)

○ 醫療慈善組織(例如英國健康基金會/癌病研究中心)

○ 新聞網站 (例如 BBC or Sky News)

○ 資訊網站 (例如 Netdoctor or WebMD)

○ 健康論壇 (例如婦女或男性健康論壇)

○ 其它,請詳述 ____

○ 沒有

14. 你的性別:(請✓所屬答案)

○ 男性

○ 女性

15. 你的年齡? (請✓所屬答案)

○ 18-25
○ 26-30
○ 31-40
○ 41-50
○ 51-60
○ 61-70
○ 71-80
○ 80+

16. 你屬於所個族裔? (請✓所屬答案)

○ 華裔

○ 蘇格蘭籍華裔

○ 英籍華裔

○ 加勒比族

○ 蘇格蘭籍加勒比族

○ 英籍加勒比族

○ 非裔

○ 蘇格蘭籍非裔

○ 英籍非裔

○ 黑裔

○ 蘇格蘭籍黑裔

○ 英籍黑裔

○ 其他,請詳述 ____

17. 你的身份是: (請✓所屬答案)

○ 英國公民或歐盟公民

○ 難民

○ 尋求政治庇護者

○ 其他,請詳述 ___________________________________

感謝你參與這個研究調查!

如果你對此研究想有更多資料或有任何問題,請與我聯絡。我的名字是Kirsty Henderson，就讀於莎芙溪大學博士研究。如果你想與我聯絡,請寫信給我:Kirsty Henderson, The University of Strathclyde, School of Applied Social Sciences, Graham Hills Building, 50 George Street, Glasgow G1 1QE。或者,你可以打電話給我:0141-548 4301。或,給我發電子郵件:kirsty.e.henderson@strath.ac.uk

Appendix D

Master Interview Schedule

My name is Kirsty Henderson and I am a PhD student from the University of Strathclyde.

Please can you read the information sheet and consent form before we start this interview. If you have any questions please do not hesitate to ask me.

I would like to ask you some questions about how you find health information.

I hope to use this information to help build a better understanding of how people from Black and Minority Ethnic groups find the health information that they need. I want to also understand how the internet may be influencing how people search for information.

This interview should take about **40 minutes.**

Pre-interview Questions:

1. Do you understand everything in the information sheet?

2. Have you understood and signed the consent form?

3. Are you happy to begin with the interview?

4. Do you want to use a pseudo name? If so what name do you want to

be known in my research as? ____________________________________

Let me begin by asking you some questions about where you live and how you use local NHS services

1. Do you **live in Glasgow**?

2. Which **part of Glasgow** do you live?

3. How long have you **lived in Glasgow**?

4. Do you have a **local community** here in Glasgow?

5. Do you **feel part of that local community**?

6. Do you know **other people in the local community**?

7. Are there **other people** in that local community who you can get **general** information about what’s going on from?

Transition to the next topic: Health & Health Services

8. What do you think you need to be **healthy**?

9. When you do need help with **your health** do you use any local NHS Services?

   -How often do you use these services?

10. Do you use any **other health or wellbeing services** in the local community?

   - How often do you use these services?

11. Do you think there is **enough health information** specifically for the African/Chinese community in Glasgow?

12. Do you use **alternative or traditional practices** or medicines, like herbal remedies or acupuncture?

13. **Why** do you use alternative or traditional practices or medicines?

Transition to the next topic: Searching & Networks

14. If you are unwell or just need information about your health, where do you go for **health** information?

15. Do you ever rely on **family/friends/neighbours** or **other members of the local community** for information about health matters?

16. **Why** would you go to them for information?

17. Roughly, **how often** would you ask them for health information?

Transition to the next topic: Group Dynamics

18. **Why** do you come to Karibu/Waverley Care /CCDP?

19. **Who** gives you information at Karibu/Waverley Care/CCDP?

20. Do you **share information** with other people at the Karibu/Waverley/CCDP?

21. Do you **share information** about health and wellbeing at Karibu/Waverley Care/CCDP?

22. Now try and think back…. have you ever **told a member of Karibu/Waverley Care/CCDP** where they can go to find health information?

Transition to the next topic: Internet

23. Do you have a **computer at home?**
-If not, where can you go to get access to a computer?

24. How **often** do you use the internet?

25. What do you **generally look at** on the internet?

26. Have you ever **looked up information about health on the internet**?

27. **Why** would you use the internet instead of other sources?

28. Which **health websites** have you look at?

29 Do you look up **general websites** about health or well-being?
-If so why?

30. Would you look at **NHS sites such as NHS 24**?
-If Yes why?
-If No, why?

31. Have you heard of a website called '**Health in my Language**?' it is an NHS website which offers health information in a number of other languages.

32. Do you **look up forums about health**? (forums are where people 'chat' about health or wellbeing)
-If so why?

33. Do you think there is **enough health information** on the internet in your first language?

34. Do you think there is **enough health information** on the internet specifically for Chinese/Africans?

35. What are the **good things** about using the internet to find health and well-being information?

36. Are there **bad things** about using the internet to find health and well-being information?

37. Do you **prefer looking up the internet** for health information rather than **seeing your doctor or other health professional**? (a health professional is anyone who works for the NHS who would offer you healthcare)
-If no, why?
-If yes, why?

Closing: Well its been a pleasure speaking with you today __________ thank you for taking the time to participate in my research study. I will be contacting Karibu/Waverley Care/CCDP in a few months to present my data results. **If you want me to send you a copy of my research findings, directly then please just contact me, my details are on the participant information sheet.**

Appendix E

Interviewee Sample

No	Organisation/ Group	Pseudo Name	Gender	Ethnicity	Age Range	Social Background
1	Barton Women's Group	Rebekah	Female	African	40	Former teacher. Mum of two. Informal leader at the Barton Group
2	Barton Women's Group	Sarah	Female	African	40+	Unemployed
3	Barton Women's Group	Mary	Female	African	60+	Retired
4	Barton Women's Group	Grace T	Female	African	30+	Full-time mum
5	Barton Women's Group	Lady Hay	Female	African	20+	Full-time mum
6	Barton Women's Group	Mrs G	Female	African	30+	Full-time mum of two, prominent figure at the Barton Group
7	Barton Women's Group	Rosaline	Female	African	30+	Full-time mum
8	Barton Women's Group	Doudou	Female	African	20+	Full-time mum
9.	Barton Women's Group	Iree	Female	African	20+	Applicant for the British Army
10	Barton Women's Group	Tasha	Female	African	30+	Full-time mum of two.
11	Waverley Care	Ozzy	Male	African	30+	University graduate now voluntary worker.
12	Karibu	Zizi	Female	African	40+	Voluntary worker
13	Karibu	Pauline	Female	African	40+	Unemployed
14	Karibu via a friend	Robert	Male	African	40+	Community campaigner and journalist
15	Karibu via a family member	Nadia	Female	African	30+	Office worker
16	Karibu	Isa	Female	African	20+	Full-time mum to her young son.
17	Karibu	Karen	Female	British – Afro-Caribbean	40+	Second generation British Afro-Caribbean lady who identifies with her African roots, works for the NHS.
18	CCDP	Kai	Male	Chinese	60+	Retired

19	CCDP	Mr Lee	Male	Chinese	60+	Traditional Chinese Doctor
20	CCDP	Gail	Female	Chinese	60+	Retired
21	CCDP	Ka	Male	Chinese	60+	Former Chinese restaurant owner now retired.
22	CCDP	Macy	Female	Chinese	50+	Retired
23	CCDP	Dan	Male	Chinese	30+	Kitchen hand in a Chinese Takeaway
24	CCDP	Ying	Female	Chinese	40+	Former Chinese takeaway kitchen staff member forced to retire due to ill health.
25	CCDP	May	Female	Chinese	60+	Retired.
26	CCDP	Fang	Female	Chinese	20+	Full-time mum.
27	CCDP	Paul	Male	Chinese	20+	Kitchen hand in a Chinese Takeaway.
28	CCDP	Vera	Female	Chinese	60+	Retired.
29	CCDP	Karl	Male	Chinese British	20+	IT support worker
30	CCDP	Cheng	Male	Chinese	60+	Retired
31	CCDP	Betty	female	Chinese	30+	CCDP worker
32	Scottish Refugee Council	Sheena	female	Scottish	30+	Development worker for Scottish Refugee Council
33	Scottish Refugee Council	Zara	female	Scottish	30+	Development worker for Scottish Refugee Council
34	Looking Local	Hazel	female	English	40+	Business Manager
35	Scottish Government	Kerry	female	Scottish	40+	Scottish Government Policy Analyst
36	Waverley Care	Maggie	female	African	40+	African Health Project Manager

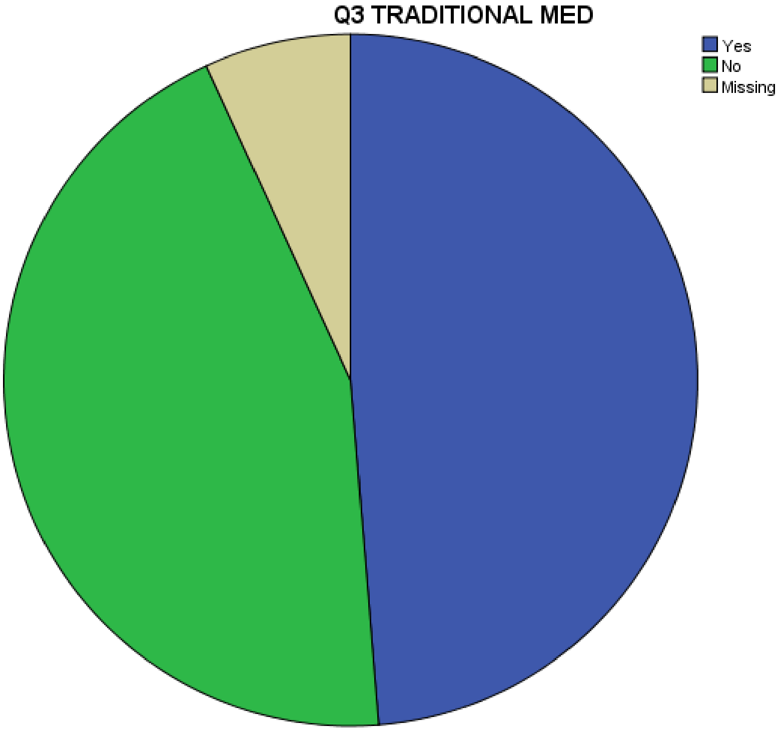
Appendix F

Questionnaire SPSS Statistical Outcomes & Pie Chart

Results from question 3 “Do you use any alternative/traditional health and well-being practices or medicines?”

Q3 TRADITIONAL MED

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	57	48.7	52.3	52.3
	No	52	44.4	47.7	100.0
	Total	109	93.2	100.0	
Missing	0	8	6.8		
Total		117	100.0		



Appendix G

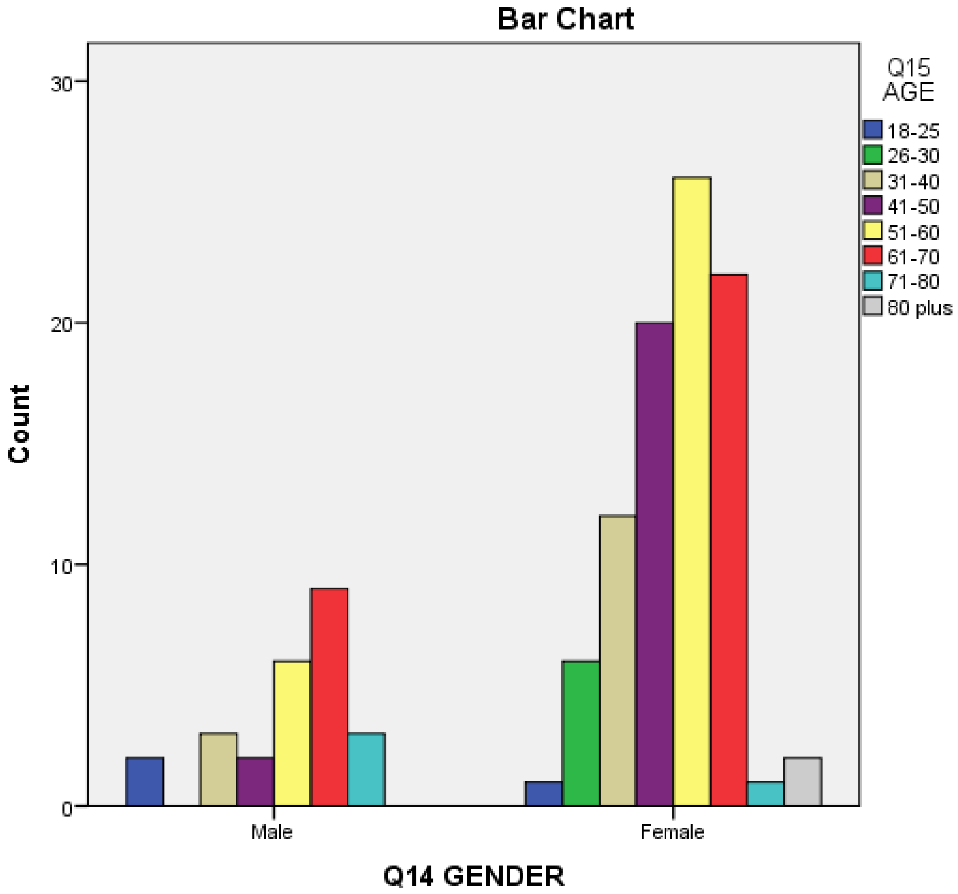
Questionnaire SPSS Statistical Outcome & Bar Chart

Age and Gender Sample Breakdown for the self-completion questionnaire exercise.

Q14 GENDER * Q15 AGE Crosstabulation

Count

		Q15 AGE								Total
		18-25	26-30	31-40	41-50	51-60	61-70	71-80	80 plus	
Q14 GENDER	Male	2	0	3	2	6	9	3	0	25
	Female	1	6	12	20	26	22	1	2	90
Total		3	6	15	22	32	31	4	2	115



Appendix H

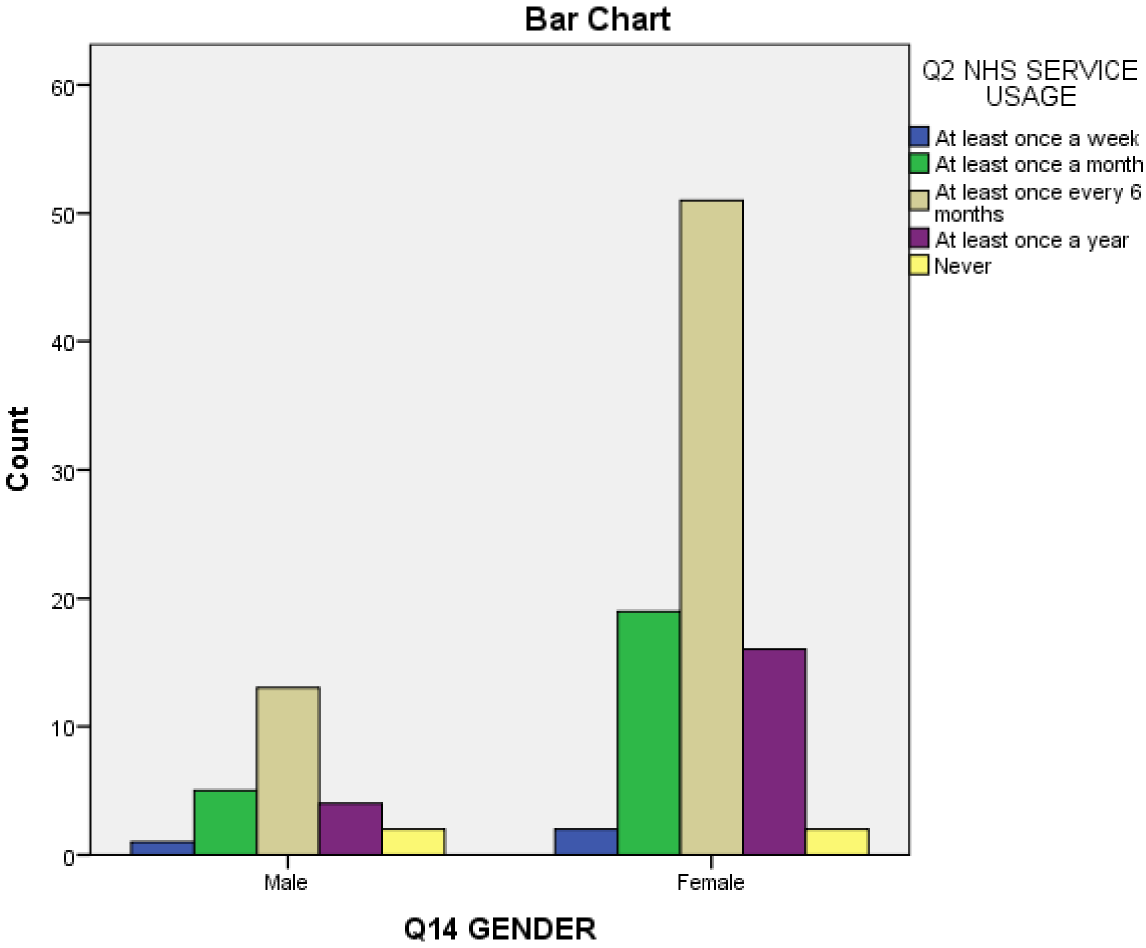
Questionnaire SPSS Statistical Outcome & Bar Chart

Results from Question 2: “Over the last year, how often have you used NHS services?”

Q14 GENDER * Q2 NHS SERVICE USAGE Crosstabulation

Count

		Q2 NHS SERVICE USAGE					Total
		At least once a week	At least once a month	At least once every 6 months	At least once a year	Never	
Q14 GENDER	Male	1	5	13	4	2	25
	Female	2	19	51	16	2	90
Total		3	24	64	20	4	115



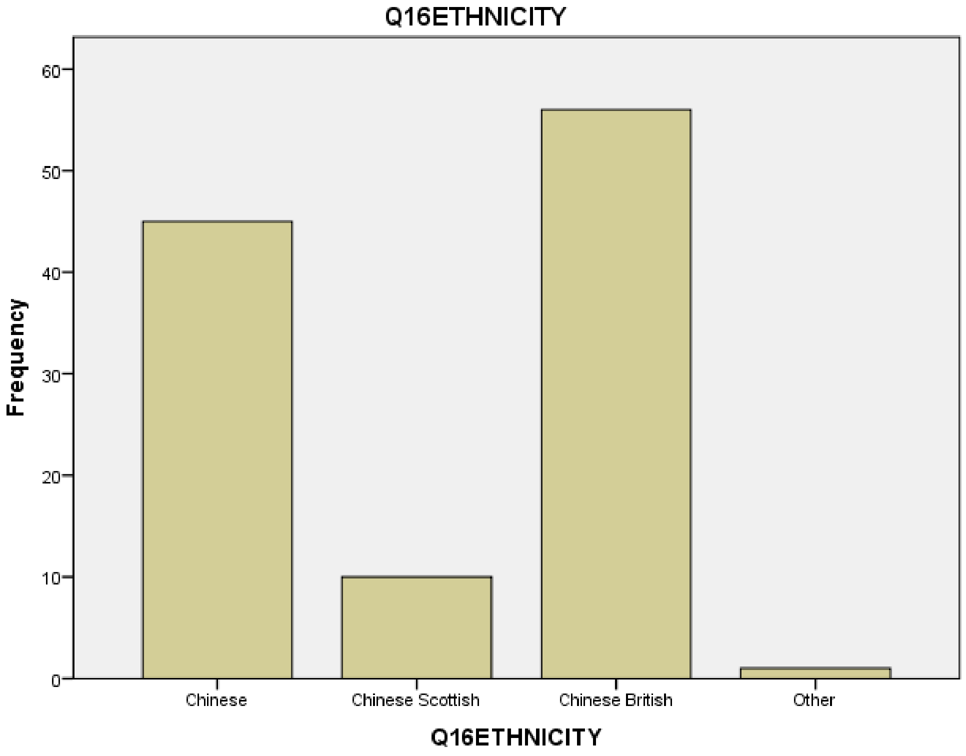
Appendix I

Questionnaire SPSS Statistical Outcome & Bar Chart

Ethnicity Sample Breakdown for the self-completion questionnaire exercise.

Q16ETHNICITY

		Frequency	Percent	Valid Percent	Cumulative Percent
	Chinese	45	38.5	40.2	40.2
	Chinese Scottish	10	8.5	8.9	49.1
Valid	Chinese British	56	47.9	50.0	99.1
	Other	1	.9	.9	100.0
	Total	112	95.7	100.0	
Missing	0	5	4.3		
Total		117	100.0		



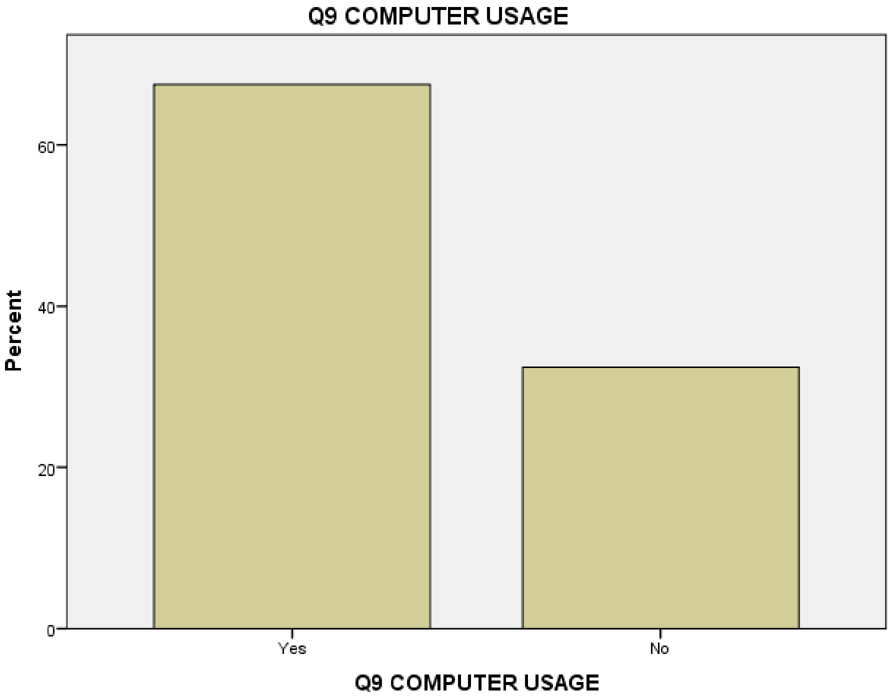
Appendix J

Questionnaire SPSS Statistical Outcome & Bar Chart

Results from Question 9: “Do you use or have you ever used a computer?”

Q9 COMPUTER USAGE

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	77	65.8	67.5	67.5
	No	37	31.6	32.5	100.0
	Total	114	97.4	100.0	
Missing	0	3	2.6		
Total		117	100.0		



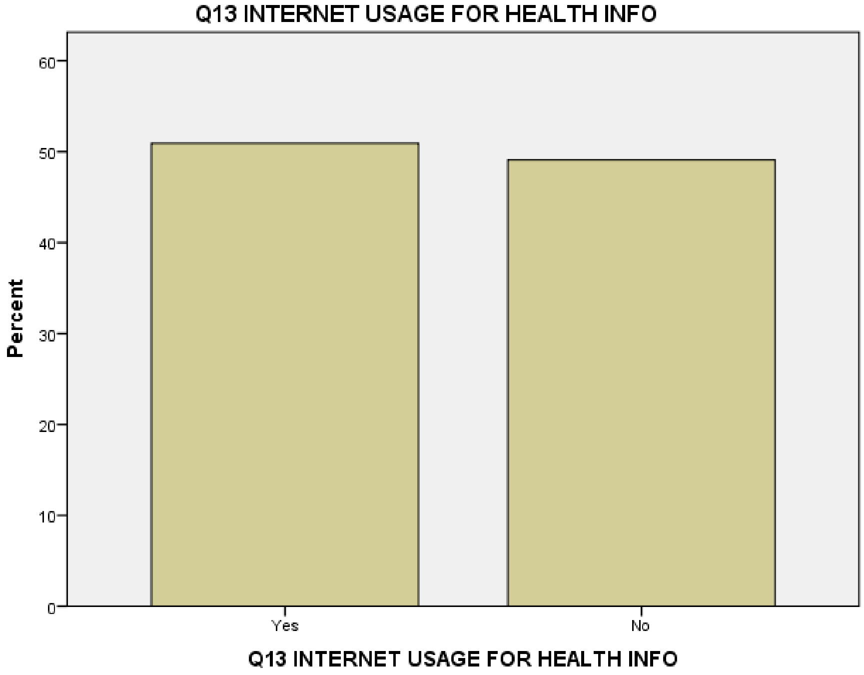
Appendix K

Questionnaire SPSS Statistical Outcome & Bar Chart

Results from question 13: “Do you ever look at information about health and well-being on the internet?”

Q13 INTERNET USAGE FOR HEALTH INFO

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	56	47.9	50.9	50.9
	No	54	46.2	49.1	100.0
	Total	110	94.0	100.0	
Missing	0	7	6.0		
Total		117	100.0		



Appendix L

Questionnaire SPSS Statistical Outcome & Bar Chart

Results from question 13a: “If yes, which webpages do you look at about health and well-being on the internet?”

Q13A WHICH HEALTH WEBPAGES

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	NHS Websites NHS 24 or Greater Glasgow and Clyde NHS	8	6.8	7.5	7.5
	Health Charities Cancer Research or British Heart Foundation	6	5.1	5.7	13.2
	News Websites BBC or Sky News	10	8.5	9.4	22.6
	Advice Websites Netdoctor or WebMD	5	4.3	4.7	27.4
	Health Forums Womens or Mens Health Forums	7	6.0	6.6	34.0
	None	44	37.6	41.5	75.5
	Advice Pages and Health Forums	2	1.7	1.9	77.4
	Other answer: Google Search	2	1.7	1.9	79.2
	Other answer Yahoo Search	3	2.6	2.8	82.1
	News websites and Advice Pages	2	1.7	1.9	84.0
	News Websites and Health Forums	3	2.6	2.8	86.8
	News websites Advice Pages and Health Forums	2	1.7	1.9	88.7
	Health Charities News Websites and Health Forums	2	1.7	1.9	90.6
	Health Forums and Other Information Yahoo Search	1	.9	.9	91.5
	Other Answer Yahoo Search Hong Kong	1	.9	.9	92.5
	Other answer Amway	1	.9	.9	93.4
	Other answer msn.com	1	.9	.9	94.3
	NHS Websites News Websites Health Forums	3	2.6	2.8	97.2
	NHS Websites News Advice Pages and Health Forums	1	.9	.9	98.1
	NHS Websites Charities and Advice Pages	1	.9	.9	99.1
	Chinese Website	1	.9	.9	100.0
	Total	106	90.6	100.0	
Missing	0	11	9.4		
Total		117	100.0