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**Migrants' Health Beliefs and their Impact on  
General Practice Encounters: an in-depth  
interview study of French- and Swahili-speaking  
Africans and General Practitioners working with  
Migrant Patients**

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Submitted in Fulfilment of the Requirements  
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## Abstract

**Background.** The growing population of migrants (including sub-Saharan Africans) in the United Kingdom poses challenges to British general practice. First, migrants tend to seek health care at times of crisis rather than for preventive measures. This is despite being at increased risk of certain chronic conditions compared with the indigenous population. For sub-Saharan Africans this includes hypertension-related diseases and some cancers. Little has been published about Africans' awareness of this risk or their knowledge of associated causative factors. Second, discordant health beliefs and healthcare expectations between migrants and doctors in the UK have been found to undermine trust during consultations with general practitioners and to lead to poor patient satisfaction. Little is known about the health behaviours of African migrants whose expectations are not met by primary care in the UK. A related area where health beliefs and practices differ between African migrants and their GPs is in the use of traditional medicines. A final challenge lies in considering the wider issues that GPs must address when consulting with migrant patients, including time pressures, organisational factors and the complex nature of problems presented by migrant patients. These issues are the focus of this study.

**Aims.** To examine African migrants' perceptions of chronic disease and their experience of seeking primary health care in the UK. To explore the impact upon GPs of caring for migrants.

**Objectives.** To explore: 1) perceptions of chronic disease risk facing African migrants and their underlying explanatory models; 2) experiences of consultations about antibiotic prescriptions; 3) traditional African medicine use in the UK; and (4) to consider the effect of workload and work patterns on GP consultations with migrants.

**Design.** In-depth interviews were conducted with 19 Africans from French- or Swahili-speaking countries, one African key informant and 13 GPs working with migrants. African participant recruitment was from community organisations and GPs were approached via an informal network of doctors. Interviews were transcribed and ten were translated by the principal investigator (three Swahili and seven French). Data analysis was undertaken following the approach of applied thematic analysis using the Nvivo software package.

Data collection and analyses were underpinned by the following theoretical frameworks: Kleinman's explanatory models of illness and of cultural health care systems and Lipsky's street-level bureaucracy.

**Results.** Narratives suggested low awareness of chronic disease risk amongst Africans. Infectious diseases were considered the dominant health threat for African migrants, mainly HIV but also tuberculosis and 'flu'. Chronic diseases were sometimes described by Africans as contagious. Explanatory models of chronic disease included bodily/dietary imbalance, stress/exertion, heredity/predisposition and food contamination. Cancer was feared but not considered a major threat. Cancer was considered more common in Europe than in Africa and was attributed by Africans to chemical contamination from fertilizers, food preservatives and industrial pollution. Evidence cited for these chemicals was rapid livestock/vegetable production, large size of farmed products (e.g. fish), softness of meat and flavourless food. Chemicals were reported to circulate silently inside the body and cancer to develop in the part where they deposit, sometimes years later.

Africans' belief in infective explanations of disease extended to minor illnesses and was manifested in an expectation of antibiotics from GPs for problems such as a sore throat. This arose from participants' experience in Africa, witnessing life-threatening infectious diseases and experience of unregulated access to antibiotics. Africans described various alternative measures to fulfil their unmet expectations, including approaching other National Health Service doctors, importing medication, and using private healthcare services in London, francophone Europe and east Africa. A further option was the use of traditional African medicine, reported by one quarter of African participants. Traditional African herbal medicine use was based upon a perception of its purity and natural origin in African soil and a deep belief in its efficacy. Consulting traditional African healers in the UK was reported to be undertaken in secret.

Some GPs and Africans described consultations in terms of pressure, processing and conflict. Migrants were reported to present with complex health problems that were frequently compounded by language barriers. GPs described a need to remain in control of consultations and this included some use of personal discretion to render their tasks easier to complete. The most common example was accepting patients' family and friends as informal interpreters – a choice that ran contrary to formal policy of only using professional interpreters. Burnout was reported to be one consequence of excessive workload for patient-centred GPs working with vulnerable groups like asylum seekers.

**Conclusions.** There is a need to improve health literacy amongst African migrants in order to promote preventive behaviours for chronic disease and alternatives to antibiotics for minor illnesses. As part of this, further research is required into the use and properties of traditional African medicine. Interventions should be built upon participants' existing knowledge of disease causation, their self-reliance in the pursuit of a healthy lifestyle and desire to retain cultural practices. One challenge to improving migrant health lies in the service dilemmas facing GPs, including excessive workload, the complex nature of migrants' presenting problems and professional dilemmas. GPs who act as advocates for vulnerable migrant patients may be at increased risk of burnout and greater consideration should be given to providing them with appropriate support.

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## List of accompanying material

One publication from this research, submitted separately from this thesis:

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## Author's Declaration

All of the work reported in this thesis was designed, conducted, analysed and written-up by the author. The following presentations have been given based on material contained in this thesis:

August 2012. Poster presentation: "West of Scotland Ethnicity and Health Network, Glasgow University. "A chronic disease is a disease which keeps coming back... it is like the flu": Chronic disease risk perception and explanatory models among French and Swahili speaking African migrants". Authors: Cooper, MJF; Harding, S; Mullen, K and O'Donnell, K.

November 2012. Presentation at Research Group, Division of Primary Care and Public Health, Brighton and Sussex Medical School: "Street-level bureaucracy and migrant consultations in general practice".

January 2013. Presentation at Divisional Seminar, Division of Primary Care and Public Health, Brighton and Sussex Medical School: "Qualitative study of health beliefs and practices of African migrants in Glasgow: explanatory models of chronic physical disease".

May 2013. Presentation at Divisional Seminar, Division of Primary Care and Public Health, Brighton and Sussex Medical School: "Traditional medicine beliefs and use amongst African migrants in Glasgow".

"I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature: Maxwell Cooper

Printed name: Maxwell John Francis Cooper

## Definitions and abbreviations

The following abbreviations are used in this thesis:

|     |  |
|-----|--|
| DRC | Democratic Republic of the Congo                     |
| GP  | General Practitioner                                 |
| HBM | Health Beliefs Model                                 |
| HIV | Human Immunodeficiency Virus                         |
| MUS | Medically Unexplained Symptoms                       |
| NHS | National Health Service                              |
| PSA | Prostate Specific Antigen                            |
| QOF | Quality and Outcomes Framework                       |
| SLB | Street-Level Bureaucracy                             |
| USA | United States of America                             |
| UK  | United Kingdom of Great Britain and Northern Ireland |

The term “surgery” is used in UK general practice to denote a family practice clinic

# Introduction

# 1) Migration and epidemiology in the African context

Africa is at the centre of what has been called “the greatest demographic upheaval in human history” (Kasongo, 2011). This is because the population of sub-Saharan Africa is predicted to rise from 856 million in 2010 to exceed two billion shortly after 2050 (United Nations Development Programme, 2012). This population explosion is the consequence of the demographic transition of African nations that is the product of significant reductions in fertility and mortality (Blue and Espenshade, 2011). This leads to circumstances where a high proportion of women are in their reproductive years and results in a period of increased birth rate, a driver of population growth known as “population momentum” (Keyfitz, 1971). Alongside this increase in total population size, Africa is experiencing significant internal demographic changes. Most notable is a major shift towards urban residence, such that Africa’s urban population is predicted to increase from 414 million in 2012 to over 1.2 billion by 2050 (United Nations News Centre, 2012). One important consequence of lifestyle changes associated with urbanisation is that Africans are now experiencing rising morbidity and mortality due to non-communicable diseases such as diabetes mellitus<sup>1</sup>, cardiovascular disorders and cancer (Aikins, Unwin, Agyemang et al., 2010).

In addition to new demographic and epidemiological changes, African nations are facing long-term economic challenges. Whilst many African economies have experienced significant improvements over the past ten years, most Africans continue to live in poverty (Centre for the Studies of African Economies, 2012). Indeed, for most sub-Saharan African countries markers of life expectancy, education, and income have stagnated or declined since 1990, leaving this region the poorest in the world (Handley, Higgins, Sharma et al., 2009). The causes of poverty in Africa are complex, but include political instability, conflict, the vulnerability of rural populations to weather extremes and the persistence of major infections, such as Human Immunodeficiency Virus (HIV) and malaria. One important consequence of poverty is mass-migration from Africa to developed countries, a phenomenon facilitated by global communication, cheaper travel and openings for employment or because people are seeking asylum.

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<sup>1</sup> Hereafter referred to as diabetes



Two dimensions of demographic and socio-economic change in Africa provide the context for the present study. First, as a result of mass-migration from Africa, clinicians working in the National Health Service (NHS) in the UK are increasingly likely to be consulted by African patients. Such migration can no longer be understood as simple links with the capital cities of a few major anglophone African nations. Instead, changing migration patterns over the past decade have led to populations that are diverse in ethnicity, religion, culture and language, a phenomenon known as “super-diversity”. That is to say, the existence of an increased number of “new, small and scattered, multiple-origin, transnationally connected, socio-economically differentiated and legally stratified immigrants who have arrived over the last decade” (Vertovec, 2006). As a result, British GPs are also increasingly likely to encounter unfamiliar cultural beliefs about illness and treatment amongst migrant patients. Additional challenges may arise from the fact that certain migrants report being unfamiliar with the primary care orientated health care system in the UK (O'Donnell, Higgins, Chauhan et al., 2008). This is because the NHS differs markedly from health care systems that exist in many African countries - for example, due to its basis as a form of socialised medicine with its emphasis on primary care as first point of contact, essentially free at the point of need and serving as a ‘gatekeeper’ to secondary care. This contrasts with health care systems in Africa which are typically funded by “out of pocket” payments for treatment and are often hospital-based. A further influence on Africans’ expectations of health care is that is that are likely to have experience of using clinicians who are not formal medical graduates (Mullan and Frehywat, 2007) and of lay medical services, including traditional healers and the use of herbal products. All these factors may result in discordant expectations between the patient and his/her GP over how illness<sup>2</sup> should be diagnosed and managed. What is more, migrants may struggle to express themselves in English and, therefore, these issues may need to be negotiated through broken English or an interpreter. This complex situation is one that risks breakdown in communication and conflict between doctor and patient.

A further dimension to clinical encounters is the diverse health needs of African migrants. Alongside concern over infectious diseases, the emergence amongst African migrants of chronic conditions as a major cause of morbidity and mortality poses new challenges in

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<sup>2</sup> Following others (Eisenberg, 1977; Kleinman, 1988), in this thesis the following terms are used: “illness” and “sickness” are considered to be the problem as perceived by the patient and “disease” as by the clinician.

consultations with GP to prevent and manage such diseases. One reason for this is because Africans are unlikely to have experienced the type of widespread public awareness campaigns about common chronic diseases that are common in western countries. In addition, Africans may be more familiar with infectious diseases amongst family and community members than with chronic conditions.

## 1.1 Migration from Africa to the UK

As a result of significant immigration and emigration the demographic picture of the UK population is a changing one. Estimated total long-term immigration to the UK during 2011 was 566,000, an annual number that has remained relatively constant since 2004 (Office for National Statistics, 2012). As a result, migrants comprise an increasing proportion of the UK population that has risen from 8% in 2001 to 12% in 2010 (Health Protection Agency, 2011). Nevertheless, the total number of immigrants in the UK remains a smaller proportion of the total population than in other major European countries, most notably Germany (13.1%), Spain (14.1%) and Ireland (19.6%) (Rechel, Mladovsky, Ingleby et al., 2013). Sub-Saharan<sup>3</sup> Africans represent a significant group of migrants to the UK and one of the fastest growing migrant populations in Europe (Boateng, Nicalaou, Dijkshoom et al., 2012). For example, between 2002 and 2009, the black African population of England and Wales grew by 6.2 percent per year, with significant migration not only from the African Commonwealth<sup>4</sup> nations, but also Somalia, Eritrea and the Democratic Republic of the Congo (Office for National Statistics, 2011a). Prior to the submission of this thesis, statistics from the 2011 census in Scotland were unavailable for the ethnicity and the continent of birth of residents. Figures from that (2011) census for England and Wales show in 2011 the following percentages for black people as part of the total population: African<sup>5</sup> 1.8%, Caribbean 1.1% and other black 0.5% (Office for National Statistics, 2011b). The number of people in England and Wales recorded in this census who had been born in Africa was 1,312,617, representing 2.3% of the total population (Office for National Statistics, 2011c). These figures, however,

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<sup>3</sup> The United Nations uses the term sub-Saharan Africa used to indicate all of Africa except northern Africa and the Sudan (United Nations, 2009). Since this report, however, the Sudan has split into two nations.

<sup>4</sup> The Commonwealth of Nations, formerly known as the 'British Commonwealth'

<sup>5</sup> Ethnicity in the UK census is self-reported. This figure may also include people not born in Africa who identify themselves as being of African heritage.

include people from North Africa as well as those born in Africa who are of Asian or European descent. It should also be noted that this figure is less than that for the number of Africans in other European countries, for example France with 1,544,156 (INSEE, 2010).

Although similar figures for black and African people in Scotland are currently unpublished it is likely that they show a significant increase over the previous census in 2001. This is particularly likely to be true for the city of Glasgow – the location of the present study – due to its status of being a receiving centre for significant numbers of asylum seekers as part of the UK government’s policy of “dispersal”. Instigated by the Labour government in 1999 in order to reduce the concentration of asylum seekers living in London and the south east of England, the dispersal policy led to the movement of asylum seekers to other parts of the UK, principally major cities such as Birmingham, Manchester and Liverpool (Burnett, 2011).

Reasons for migration may be categorised into ‘push’ and ‘pull’ factors (Health Protection Agency, 2011). Emigration due to socio-economic deprivation, civil war, and natural disasters in the home country comprise ‘push’ factors and the desire for employment, education, and family re-unification represent ‘pull’ factors. The result is that migrants are a heterogeneous population and include those seeking work, family dependents, students, refugees, asylum seekers and undocumented individuals. It is important to consider such categories in any research on the health of migrants because there exist significant variations in mortality and morbidity amongst people who migrate for different reasons (Jayaweera, 2011). People who migrate due to “push” factors are considered to have a more vulnerable existence in their adopted country, with resulting negative effects upon morbidity and mortality. This has particular relevance to Africans for it is recognised that a significant proportion of migrants leave their home country as a result of “push” factors, in particular lower levels of economic development and political instability in many such countries (de Haas, 2008). **The nature of migration due to “push” factors is considered in depth in this section because many African participants in the present study originally came to Europe as asylum seekers.**

Evidence of the importance of “push” factors in migration from Africa lies in the large population of internally displaced people within the continent as well as the number of asylum seekers and refugees who come to the west from African countries. Sub-Saharan African countries contain an estimated 9.7 million internally displaced people (Internal

Displacement Monitoring Centre, 2011) and Africans constitute about one third of the global refugee population (Kohnert, 2007). African refugees and asylum seekers are considered to be a particularly vulnerable migrant population (Kamya, 1997), especially women and children who often suffer sexual and physical abuse and/or trafficking (Jayaweera, 2011). African refugees have little control over their journey, including the particular country in which they ultimately end up seeking asylum (Cooper, 2010; Crawley, 2010). Their voyage to Europe may include inhuman living conditions in refugee camps and lack of access to health care (Stauffer, Kamat, and Walker, 2002). In addition, many refugees have fled famine, war, violence (Morris, Popper, Rodwell et al., 2009) and torture (Burnett and Peel, 2001a; Burnett and Peel, 2001b).

That African migrants now form a significant and diverse population within the UK can be seen from immigration figures. For example, in 2008 the four African nations with the greatest number of asylum seekers to the UK were Zimbabwe, Eritrea, Somalia and Nigeria, with a combined total of 7585 applications (Information Centre about Asylum and Refugees, 2009). The relationship between seeking asylum in Europe and civil unrest in Africa can be inferred from the first three of these countries, all of which have recently experienced military conflicts. There is, however, an evolving pattern of migration from Africa for asylum – for example by 2011 the African nations producing the greatest number of people seeking asylum in Britain were Eritrea, Libya, Nigeria and Sudan, with a total of 2434 applications (Refugee Council, 2012). This illustrates not only the effect of *emerging* conflicts (Libya and Sudan) but also the overall decline in asylum applications to the UK since the early 2000s. Indeed, global asylum applications to the UK peaked in 2002 (84,130) and decreased to their lowest in 2010 (17, 916) (Scottish Refugee Council, 2012). The precise reasons for this decline remain uncertain but are likely to lie in stricter border control, reduced demand or factors related to the way in which data are recorded. It should also be borne in mind that such figures may conceal significant undocumented migration.

Whilst there are no detailed statistics available on the total number of asylum seekers and refugees in Glasgow (The Information Centre about Asylum Seekers and Refugees in the UK, 2010), the geographical location of the present study, it is estimated that more than 25,000 asylum seekers came to Scotland between 2000 and 2008 (Campbell, 2008). In August 2006, there were over 5,000 people seeking asylum in Scotland, including Africans from the following countries: Democratic Republic of the Congo (8%), Congo Brazzaville

(3%), Somalia (8%), Zimbabwe (4%), Algeria (3%), Sudan (3%) and Nigeria (2%) (Cosla, 2010). By 2008 the number of people seeking asylum in Scotland had fallen to about 2,000 (Campbell, 2008). A further reason why statistics for the number of African asylum seekers and refugees in Scotland are uncertain is because they are a mobile population and many subsequently move to other parts of the UK, in particular London, especially if they are given leave to remain in the country.

Once within Europe, African migrants are not an easily identifiable, homogeneous group (Jonsson, 2009). This is likely to be a result of their wide variety of countries of origin and diverse ethnic backgrounds as well as their often experiencing low socio-economic status (Boateng, Nicalaou, Dijkshoom et al., 2012). That some African migrants belong to higher socio-economic groups is evident in the presence of a significant number of Africans who work as doctors within the NHS. For example, there are 6,520 black African doctors registered with the UK General Medical Council and the top 10 countries of qualification include three African nations: South Africa, Nigeria and Egypt (General Medical Council, 2014). Nevertheless, many African migrants experience language barriers, family disruption as well as prejudice and discrimination from the host population (Svenberg, Mattsson, and Skott, 2009). In the UK context the inequality faced by migrants has been described as “enforced discomfort” (Delamothe, 2012), a phrase that hints that government and society might do considerably more to ease the life of migrants in this country. As a consequence of such discomfort, African migrants’ experience of their new life in the west has been found often to be framed in a state of longing for their homeland (Svenberg, Mattsson, and Skott, 2009). Social hardship is important because it is known to influence both mental and physical health in migrants (Jayaweera, 2011). This is particularly important in the case of illegal or undocumented migrants who are recognised to experience not just lack of access to health care (World Health Organisation, 2010) but exposure to major social risk factors for poor health. Challenges facing undocumented African migrants include unemployment, financial deprivation, exposure to crime, substandard housing and poor diet (Yebei, 2000).

One coping strategy for African migrants is fulfilled by placing emphasis upon extended family and social networks (Vaughn and Holloway, 2009). Family and community are an important part of African society and are typified by the notion of “Ubuntu” (“humanity”)<sup>6</sup>.

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<sup>6</sup> This term has been translated in various forms according to the specific Bantu tongue and include “a moral quality of a human being”, “generosity” and the “capacity to connect with another person” (Gade, 2012). In standard coastal Swahili language its form is “utu”.

Although 3.3% of the population of England and Wales identified themselves as black in the 2011 census (Office for National Statistics, 2012), this population is very diverse in terms of background, culture, identity and language (Agyemang, Bhopal & Bruijnzeels, 2005). As a result of this and the fact that some regions are more ethnically diverse than others, African migrants may not identify with or establish social networks with the wider black British population. Instead, there is evidence that they establish relatively closed cultural group and these are poorly understood by other members of the society of the host country (Yebei, 2000). Such networks influence members' health-seeking behaviour. This is because friends, family and support agencies are often migrants' main source of information regarding the location of their nearest GP and the process of registering with a doctor (Bhatia and Wallace, 2007). At the same time, African migrants maintain strong links with family and other supportive contacts abroad. As a result, significant "transnational therapy networks" are known to operate between Africa and Europe and these serve the transfer of money and medicines (Krause, 2008). Although African migrants typically work hard to send money to relatives in their country of origin (Yebei, 2000), it should be noted that assistance flows in both directions. For example, herbal remedies considered unobtainable in the UK have been reported to be sent to Africans in London and, likewise, western medicines to Africa (Thomas, 2010). A further source of personal support for African migrants faced with cultural adversity is religious faith (Kamya, 1997; Vaughn and Holloway, 2009). Although this is recognised to be an important source of inner strength, there is evidence that for HIV positive African migrants in England the church may be perceived as a space that lacks confidentiality and serves to *generate* stigma (Chinouya & O'Keefe, 2005). This may be one reason why there exists evidence that transnational networks serve to maintain mutual religious support and prayer (Krause, 2008). Little is known about the existence or nature of transnational networks for Africans in Scotland. This is important because African communities in Scotland exist at a significant distance from other British cities with large African populations and in the absence of direct flights from sub-Saharan Africa.

## **1.2 Epidemiological transition to chronic disease: Africa's "double burden"**

Alongside significant demographic shifts, many African countries have experienced epidemiological changes over the past decade as people increasingly adopt aspects of

modern lifestyles. This consists of new patterns of morbidity and mortality in African countries, in particular the emergence of chronic conditions as major health problems - for example, hypertension, cardiovascular disease, diabetes, asthma, epilepsy, cerebrovascular disorders, cancer, and arthritis (Gill and Beeching, 2004a). The shift in morbidity and mortality from infectious diseases to chronic conditions is known as the “epidemiological transition” (Omran, 1971). Africa, however, is unique as the continent now facing a “double burden” of infectious and chronic disease. What is more, this double burden reflects a major health inequality not just between continents (i.e. between Africa and western Europe) but also across social class within Africa. This is because, whilst affluent African communities are experiencing a higher risk of chronic diseases, poor communities are more likely to face increased risk of both infectious diseases *and* chronic conditions (Agyei-Mensah and Aikins, 2010).

As a consequence of the epidemiological transition, the world now faces a global epidemic of chronic disease. Indeed, non-communicable chronic conditions have now become the greatest cause of death in the world (Yach, Hawkes, Gould et al., 2004). The global epidemiological transition has been attributed to the adoption of less healthy diets, physical inactivity, tobacco use, urbanisation, increased life expectancy and poverty (Gill, Mbanya, Ramaiya et al., 2009; World Health Organisation, 2005). Despite these causative factors that essentially arise from adopting modern lifestyles, the burden of chronic disease is not borne solely by city dwellers. For example, there is evidence that obesity – a major factor in the causation of many chronic diseases – is increasingly common in developing countries amongst semi-urban and rural areas and younger age groups (Prentice, 2006). As a marker of the scale and impact of this, the global epidemic of obesity has earned its own epithet: “globesity” (Deitel, 2002).

The chronic disease epidemic has particular relevance to Africa and to African migrants because, over the next decade, Africa is the continent expected to undergo the greatest rise in mortality from these conditions (Aikins, Unwin, Agyemang et al., 2010). Already in Africa there is an increasing incidence of cancer (Parkin, Sitas, Chirenje et al., 2008), ischaemic heart disease (Mensah, 2008b), diabetes (Levitt, 2008) and obesity (Dalal, Beunza, Volmink et al., 2011) and the lifetime risk of dying from cancer amongst women is almost double that of women in developed countries (Parkin, Sitas, Chirenje et al., 2008). Hypertension is known to be a major public health burden in Africa and is considered by some to be rising (Bosu, 2010). Data from community based studies in west

(Cappuccio, Micah, Emmett et al., 2004; Spencer, Phillips, and Ogedegbe, 2005) and east Africa (Edwards, Unwin, Mugusi et al., 2000) suggest a background rate of hypertension of 28 - 30%. Thus, the prevalence of hypertension in Africa as a whole is close to that of the UK, where rates for adults in Scotland in 2009 were 35.5% for men and 30.9% for women (Scottish Health Survey, 2011) and in England in 2011 to be 31% for men and 28% for women (Health and Social Care Information Centre, 2012).

Although hypertension rates appear to be broadly similar between Africa and the UK, there are data to suggest that underdiagnosis and undertreatment are significantly higher in Africa than in the UK. African studies point to levels of detection and treatment that are worse than the “Rule of Halves” (Wilber and Barrow, 1972). This rule states that half of those affected by hypertension are detected, half of these are treated and only half of these – in turn - are adequately controlled (Wilber, 1973). In Africa, detection and treatment appear to be achieved in one third of patients or fewer. For example, one community-based cross-sectional survey of hypertension in west Africa (in Ghana) found that of 1337 subjects identified with hypertension, 34% were aware of their diagnosis, 18% were treated, and 4% were controlled (blood pressure < 140/90 mm Hg) (Amoah, 2003). In the context of older adults in rural east Africa (Tanzania), undertreatment has been described as a “rule of sixths” (Dewhurst, Dewhurst, Gray et al., 2012). In this survey of 2223 adults over 70 years of age, two sixths of hypertensives had been previously detected, one sixth of those previously detected were on treatment and one sixth of those on treatment were adequately controlled. Relevant to these observations is evidence that inequalities in detection appear to exist across gender. The indication for this comes from South Africa where far fewer hypertensive men (9%) than women (23%) have been found to be aware of their diagnosis (Peltzer, 2004). As a major preventable cause of premature morbidity and mortality from heart disease and stroke, these findings clearly point to a need for cost-effective interventions in order to promote primary prevention of hypertension alongside improved strategies for diagnosis and treatment.

Control of the global epidemic of chronic diseases such as hypertension requires early diagnosis and adherence to lifestyle modifications and/or pharmacological treatments. Evidence exists for therapeutic interventions in most chronic diseases (World Health Organisation, 2005). What is more, this may be delivered through effective and affordable services in Africa, for example nurse-led management of hypertension and diabetes (Lekoubou, Awah, Fezeu et al., 2010). Despite this, even in urban areas significant under-



diagnosis, treatment, and control of hypertension exist in Africa (Addo, Smeeth, and Leon, 2007). Failure to detect and treat hypertension is related to a range of wider causes, including lack of awareness, poverty and struggling health care systems. A further challenge to long-term care in Africa is reported to be claims by certain traditional healers of rapid cures for chronic diseases (Kolling, Winkley, and von Deden, 2010). This observation points to the important role of socio-cultural factors in health behaviours and forms an important part of the present study, where traditional medicine beliefs and use amongst migrants are considered.

### **1.3 Ethnic patterning of mortality and morbidity of African migrants**

African migrants represent a diverse population in terms of ethnicity, culture and migration history. This is important because morbidity and mortality in migrants reflects different exposure to disease risk factors encountered before, during and after migration. Most migrants are young and relatively healthy (World Health Organisation, 2010), a phenomenon called the “healthy migrant effect”. This results from self-selection of healthy individuals at the time of migration but this benefit is known often to be a short-lived benefit (Fennelly, 2007). In England and Wales people from east and west Africa experience Standardised Mortality Ratios for all-cause mortality that are significantly higher than the national average (Adelstein & Marmot, 1991; Wild, Fischbacher, Brock et al., 2007). In addition to differential exposure to risk factors, this is likely to reflect differences in access and use of health care services. Evidence for this comes from statistics relating to diseases where outcome is closely associated with obtaining access to health care. For example, black Africans in the UK are known to be at increased risk of tuberculosis (Adelstein & Marmot, 1991) and late diagnosis of HIV infection (Health Protection Agency, 2012). A further factor may be related to increased maternal mortality, given that the incidence of maternal death amongst black African women in the UK is sevenfold greater than the indigenous white British (Drife, 2005).

Central to the present study is strong evidence of inequality in morbidity and mortality from chronic disease between migrant Africans and non-migrant populations. First, Africans who migrate have been found to have higher blood pressure and be at greater cardiovascular risk than their African-born, non-migrant counterparts (Dominguez, Galioto, Pineo et al., 2009). Second, higher rates of hypertension exist in people of

African descent in the UK than in the indigenous population (Agyemang and Bhopal, 2003; Harding and Maxwell, 1997; Wild, Fischbacher, Brock et al., 2007). Similarly, in Europe, migrants from Africa experience increased mortality and morbidity due to stroke and diabetes (Harding, Teyhan, Rosato et al., 2008; Vandenheede, Deboosere, Stirbu et al., 2012). Surprisingly, however, people of direct African descent in the UK have been found to have rates of ischaemic heart disease that are lower than national rates (Harding, Rosato, and Teyhan, 2009). The cause of this surprising pattern is unclear but may lie in reduced smoking and lower cholesterol values in African migrants.

The importance of chronic disease is underlined by evidence that major neoplastic diseases, such as breast, colon and prostate, are leading causes of cancer deaths in African migrants (Harding, Rosato, and Teyhan, 2009). As gastrointestinal cancers have previously been reported to be low in African migrants (Grulich, Swerdlow & Marmot, 1992), the presence of colon cancer in this list indicates that dietary habits are likely to be changing to resemble more closely those of the indigenous population. Rates of prostatic cancer are reported to be higher worldwide in populations of black men (Kheirandish & Chinegwundoh, 2011) and it has been suggested that this pattern follows the trans-atlantic slave trade routes between 1450 and 1900 (Odedina, Ogunbiyi & Ukoli, 2006). Evidence of increased rates in black populations comes from west Africa, the Caribbean, the USA and the UK (Kheirandish & Chinegwundoh, 2011). In London, the age-adjusted rates of prostatic cancer have been found to be 647 per 100,000 for African-Caribbeans, 213 for Europeans and 199 for South Asians (Chinegwundoh, Enver, Lee et al., 2006). Other malignancies found to be more common in African migrants to England and Wales include liver (Adelstein & Marmot, 1991), non-Hodgkin's lymphoma, multiple myeloma and (in women) neoplasm of the placenta (Grulich, Swerdlow & Marmot, 1992).

As a result of the high rates of hypertensive disease, diabetes and certain cancers amongst African migrants, the beliefs and behaviours relating to these conditions comprise a major focus of the present study. Despite this, the emerging epidemic of chronic disease is not confined to Africa populations in the UK. For example, South Asians in England and Wales have been found to experience increased mortality from stroke and – in contrast to Africans - coronary disease (Harding et al., 2008). They also develop type II diabetes at an earlier age and more commonly encounter clinical complications (Gholap, Davies, Patel et al., 2011). One reason for this may be related to evidence of significantly increased body mass index amongst the South Asian diaspora compared with those who do not migrate

(Madrigal, Brady, Raxter, et al., 2011). In contrast to African migrants, south Asians in England experience *lower* overall levels of cancer than the white population (Harding & Rosato, 1999). Reasons for this appear to be related to variable risk exposure associated with cultural practices. For example, lower breast cancer rates in Asian women has been found to be explained by differences in age of menarche, childbearing, breastfeeding and alcohol consumption (Gathani, Baalkwill, Green et al., 2014). That is to say, once these factors were controlled for the background risk of breast cancer was found to be the same in Asian and white women in England.

A further dimension of the epidemiological transition is evidence of the impact of socio-economic inequality on mortality within African migrant populations in Europe. The mortality rate from coronary heart disease amongst Africans in Portugal who are in a manual class has been found to be twice that of those in a non-manual class (Harding, Teyhan, Rosato et al., 2008). Similarly, death rates from AIDS amongst African migrants are higher amongst men from manual occupational classes than those from non-manual groups (Williamson, Rosato, Teyhan et al., 2009). This is consistent with a large body of evidence for the social patterning of ethnic differences in chronic disease mortality and morbidity in the UK (Davey-Smith, Chaturvedi, Harding et al., 2000), elsewhere in Europe (Harding, Teyhan, Rosato et al., 2008; Vandenheede, Deboosere, Stirbu et al., 2012) and the USA (Krieger, 2000). Such observations support the notion that social inequalities (Marmot, 2010; Marmot, Stansfield, Patel et al., 1991) and ethnic differences (Nazroo, 2003) have an important influence upon health and illness.

Three overarching explanations have been advanced to account for observed health inequalities between ethnic groups: genetic variation, cultural factors and the impact of differential material disadvantage. The foremost is not considered further in this thesis as there is little evidence for its basis (Nazroo, 1998). The latter two underpin the present study. First, for certain chronic diseases there may be socio-economic factors that lead to reduced disease detection and inferior treatment amongst people of black African origin, for example in prostatic cancer (Kheirandish and Chinegwundoh, 2011). A driver behind such differences is the impact of the wider socio-economic conditions under which migrants live that influence individual behaviour and perceived personal agency (i.e. control) over life choices that impact upon health (Factor, Kawachi, and Williams, 2011). Second, are those culturally distinct beliefs and behaviours that influence exposure to risk factors, for example through diet. These factors affect migrants because health-related

behaviours do not change rapidly upon arrival or follow a linear trajectory as people adapt to the culture of their new country (Jayaweera and Quigley, 2010). Indeed, studies amongst migrants to the UK point to the important influence of migration upon health related beliefs and behaviours and that these continue to influence disease risk as people adapt to the new socio-economic and cultural context of their host country (Bache, Bhui, Dein et al., 2012; Scanlon, Harding, Hunt et al., 2006). Whatever their origin may be, the existence of ethnic health inequalities indicates a need for improved health promotion, screening, prevention and treatment for migrants. As the first point of contact for most health care encounters in the UK, these issues have particular relevance to general practitioners.

## **1.4 The UK National Health Service: challenges of caring for migrant patients in general practice**

Although ethnic inequalities in health exist in the UK, they are considered to be less clear than in the USA (Nazroo, Falaschetti, Pierce et al., 2009). One reason for this is likely to be the increased use of, and accessibility to, primary care in many European countries compared with the USA (Uiters, Deville, Foets et al., 2009). This is consistent with evidence from both national and international studies that the primary care approach is associated with a more equitable distribution of health in populations (Starfield, Shi, and Macinko, 2005). The health care system in the UK is one based upon primary care, specifically general practice. British general practice is a comprehensive and team-based approach to primary care which has its historical roots in the legal recognition in the early eighteenth century of the right of apothecaries to practise clinical medicine. Thus, general practice is a long-accepted “third way” that is distinct from the traditional division of medical professions into physicians and surgeons (Jones, 2006). This generalist approach to medicine is considered to be both an affordable way to provide health care and one that offers distinct advantages to patients, for example comprehensive, personal and longitudinal care (Starfield, 1994). One consequence of these attributes is a phenomenon known as the “paradoxical payoff” of primary care: in contrast to secondary care, the generalist approach leads to improved whole-person and system outcomes despite perceived poorer quality disease-specific care (Stange, 2009). Such benefits are likely to be the result of a health care system that is organised to achieve anticipatory care. That is to say, for general practice in the UK, near universal patient coverage, promoting primary

prevention, absence of user fees, long-term commitment to individual patients and coordination of care (Watt, O'Donnell, and Sridharan, 2011). A wider dimension of this strategy is the role of the primary care team in tackling fragmentation in health services and patient care (Stange, 2009).

The changing patterns of migration mean that an increasing number of GPs who practise in Britain will be asked to provide care for African migrants. This calls for both clinicians and NHS organisations to engage in promoting cultural competence. Cultural competence is an evolving process through which individuals and organisations develop self-awareness, knowledge and the application of skills to create an environment where patients and staff from diverse backgrounds feel safe and valued (McGee and Johnson, 2013). This is important in order to meet the health care needs of members of minority groups and to tackle inequalities in health. Part of this is the provision and proper use of effective strategies for communicating with patients for whom English is not their first language. As greater numbers of migrants to the UK have been arriving from non-Commonwealth African nations, GPs can no longer automatically expect such patients to communicate fluently in English. This situation means that GPs may increasingly need to learn how to use interpreters effectively in order to communicate with African patients and their families.

A further challenge lies in improving access to primary health care for migrants. There is evidence that using such services can prove particularly problematic for asylum seekers and refugees in the UK (O'Donnell, Higgins, Chauhan et al., 2007). This phenomenon was evident in organisational problems associated with the dispersal programme of asylum seekers described in Section 1.1: translocation led to difficulties obtaining registration with medical practitioners and poor continuity of care, particularly for vulnerable patients such as pregnant women and the elderly (Johnson, 2003). Access issues, however, are not solely the product of logistical errors. This is because although African migrants value health highly (Obrist and Buchi, 2008), they may not know how to use UK general practice services in an optimal way. This can be the result of previous experience of health care systems abroad or the fact that migrants may present with health beliefs and expectations of health care that differ significantly not just from the majority white population but also from their own GP. A further issue is that African migrants may look to alternative health care services that are unfamiliar to GPs, for example the use of imported traditional medicines.

Many African migrants have individual health care needs that differ from those of other patients in general practice and which pose particular challenges. First, African migrants experience increased rates of certain infectious conditions, in particular HIV. Whilst important, this issue is not the focus of the present research. Second, African migrants often present with mental health problems as a result physical or psychological trauma experienced as part of their journey coming to this country. Finally, African migrants experience high rates of chronic diseases, in particular hypertension-related ones. This chronic disease epidemic challenge the hospital-based, single-disease framework to which most health care systems, medical research, and medical education are configured (Barnett, Mercer, Norbury et al., 2012). To counter problems such as these, an expanded role for primary care services and community-based interventions has been advocated (Allotey, Riedpath, and Yasin, 2011). This includes ensuring access to appropriate care, effective health promotion, targeted screening and supporting adherence to long-term pharmacological therapy. General practice is ideally positioned for this, with its focus on patient-centredness and continuity of care.

A final challenge to the medical care of African migrants is the paucity of research into their health (Boateng, Nicalaou, Dijkshoom et al., 2012; Vaughn and Holloway, 2009; Warfa, Bhui, Craig et al., 2006). One area where this is lacking relates to the working conditions of GPs who care for migrant patients and how this affects quality of care. This is relevant not only because of the rising number of foreign-born people in the UK, but because the NHS is currently facing a raft of changes. Financial austerity, an ageing population and the emergence of multimorbidity as a common pattern of illness are placing additional burdens upon NHS resources and staff workload. Research into the work patterns of clinicians who care for migrants could have important implications, not only for the training of medical students, GPs and other health care professionals, but also for promoting the wellbeing of newly arrived Africans.

## 1.5 Study aims

The present study set out to use in-depth interviews to examine GPs' and Africans' experiences of conflicting expectations in primary care consultations. During early interviews two additional research areas emerged that are included below as Aims two and three:

1. To explore discordant expectations in consultations between GPs and migrant patients and the consequences of these.
2. To explore beliefs and experiences in these two groups about the use of traditional medicines in the UK
3. To understand the explanatory models of illness used by Africans, with particular reference to chronic physical disease.

## 1.6 Study objectives

The objectives of the study arose from discussions with colleagues and leaders of African community groups in Glasgow. These conversations led to the original focus of this work, namely an exploration of the discordant expectations in consultations between migrants and GPs, especially with reference to Africans. At the outset the objectives included an examination of the effect of conflicting expectations on GPs, in particular where these might pose professional dilemmas or other effects upon doctors. As reported above, during early interviews two additional issues emerged as important areas. The first of these was the unexpected revelation that many participants were using traditional medicines within the UK. Second, the low awareness of chronic disease risk uncovered during early interviews with Africans led to a more focused examination of the explanatory models for major non-communicable physical diseases. Thus, the objectives of this study were the following:

1. To explore how discordant expectations are perceived, negotiated and managed by GPs and Africans, with particular reference to requests for antibiotic prescription
2. To describe Africans' formal and informal action taken when their expectations of general practice were not met, in particular seeking alternative services
3. To identify professional dilemmas reported by GPs working with migrants
4. To explore traditional medicines use by Africans in the UK and reasons for this
5. To describe Africans' and GPs' reported beliefs as to which diseases represent the greatest threat to the African community
6. To describe Africans' explanatory models of major chronic physical diseases

This study intentionally set out *not* to examine experience of serious mental health problems amongst African participants. This is because many asylum seekers and refugees have encountered trauma, family separation and torture during their journey to Europe (Burnett and Peel, 2001a; Burnett and Peel, 2001b). It was, therefore, felt inappropriate to risk upsetting participants by eliciting traumatic accounts during interviews<sup>7</sup>.

## 1.7 Literature search strategy

An extensive corpus of research literature exists in the three areas that form the context of the present study. Presenting all these bodies of literature in their entirety within this thesis would be impossible. As a result, the critique of the literature presented here is not a systematic review of these topics and does not conform to the full standards of formal methods for reporting systematic reviews, such as the PRISMA Statement (Liberati, Altman, Tetzlaff, et al 2009) or other similar guidance. Where the use of such guidelines is requested by medical journals there is evidence of increased quality of methodology and reporting (Panic, Leoncini, de Belivis, et al 2013). Nevertheless, the PRISMA Statement

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<sup>7</sup> The application for ethical approval stated: "It is possible that participants may feel uncomfortable discussing certain issues that may arise during interviews. Clinical topics that might elicit discomfort in interviews include sexual health, mental health and torture. In the present study no requests for information in these areas will be made... potentially stressful issues will therefore not be sought specifically"



is currently endorsed by less than half of major medical journals (Panic et al 2013, Tao, Li, Zhou et al., 2011). A further challenge was that the focus of qualitative research typically emerges during the study (i.e. from the interviews) and it is necessary to undertake the literature search after data collection is completed.

For these reasons, literature was searched for in a targeted but structured fashion in the following fields that comprise the areas where the present research contributes new knowledge:

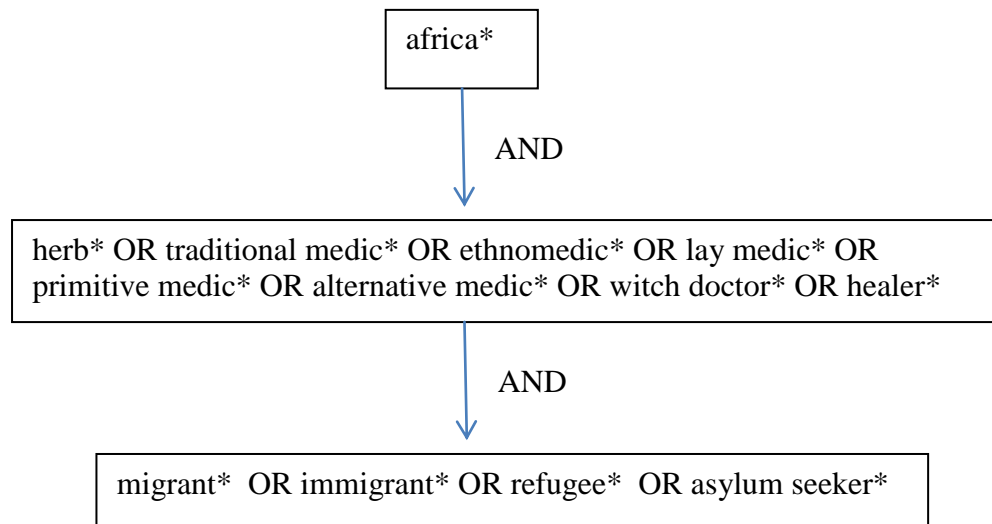
1. The use by migrant and minority ethnic groups of, and satisfaction with, health care in the UK and other western nations.
2. Traditional medicine beliefs and practices of African migrants
3. Explanatory models of chronic physical disease amongst Africans and African migrants

Identifying relevant data for area one above proved particularly challenging and the approach undertaken is discussed in Chapter Three where this aspect is presented. The main approach to identifying literature for areas two and three was through structured searches using the following databases: Pubmed, Embase, International Bibliography of the Social Sciences and Web of Science. Studies of traditional medicine use by African migrants were also sought from The Allied and Complementary Medicine Database (AMED). The choice of these databases arose from consultation with research colleagues and a professional librarian. In addition, literature was identified using Google's generic search engine that draws upon its academic tool 'Google Scholar'. Studies were searched from 1980 onwards and limited to publications in English. The literature reviews presented here were complemented by resources suggested by colleagues and study supervisors. Additional evidence was identified by reading references contained within identified papers and by reviewing related citations suggested by databases.

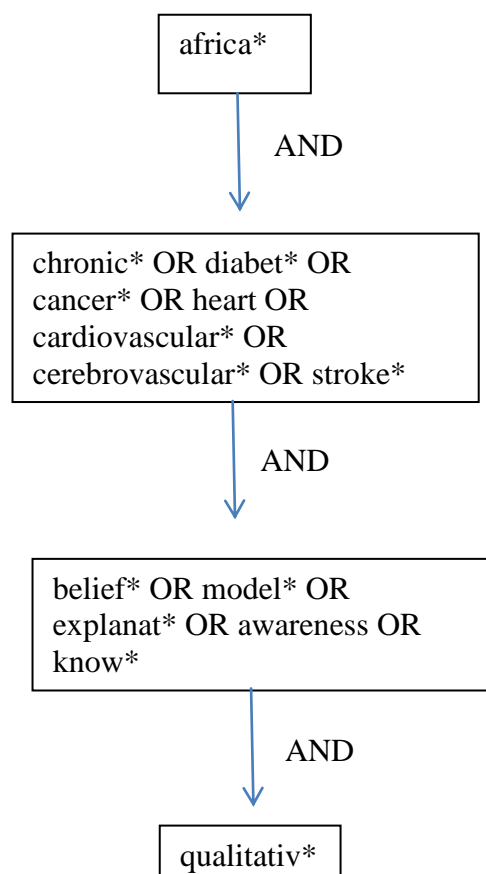
The literature search strategies undertaken between May and July 2013 are outlined below in Figures One and Two. In each case the search term “Africa” was modified to names of individual countries in order to identify data relating to the regions of origin of the majority of participants in this study, namely eastern African nations and the Democratic Republic of the Congo (DRC). It should be noted, however, that even this approach may fail to detect sources of information due to the fact that country and city names or spelling have changed since independence; for example, prior to 1997 the DRC was known as Zaire.

During the search process it was necessary to adapt the strategy in order to conform to the input style of individual databases. For example, the Allied and Complementary Medicine Database already has a preset category entitled “traditional medicine African”. As a result, the searches outlined below illustrate the broad way in which evidence was sought from databases. Throughout the search process, words were reduced to their stems and the ending replaced with an asterix. This was in order to identify multiple string forms, for example the term “ethnomedic\*” would capture related words such as ethnomedicine and ethnomedical.

**Figure 1. Literature search strategy for traditional medicine beliefs and practices of Africans and African migrants**



**Figure 2. Literature search strategy for explanatory models of chronic disease amongst Africans and African migrants**



Identified papers were reviewed by title and abstract in order to exclude sources that had little direct relevance to the present study. One way through which this search was narrowed was by targeting data directly relating to *first generation* sub-Saharan Africans in Britain and other developed nations. This is because traditional African beliefs are believed to be less relevant to second generation migrants, whose adolescence – a key period during which behaviour patterns are formed – is spent in the UK (Higginbottom, 2000). One challenge to identifying relevant sources was that in the UK sub-Saharan Africans are sometimes categorised within the term ‘black African’. Whilst these ethnic categories are official terms and widely used in UK studies as well as in the 2011 national census, such categorisation can conceal significant heterogeneity and possess ‘fuzzy’ boundaries (Aspinall and Chinouya, 2008). This meant that in some cases it was not possible to identify first generation migrants as participants in studies that considered “black African” people in the UK. Similar challenges arose with African-Americans. This is important because most published evidence about the health beliefs of black people comes from studies on African-Americans (Vaughn and Holloway, 2009). Despite this, it is recognised that it may not be possible to identify migrant Africans as participants in studies of African-Americans (Thomas, 2008). Given that most African-Americans have family roots in the USA or Canada that extend back for many generations and their communities have developed their own cultures that are distinct from continental African ones, such studies are only considered here where they clearly include first generation African migrants or offer knowledge into areas where evidence relating to direct African migrants was lacking.

Through the search process described above, 15 qualitative studies of explanatory models of chronic diseases were identified from Africa and five amongst African migrants to western countries. Thirteen studies of the use of traditional medicines by African migrants were identified. These are all presented in Chapter Four. Before considering this, it is necessary to consider the theoretical perspectives that underpin the present thesis and to examine Africans’ use of health care services.

# Theoretical approach

## **2) Theoretical approaches to the present study**

Theory is a conceptual way of looking at the world and provides a lens to examine and interpret research findings. Thus, theory may be considered to be a set of assumptions or concepts against which empirical research can be tested. Theory provides a generalisable framework that can be applied across individuals and/or settings, allowing findings to be built upon existing knowledge and to lead to identification of areas that should comprise future research agendas (Eccles, Armstrong, Baker et al., 2009). Beyond this, findings from studies can lead to refinement of underlying theories or greater understanding of their application in a specific context.

The present study considers the health beliefs and practices of African migrants in the context of British general practice. Two theoretical approaches form the basis of this thesis. These belong to different schools of thought, namely health psychology and organisational sociology. As a result, they offer divergent perspectives on the complex issues considered in this thesis such as illness beliefs, treatment behaviours and use of health care. First, is one way of examining and interpreting people's health beliefs that was advanced by the American psychiatrist and anthropologist Arthur Kleinman. In this thesis, Kleinman's (1978) explanatory models of illness are considered within his wider notion of cultural health care systems. Second, is an approach to understanding the working patterns of staff within public sector services developed by the American political scientist Michael Lipsky, known as street-level bureaucracy (Lipsky, 2010).

### **2.1 Health beliefs: Kleinman's explanatory models of illness**

It is recognised that lay people of all backgrounds hold powerful beliefs to account for the origin of illnesses that they encounter in their everyday life (Gabe, Bury, and Elston, 2004). These lay beliefs affect illness behaviour (Greenhalgh, Helman, and Chowdhury, 1998) and are employed in encounters with health care professionals (Howitt and Armstrong, 1999; Pavlish, Noor, and Brandt, 2010). Nevertheless, health beliefs are more than just a simple antecedent to an individual's choice of health-seeking behaviour whenever he or she is ill. They embrace people's wider understanding of what constitutes illness and health and the prevention of disease (Blaxter, 1990; Herzlich, 1973). A further dimension is that salutogenic (health-promoting) beliefs influence people's behaviour and

thus provide an opportunity for health promotion - for example, by encouraging the adoption of preventive lifestyles.

Lay health beliefs should not be considered to be simplistic models. This is because they are known to be complex (Williams and Calnan, 1996), deep-rooted (Currer, 1986) and dynamic (Helman, 2007). Despite being responsive to personal circumstances such as emotional states (Lupton, 1994), lay health beliefs may be surprisingly resistant to change (Helman, 1978). Clearly, this situation poses a challenge to both clinicians and public health practitioners who seek to reduce the risks that people face as a result of their decisions about health care and lifestyle choice. A further challenge to researchers is that the specific origins of an individual's health beliefs are often difficult to discern (McAllister and Farquhar, 1992) and, indeed, people may be unaware of the reasons for their health behaviours (Cornwell, 1984). Nevertheless, certain factors are believed to shape health beliefs. For example, it is recognised that children pass through key stages in their understanding of disease aetiology, starting with simple contagion theory and later incorporating more complex causes, such as physiological processes and moral transgression (Bibace and Walsh, 1980; Marks, Murray, Evans et al., 2008; Piaget, 1930). A further influence is the wider cultural context in which people grow up and live (Helman, 2007). It is essential for clinicians and researchers to consider the cultural context in which people form their beliefs so as to ensure that treatment and health promotion messages are provided in a form that is appropriate for the particular patient and population. These challenges are likely to be greater for groups of people whose culture, religion and language differ considerably from those of the majority of citizens. This is indeed the case for Africans in the present study as they belonged to societies with beliefs and traditions that are substantially different from those of the majority white population in Britain.

A further influence on people's lay health beliefs is their interactions with formal health care systems and the explanations that they receive from health professionals; that is to say, the accepted biomedical<sup>8</sup> perspective (Shaw and Woodward, 2004). This is important because the clinician is as much a product of his/her culture and education as his/her patient. Indeed, some people question whether lay and professional health beliefs actually constitute distinctive entities (Davison, Davey Smith, and Frankel, 1991; Shaw, 2002).

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<sup>8</sup> The term biomedicine is used to refer to science-based treatment in the western medical tradition. In this thesis the adjectives biomedical and western are taken to be synonymous, even though this approach is now a global phenomenon

Others, however, emphasise that lay beliefs must not be considered simply to be watered-down versions of the biomedical model (Schultz Kleine and Hughner, 1999). For the researcher, this situation may be clouded by the fact that lay people often employ biomedical terminology within their ideas about health (Blaxter, 1990; Helman, 1978). What is more, it has also been noted from research in London's East End that people construct their health beliefs in separate 'public' and 'private' versions, where the latter is more complex and constructed at multiple levels (Cornwell, 1984). Given that the health beliefs reported by an individual depend upon the person to whom they are speaking (Helman, 2007), the researcher is confronted with the additional challenge of trying to discern true beliefs from those that are presented because they are considered socially acceptable (Lupton, 1994). It is likely that such issues are important in the context of the present study, where the principal researcher belonged to different ethnic, religious and linguistic categories from many of the participants.

Although people are often aware of official messages about risk factors for disease, the dominant influence on their beliefs often lies in personal observation of others with the particular condition (Davison, Davey Smith, and Frankel, 1991). For example, people ascribe particular value to the unwarranted survival of seemingly obvious "candidates" for a particular disease, as well as the anomalous death of unlikely sufferers (McConnachie, Hunt, Emslie et al., 2001). This situation illustrates the influence upon people's health beliefs of first-hand, lived experience of illness and suggests that individuals may even fail to recognise their personal risk of disease. Clearly, this scenario poses practical challenges to health promotion. A further dimension to this is the fatalistic beliefs about illness that lead some people not only to ignore health promotion and their own risk factors, but to indulge in higher risk behaviour. This situation arises because health beliefs and behaviours often have their own complex and hidden logic. Even unhealthy beliefs and behaviours, such as smoking, may therefore make sense when considered within their social context (Lawlor, Frankel, Shaw et al., 2003). In this example, smoking can represent for some individuals a practical means of coping with lack of control over social and economic problems, such as unemployment and emotional isolation (De Vogli and Santinello, 2005). Identifying the complex experiences and beliefs that underlie risk-taking behaviour represents a significant challenge to researchers and, again, particularly so where they belong to different cultural groups or social classes from their study participants.



One theoretical approach to examining and interpreting the complex and multi-layered nature of peoples' health beliefs is Kleinman's explanatory models of illnesses (Kleinman, 1978; Kleinman, 1988; Kleinman and Benson, 2006). Explanatory models seek to capture the powerful meaning and symbolism that people use to interpret states of illness and the working of the body. They have been defined as the "notions about an episode of sickness and its treatment" that are employed by people engaged in the clinical process, that is to say including health care professionals (Helman, 2007). This approach is an anthropological one founded upon the notion that health care interactions are part of culturally constructed medical systems, where the biomedical viewpoint is considered to be but one of many competing perspectives upon illness and treatment. In order to elicit people's explanatory models, Kleinman advocates putting the following questions to patients or study participants (Kleinman, 1978) modified and cited by Kirmayer and Bhugra (2009):

1. What do you call your problem?
2. What causes your problem?
3. Why do you think it started when it did?
4. How does it work?
5. What is going on in your body?
6. What kind of treatment do you think would be best for this problem?
7. How has this problem affected your life?
8. What frightens or concerns you most about this problem or treatment?

Kleinman's explanatory models approach was selected for the present study for the following reasons. First, it is recognised that it leads to rich qualitative data, including accounts of social, cultural and ritual symbolism (Bhui and Bhugra, 2002). This was considered important in the context of African migrants, whose beliefs and behaviours arise from deep-rooted cultural and religious traditions. This was particularly relevant to one aspect of the present study, namely the cultural beliefs and behaviours associated with the use of traditional African medicines. Second, was Kleinman's open-minded approach to people's beliefs, which are explored from the participant's own perspective and without predetermined assumptions. In this way, the explanatory models approach is entirely a pluralist one, eliciting what the meaning of illness and treatment is to a specific individual and accepting non-biomedical causes of illness (including supernatural ones) that may appear unreal or inconsistent to an outsider. This was considered important in a study that included African participants, for whom supernatural forces are a widely reported

explanation of illness causation (Murdock, 1980). Third, the model was chosen for its flexibility, in particular because it can be extended to include the examination of people other than just the patient and clinician. This was important because most African participants in this study were healthy and their beliefs about the causes, nature and consequences of common chronic diseases were expected to be tentative. Such uncertainty and inconsistency are a recognised aspect of peoples' beliefs about chronic disease, as a result of the unpredictable course of the illness, its unlimited duration, the existence of alternating periods of crisis and remission, and – at times – its asymptomatic nature (Scandlyn, 2000).

Finally, the explanatory models approach was chosen because it goes hand-in-hand with calls to improve the quality of clinical care for minority ethnic groups. That claim is based upon Kleinman's belief that it can promote the cultural competence of clinicians, in particular the communication skills necessary to explore unfamiliar explanatory models and to elicit what is really at stake for patients in the lived experience of their illness (Kleinman and Benson, 2006). He supports this belief with evidence that where the explanatory models of patient, family and clinician are similar, there exists improved care on multiple levels, including communication, adherence to treatment and satisfaction (Kleinman, 1978). As one area of the present study is to consider people's explanatory models of chronic disease, a further benefit of Kleinman's approach is that it offers insight into people's beliefs about long-term medication adherence. Adherence is important because, in the pursuit of health, patients are likely act upon their own explanatory model which may lead to expectation of therapeutic interventions that are inconsistent or even incompatible with a biomedical model. Discordant explanatory models of chronic disease may lead to worse clinical outcomes (for example, in hypertension control (Heurtin-Roberts and Reisin, 1992)) and to harmful interactions between prescribed and informal medication (Bhui and Bhugra, 2003),

It should be noted that the present study examines the explanatory models of illness of individuals rather than a specific society or population. That is possible because people's explanatory models remain distinct from the general beliefs about illness causation that are held by their wider society (Helman, 2007). Nevertheless, individuals' explanatory models remain deeply rooted in their own cultural and socio-economic context. The present study endeavoured to consider individuals' beliefs within the context of their personal backgrounds and present circumstances.

### **2.1.1 Kleinman's concept of cultural health care systems**

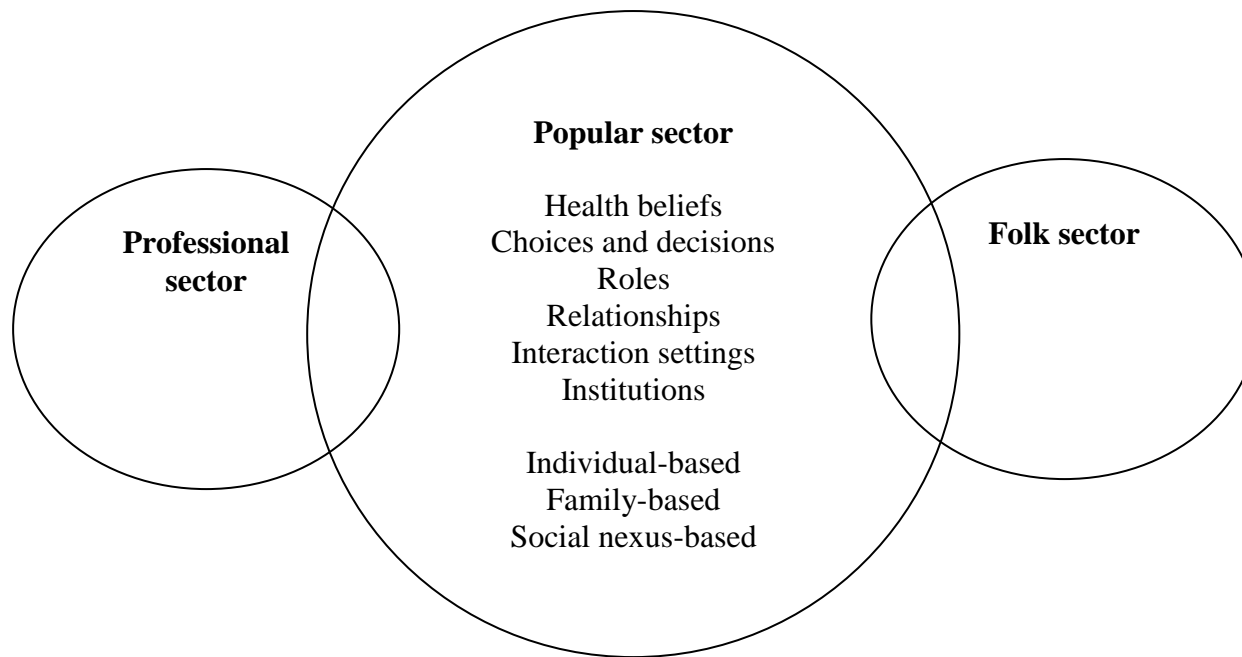
Every medical system is a product of the culture, social space and geographical location where it operates. This means that illness and healing should not be interpreted solely in terms of the experience of symptoms or the interaction between a patient and a therapist. Illness and therapy, instead, need to be viewed in a dynamic way that incorporates socio-cultural influences upon individuals' health behaviour and the diverse range of treatments and healers available. Within any specific cultural context, these treatments and therapists are likely to be imbued with their own social or symbolic value. What is more, the medications and healers available may arise from contradictory medical systems - for example, traditional and biomedical ones. One way to interpret this diverse situation is through Kleinman's (1978) notion of cultural health care systems<sup>9</sup>. This is illustrated overleaf in Figure Three.

Kleinman's model provides additional theoretical insight by considering the local variation in the way in which a given cultural health care system functions. His dynamic model offers broad insight into the diverse range of treatments and therapists that are available in a given geographical area. These factors are considered within their specific cultural context. This is important because behind health beliefs and behaviours lie complex meanings and social norms that relate to the people and products involved (Kleinman, 1978). In this model, the sectors of health care are understood in terms of overlapping, professional, folk and popular domains. It should be noted that people's health beliefs form a key part of this model, namely within in the popular sector.

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<sup>9</sup> In this thesis the term "*cultural* health care system(s)" is used to distinguish this theoretical model from governmental or private health care systems such as the National Health Service

**Figure 3. Health care system: internal structure. Modified from Kleinman (1978). Points of interaction, entrance and exit exist where sectors meet**



### ***2.1.2 Discounted approaches to health beliefs***

Certain other theoretical frameworks were considered during the present study but not adopted. These are now examined briefly. These included those theories that employed social cognition models, for example the Health Beliefs Model (HBM). Certain aspects of the HBM formed a part of the present interview schedule with Africans - for example, enquiring about participants' "perceived susceptibility" to individual chronic diseases (Rosenstock, Strecher, and Becker, 1988). Nevertheless, the HBM was not chosen for the present study because its focused approach was not consistent with the exploratory nature of the interviews. As reported earlier, it was expected that many healthy African participants in the present study may only possess superficial knowledge of the chronic diseases that were being considered. It was, therefore, thought unlikely that findings could be used to construct a full HBM model of the participants' attitudes and beliefs. In addition, the social cognition models focus upon the ways in which people make decisions in the context of health behaviour. Such an approach fails to consider the origins of people's beliefs about disease aetiology, instead focusing upon perceptions of more global notions of risk and probability. This is particularly important in the context of African migrants whose explanatory models of disease may be complex and cannot be assumed to be close to those of a western researcher. There was, therefore, a need to consider in greater depth the cultural perspective to participants' explanatory models in order to gain a better understanding of the beliefs and intentions behind participants' behaviours.

Second, the theoretical perspective of acculturation was considered, but not adopted in a quantitative or qualitative form. This is because measuring and explaining acculturation is often conducted using scales (Abraido-Lanza, Armbrister, Florez et al., 2006). Some of these have been validated for individual minority populations, such as African-Americans and Hispanics in the USA (Klonoff and Landrine, 2000; Landrine and Klonoff, 1994). Nevertheless, they may not be suitable for use with more diverse groups such as refugees (Gerritsen, Bramsen, Deville et al., 2004) or Africans coming from a range of different countries. No validated acculturation scale specifically for African immigrants could be identified in this literature review (McCarty, 2005). Quite apart from this, validating such a tool was beyond the scope of the present research.

A further dimension of migrants' health beliefs is the way in which these these impact upon health care consultations. In order to consider this a separate theoretical approach was selected that focused upon organisational systems. This theory, street-level bureaucracy, was adopted in order to consider the wider issues of time, resources and working patterns of health care workers who cared for migrants.

## **2.2 Migrant interactions with health care: street-level bureaucracy theory**

This theory was first espoused by Michael Lipsky in an article in 1971 (Lipsky, 1971) and later in (the two editions of) his landmark book "Street-level bureaucracy: dilemmas of the individual in public services" (Lipsky, 2010). Lipsky's work focused on public sector workers in the USA, in particular those working in the police and judiciary, prison service and social services. Later studies, including some from the UK and Africa, have explored the applicability of street-level bureaucracy to health care. This section of the thesis presents the basis of this theory and then considers its applicability to UK general practice.

Lipsky's theory is based upon the following three assumptions. First, the exercise of extensive personal discretion is a critical dimension of the work of many public sector employees. Specifically, those who possess significant autonomy are workers with roles that involve direct interaction (providing information, negotiation, and seeking agreement) with clients<sup>10</sup>. Second, in public services demand from clients will always outstrip supply. Such limited resources may be financial or consist of access to services or time spent with employees. One consequence of this is that employees must practise "mass processing" of clients. Lipsky (2010) states that one reason why street-level bureaucrats must do this is because in public service clients are 'non-voluntary': that is, most citizens cannot obtain essential services elsewhere - for example, by seeking private alternatives to state organisations. Finally, that as a consequence of limited resources such employees will typically be unable to perform their role to the highest standard possible. Thus, employees of public sector service organisations must "labor [sic] [against] huge caseloads, ambiguous agency goals, and inadequate resources" (Lipsky, 2010). As a result of excessive workload and uncertainty, the pragmatic decisions made by workers who must use their own personal discretion over resource distribution on a case-by-case basis

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<sup>10</sup> In this thesis the term "clients" is used to describe users of public service organisations.

ultimately becomes the *de facto* policy of the organisation. As a result, the “bottom-up” perspective of front-line workers can be considered to subvert the top-down discourse in policy formulation (Moyo, 2010). The ambiguous and complex nature of public service work is illustrated in the following assertion:

*“Street-level bureaucracies are the coal mines of welfare where the “hard, dirty and dangerous work of the state” is done” (Bovens, 2006).*

Street-level bureaucrats are faced with conditions of limited resources at various levels: time constraints, large case loads, bureaucratic tasks such as “form-filling” that restrict time with clients and limited information about cases. Nevertheless, employees must process their workload quickly and efficiently. As a result of “a great reservoir of [unmet] demand”, Lipsky (2010) questioned whether even substantial expansion of personnel budgets could ever decrease workload pressures. Instead, he predicted that increased capacity would result in on-going expansion of the same level of service quality at a higher volume. Workers are, thus, deemed to be trapped in a “cycle of mediocrity” (Lipsky, 2010). Another consequence of the pressures facing public sector workers is that they may be forced to “deny the basic humanity” of clients because they are unable to offer all services to every individual. This is likely to have implications for employee motivation and burnout, an area that remains poorly studied through the application of street-level bureaucracy theory to UK general practice.

Lipsky (2010) notes that employees of public organisations are faced with ambiguous and conflicting aims and targets in fulfilling their work. This is because job performance and outcomes are hard to measure, embrace multiple variables and fail to recognise the complex nature of the tasks and the different people involved in implementing policy. The overarching mission or aims of some organisations may be idealised and impracticable. This, coupled with the relative autonomy of the individuals involved, renders it difficult for managers to know whether individual workers are fulfilling tasks adequately and in accordance with formal policy. As a result, employee behaviour within organisations tends to “drift towards” actions that comply with the chosen methods employed to evaluate performance. For example, this might consist of closing a set proportion of cases within a specific time-frame. In this situation, workers could be driven towards ensuring that the maximum number of uncomplicated cases are opened in order to optimise the rate at which they are subsequently closed. Ultimately, it may become virtually impossible to achieve accountability amongst front-line workers and attempts to do so can prove not just

ineffective but inadvertently lead to an erosion of service quality.

In this environment, one consequence of exercising personal discretion over the use of limited resources by street-level bureaucrats is the evolution of personal working patterns to cope with the competing priorities of their job. In this way, street-level bureaucrats can be envisaged as “inventive strategists” who find innovative solutions to ambiguous and complex work settings (Moore, 1987). Such strategies arise from both workload volume and the fact that client encounters normally take place away from direct scrutiny by others, for example line managers or the general public (Bovens, 2006). Examining such rule-bending that may become established as “silenced norms” clearly poses challenges to the researcher (Maynard-Moody and Musheno, 2003), particularly in the context of professionals such as GPs. These work patterns seek to make tasks less complex and more effective at obtaining client co-operation with the service’s procedures for mass-processing of cases. Gaining client cooperation is considered essential in a street-level bureaucracy not only to facilitate the processing of cases but also to prevent front-line employees adopting coping strategies that degrade into a process of “labeling [of clients] and rudeness...[that] prompt a cycle of negative behaviours and attitudes” (Bovens and Zouridis, 2002).

Client compliance with work patterns may be enforced in many ways. First, through interacting with clients in settings that symbolise, reinforce and limit the client’s inferior status. Examples cited by Lipsky (2010) include imposing information desks, offices that lack privacy and uncomfortable seats. Second, by restricting resource provision to individual clients as part of a process of rationing. This may be implemented through monetary barriers, enforced queuing, and limiting the provision of information to clients. Lipsky notes that a key component to controlling clients and the work situation is founded upon the requirement for clients to attend the office workspace *in person* in order to gain access to services. This may be seen in the context of asylum seekers in the UK where they must routinely attend in person to receive support from social services and legal aid.

Finally, Lipsky (2010) specifically states that one *inevitable* consequence of a street-level bureaucracy is inequality in service delivery: that is to say, that resources must ultimately be allocated differentially between categories of clients. To illustrate this, Lipsky specifically points to the triaging of casualties by emergency medical services as one example. In other public services, factors that may determine differential treatment between clients include age, socio-economic status and characteristics such as being



pregnant or having young children. A further factor leads to differential treatment of clients: decision-making undertaken by street-level bureaucrats is considered to be highly influenced by the likelihood of an individual client's situation being "redeemable", that is likely to result in an outcome consistent with the aims of the organisation. As a result of such practices, workers may operate a system of "streaming" and "creaming [off]" those clients who are most likely to have a positive outcome (Lipsky, 2010).

Lipsky also notes that as workers develop routines and stereotypes in order to achieve their tasks they adopt psychological perspectives that rationalise those work patterns and beliefs about clients. One example cited of how this can affect practice is the following: workers who are expected to close a certain number of cases (and thus open time-consuming new ones) may be slow to chase up the required documentation or appointments and attribute such delays to the fact that low-income clients are disorganised or struggle with the English language. Such behaviour may arise from wider societal attitudes towards certain categories of people or their behaviour. Therein clearly lies potential for abuse. This is because street-level bureaucrats are typically required to make decisions on the spot, in private and without access to all the required information. In interactions there is significant imbalance in power: clients are largely deferent to street-level bureaucrats who retain control over access to services and resources. This power may be manipulated and abused in practical ways - for example, by limiting access to referral services as part of managing excess caseloads.

An important dimension to differential decision-making is that the clients with whom street-level bureaucrats interact are typically not members of their own racial or socio-economic group. Lipsky describes this as not belonging to workers' "primary reference group". What is more, he notes, client groups are often detached from the formal procedure by which the processes and targets of public services are set. Indeed, in the USA, bodies that represent typical street-level workers (e.g. police and teachers) are considered to resist lay or client representation in this process, presumably because they may lack understanding of the complex nature of the employees' tasks. This scenario clearly highlights a major divide between worker and client, something Lipsky describes as part of wider "social cleavage". Rightly or wrongly, street-level bureaucrats may thus be vulnerable to accusations of bias against a particular ethnic group, towards whom they may be perceived to act in an unfair or cynical way. Indeed, the very function of street-level bureaucracies may be construed as one that serves to maintain established divisions and

prejudices in society.

### ***2.2.1 Client advocacy in street-level bureaucracies***

One important component of street-level bureaucracy is the notion of “client advocacy”. Lipsky (2010) suggests that street-level bureaucrats are often motivated by helping others and he defines such advocacy as workers’ using “their knowledge, skill, and position to secure for clients the best treatment ... consistent with the constraints of the service”. Nevertheless, two overarching tensions may result from a worker’s concern for an individual client. First, client advocacy can directly conflict with the need for efficiency and the mass processing of cases. As such, on the front-line, “every minute devoted to one client means less time for others” (Lipsky, 2010). Thus, street-level bureaucrats are driven to question whether it is profitable to expend additional time and resources seeking information about any single individual or their personal situation. Second, concern for an individual may also conflict with the overarching “social engineering” aims of an organisation. Similarly, special treatment for an individual may run counter to organisational policy which specifically seeks to treat all clients equally.

As a result of such tensions, Lipsky notes that workers do not claim to fulfil their role perfectly but, instead, endeavour to express altruism by “doing good” in some way. Lipsky (2010) notes other important consequences. First, in an attempt to fulfil the “myth of altruism”, workers tend to “devote a relatively high proportion of energies to concealing lack of service and generating appearances of responsiveness”. Second, job dissatisfaction may lead to absenteeism, low morale and poor performance amongst workers. Lipsky notes that street-level bureaucrats are likely to “drop out or burn out relatively early in their careers”. This tends to occur in those who fail to combine client care with mass-processing by finding “an acceptable balance between public aspirations for the work and the coping requirements of the job”.

Despite emphasis within organisations on respecting the autonomy of clients as individuals, Lipsky notes that there is a paucity of training to prepare such employees to manage problematic practical issues, such as large case loads. He states that education tends to focus on ethics and interview technique, instead of training in “real world” coping strategies. This may be interpreted as a desire to underscore the ethical principles that are enshrined in the professional training and core values of lawyers, doctors, teachers and

others. There clearly lies conflict between these overarching principles and the pragmatic ways in which front-line staff must process cases in order to undertake their work. This discrepancy is a particular challenge for workers (like doctors) whose performance is regularly reviewed by a national professional regulatory body. Ethical principles and professional values may not be so prominent in the training of lower level workers who lack formal representation or higher status in society.

### **2.2.2 Health care and street-level bureaucracy theory**

Lipsky (2010) considers street-level bureaucracy theory to be applicable to a wide range of public sector workers, including teachers, social workers, police officers, judges, public lawyers, welfare workers and, on occasions, health workers. Lipsky may not have considered in greater depth the notion of “doctor as street-level bureaucrat” because clinical interactions not only occur behind closed doors but access to their documentation is highly privileged. Furthermore, his theory examines public service workers in the USA where much medicine is practised according to the private model. A further reason for his limited examination of the medical profession is that Lipsky describes street-level bureaucrats as sometimes being “low-level” employees and yet still retaining significant autonomy over certain aspects of clients’ cases. Thus, he may have excluded doctors from parts of his theses as he wished to focus upon the effect on policy of large numbers of “low-level” employees. Nevertheless, soon after the emergence of Lipsky’s book, it was advocated that his theoretical framework should be applied more widely in order to understand the dilemmas faced by medical doctors:

*'A danger with the Lipsky volume is that health specialists will construe it narrowly. On the surface, the book may seem to apply only to large scale public organizations with salaried staffs, such as the Veterans Administration hospital system... [but] the conditions defining street-level bureaucracies may be far more applicable to health programs than at first meets the eye' (Thompson, 1983)*

Indeed, a number of authors has since considered street-level bureaucracy in the context of health care. First, urban public hospitals in the USA have been considered to possess many of the defining characteristics of Lipsky's street-level bureaucracy. In particular, in one interview study, employees working in a range of hospital roles described their jobs in terms of the following criteria that conform to the theory of street-level bureaucracy (Johnson and Thomas, 1991):

- Clients are from low-income backgrounds and essentially “non-voluntary” (i.e. no alternative options for service access elsewhere)
- Funding tends to be inadequate
- Client demand often exceeds institutional capacity
- Hospital staff are asked to meet conflicting goals of providing quality care but at cut-rate costs

Whilst workers in this study of urban public hospitals were faced with many of the pressures of a street-level bureaucracy, the authors concluded that a key deviation from the model lay in the area of satisfaction of the workers: contrary to street-level bureaucracy theory these professionals were “largely satisfied” with their work (Johnson and Thomas, 1991). Participant concern was, instead, directed at constraints on their role and at certain parts of society which expressed disdain for their work.

Some of these findings corroborate research from a second study that was undertaken in South Africa using quantitative questionnaires and in-depth interviews with nurses (Walker and Gilson, 2004). That study found that nurses were “bitter” but “satisfied” in their role. Satisfaction arose from commitment to their profession and to the community that they served, despite a workload that could lead to stress and a need to compromise aspects of patient care. Behind this was concern that free access to health care had led to patients’ presenting inappropriately for treatment, such that one nurse stated that “they are fooling the clinics: most of them [patients] should not worry to come”. One effect of additional workload associated with free access was reported to be burnout in nurses: in particular, 56% and 21% of participants reported respectively that this was either a very important or important consequence of their working environment. One participant suggested not only that the role of a nurse could be dehumanising but that burnout led to nurses seeking work elsewhere:

*“It would be so nice if nurses were recognised as human beings: if nurses were also given their rights. They are not meeting our needs. They think we are greedy, but if you compare with other civil servants, especially the MPs, their salaries are nice and comfortable. We are working, trying to maintain a good standard of health but at the end of the day nobody recognises it. It is hurting, that is why you see nurses are so burnt out, and leaving, the best thing for them is just to go outside [i.e. work elsewhere]” (Walker and Gilson, 2004)*

Finally, another study from South Africa was identified that considered street-level bureaucracy in the context of migrant health care. It used interviews, focus groups and participant/non-participant observation to explore the nature of the interaction between migrant and health care providers with a view to assessing how this impacts upon

migrants' access to health care (Moyo, 2010). The author begins by highlighting broader issues facing those migrants who must interact with a street-level bureaucracy. First, that the existence of migrants in society renders the notion of the "public" into what he calls a "contested space". Second, the vulnerable status of migrants means that their relationship with employees is one that is likely to be asymmetric. That is to say, migrants tend to have limited choices and reduced influence in interactions with street-level bureaucrats. One example of this phenomenon in clinical practice was reported to be where a migrant patient was told that they could not receive an xray examination because that service was reserved for South African citizens (Human Rights Watch, 2009). Although Moyo's study did not directly observe such diversity in the delivery of clinical care, it was reported to occur during registration of patients:

*"Patients often produce documents without the frontline staff asking, and sometimes the frontline health care provider asks for the documents though they are not a requisite for access to primary health care" (Moyo, 2010, p68)*

That rules were flexible was illustrated by a case where reception staff were supposed to alert the police about a suspicious form of identification but ultimately chose not to do so. The reason for this was suggested to be self-serving, namely a desire not to expend considerable time acting as a witness at court. Nurses were reported to treat migrant patients in a perjorative way but appeared to be aware that this was inappropriate behaviour and were keen not to be reported to management:

*Participant 1: When I got there, they [receptionists] were complaining about the fact that I had been assisted at the MSF [Médecins Sans Frontière clinic]. They spoke in Zulu and thought I couldn't hear. They were talking about an incident that had happened the previous day involving a man from Zimbabwe who had threatened to get the nurses arrested for ill treating his wife.*

*Interviewer: Did that influence the way they treated you?*

*Participant 1: I think that is what they always do to Zimbabweans because they always complain when handling foreigners*

*Participant 2: When I was at the hospital there was a lady from Nigeria who had been there for three days and the nurses were saying she should go and give birth in Nigeria. They were busy complaining while the lady was in pain.*

*Participant 3: If they hear that your husband has come to see you they begin to speak to you well. They change the way they speak to you.*

*Interviewer: Why?*

*Participant 3: They fear that the husband might go and report to management and get them into trouble. When he is gone they start again (Moyo, 2010) p88-89*

The incident of the Zimbabwean man who had threatened clinical staff with legal action on the previous day was reported to reveal transference by the nurses of aggression towards other members of the same vulnerable patient group, in this case according to nationality.

Indeed, the author describes one case where a patient was apparently assaulted by a member of staff. One reason for such behaviours may lie in the finding in this study that clinic staff reported being overworked and underpaid. That belief was considered to lead to discrimination against patient groups who could, by some at least, be considered the cause of this excessive workload. Behind this lay a notion of dehumanisation, in particular because the health care providers were reported to see themselves as caring for a population that did not deserve such service (Moyo, 2010).

In the study above, migrants reported a variety of experiences, ranging from positive accounts of good treatment to cases of verbal and physical abuse. Migrant patients reported that central to determining quality of care was language use, specifically speaking the main language of the frontline staff - in this case Zulu. In this way, migrant patients could be identified and reminded by staff of the need to preserve government resources for citizens. Finally, the author reported that the unacceptability of being a migrant was likely to become conflated with that of the generically “troublesome” patient.

### ***2.2.3 Street-level bureaucracy and general practice in the UK***

Literature relating to this area was sought using the databases described in Chapter One and the search terms “street level” OR “street-level” OR “lipsk\*” and combined with “general pract\*” OR “family medic\*”. Four studies were identified that focused upon street-level bureaucracy as a theoretical framework in order to interpret the way in which general medical practice operates in the UK. Those studies are only presented here briefly as they mainly considered performance management as part of GPs’ employment status as “independent contractors” within the NHS in the UK: that is to say, to examine the implementation of guidelines and performance measures and their effect upon practice. One reason for that focus may have been that identifying street-level behaviours is harder once they are established and have become routine practice.

In one study that used participant observation and document examination in an English primary care group, McDonald (2002) considered ways in which the work of GPs was consistent with Lipsky’s (2010) theory of street-level bureaucracy. She reported that GPs were able to exercise “huge” discretion in their professional role. This was illustrated in adherence to guidelines for the prevention of coronary (ischaemic) heart disease: contrary to the guidelines that GPs were expected to follow, this study described “wide variation” in

the prescribing of statin drugs to lower cholesterol and inconsistent patterns of referral to new secondary care services for patients with ischaemic heart disease. Where such hospital services were taken-up, this tended to be because they offered “avenues down which to send “problem patients” who took up large amounts of GP time”. Because of conflict between the demands of performance management (expressed, for example, through clinical guidelines) and the expectations of patients, McDonald concluded that:

*“The picture that emerges from this case study is one of reactive decision-making in the context of multiple objectives, with clinicians adopting implicit rationing to cope with service demands. This is marked contrast to the rational model of decision-making that underpins health economic analysis... Restricting the powers of individual GPs to allocate resources according to their own discretion risks undermining the ability of the system to cope with the gap between supply and demand” (McDonald, 2002)*

McDonald’s work is important because it documents autonomy in the GP workplace and the use of strategies to achieve tasks, even where this appeared to run counter to formal guidance. Some of the conclusions concur with findings in the second study identified that GPs may find clinical guidelines too complicated and that, even in surgeries where clinicians held positive attitudes towards guidelines, they had little effect on behaviour (Checkland, 2004). A Lipskian approach to implementing policy was suggested in Checkland’s study in the way that certain features of guidelines had been adopted *prior* to their formal introduction because they were already perceived as “making the job easier”. Whilst recognising the street-level notion of GPs’ possessing significant personal discretion, Checkland concluded that they were, at least in part and for the time being, exempt from the full operation of a street-level bureaucracy as a result of their professional status:

*“Lipsky argues that the two best defences against the negative effects of street-level bureaucracy are a strong ethic of professionalism and the intelligent involvement of service users. General practitioners in the UK are protected from the full force of the [workplace] pressures outlined by Lipsky by their status as independent contractors and by their professional power. Current trends in the health service, however, may limit these protective factors. First, salaried practice is becoming more common.... This will put many GPs in the position of employees, subject to management by their employers. Secondly, it has been argued that the move towards scientific-bureaucratic medicine and performance management by targets will reduce professional autonomy”(Checkland, 2004)*

One account of the impact of GPs’ employment status upon their working pattern was illustrated by the third source identified. This qualitative study from the North of England examined perceptions of financial incentives for GP practices that consist of population-

based clinical targets known as the Quality Outcomes Framework (QOF) (Cheraghi-Sohi, 2011). Cheraghi-Sohi's interviews found that financial incentives strongly influenced the responses of GP principals, an observation that is unsurprising given the role of such persons as owners of, rather than employees in, the surgery. Salaried GPs (i.e. doctors contracted within a surgery, rather than practice-owning GPs), however, reported that they believed in the same clinical targets but for a different – and non-financial – reason. This was because they perceived QOF targets as being evidence-based and, therefore, these GPs reported that they complied with management policy because they believed it to be beneficial to patients. Cheraghi-Sohi concludes that this finding implies that the application of Lipsky's framework to explaining GP behaviour in relation to QOF is less useful than previously believed. That may, however, not be the case if one interprets the behaviour of salaried GPs outlined above within Lipsky's notion of client advocacy. A further reason to question Cheraghi-Sohi's conclusion is that salaried GPs may be unable to practise what they profess with regard to every patient, at least not at times when clinical demands are particularly heavy. If this is the case, such a claim could be consistent with Lipsky's (2010) notion of the "myth of altruism". Indeed, Lipsky specifically notes that organisations rarely examine whether such fair treatment of clients actually takes place or not. Thus, it would be informative to review the actual performance of salaried GPs who claim to adhere fully to QOF guidelines by examining their documentation of such targets during clinics. This is because they may be unable to achieve this admirable claim in the real world of front-line general practice, finding themselves compelled to compromise and target those who they consider to be most needy or most likely to fulfil the given outcome measure. If this scenario were proved true, it would suggest that the claims of salaried GPs actually fulfilled Lipsky's notion of street-level bureaucracy by providing evidence of the "myth of altruism" and a need to act as an "innovative strategist" (Moore, 1987).

One area where it is recognised to be practically difficult for GPs to fulfil policy expectations is unscheduled care for patients with long-term conditions: this comprised the focus of the fourth paper identified (Drinkwater, Salmon, Langer et al., 2013). Drinkwater's interview study with GPs, nurses and case managers found that GPs considered working in out-of-hours services to be inherently more risky on account of their lack of prior knowledge about individual patients. This made decision-making more complex, as GPs were unable to draw on an understanding of a patient's "typical" behaviour. As a corollary, they described seeking to prioritise patient safety - for example, being more likely to admit a patient to hospital in cases of clinical uncertainty. Clearly



such behaviour ran counter to targets designed to reduce the use of unscheduled care and it led to a tension between fulfilling this aim and delivering what was perceived to be optimal care to individual patients. In addition, health care professionals viewed use of unscheduled care as a necessary component of care for patients with long-term conditions, thus illustrating a conflict between expectations of management and the practical realities of the workplace. As a result, the authors call for policy to aim for whole-system change rather than reliance upon individual health care professionals to introduce changes into their practice.

The studies outlined above offer some evidence that the working patterns of GPs are consistent with street-level principles. That said, they also point to inconsistency in other areas and this appears to arise from the professional status of GPs. This is unsurprising given that Lipsky's theory emerged from studies of what he termed "low level" workers in public service organisations. GPs are likely to differ from typical street-level bureaucrats not only by possessing higher social status, but because they earn larger salaries and exercise greater control over their working environment. Nevertheless, little evidence exists over the role of street-level bureaucracy theory in the context of the wider, day-to-day interactions between GPs and their patients. Other than Moyo's (2010) South African study, no research relating to street-level theory and migrant care in primary care was identified when preparing this thesis. Studies using street-level bureaucracy in UK general practice have not, it appears, considered the patient's perspective. The present study builds upon such gaps in the understanding of the application of street-level bureaucracy theory to general practice. In particular, the thesis seeks to examine the accounts of Africans and GPs working with migrants to consider whether these are consistent with the principles of street-level bureaucracy.

The following chapter describes two geographically diverse contexts in which Africans receive health care. These are presented in two separate domains: traditional approaches undertaken by many people within the continent of Africa and the use by migrants of formal western health services.

# Background

### **3) Africans' use of health care: traditional and biomedical systems**

As reported in the last chapter, Kleinman (1978) described three areas that comprise his concept of cultural health systems, namely the folk, popular and professional sectors. This chapter presents literature relating to what can be perceived to be the two ends of such cultural health systems in the context of migration. That is to say, first, the way in which people in sub-Saharan Africa utilise traditional medical systems, including herbal remedies and traditional healers. Second, is the use of western health care services by migrants. Where relevant data were available, that section describes what is known in the context of migrants from sub-Saharan Africa.

#### **3.1 African traditional medical systems**

Evidence for this section was generated from the literature search illustrated in Figure One. This search was, however, undertaken without terms relating to migrants in order to consider use of traditional medical systems in Africa. Additional sources arose from discussion with colleagues and wider reading in the area. This was necessary because the literature relating to African traditional medical systems is vast and draws upon a wide range of social sciences, especially anthropology. What is more, research in this area extends back well over a century. As a result, information was sought that pertained most closely to the areas of origin of the participants of the present study, namely eastern Africa and the DRC.

Although African societies possess a wide range of approaches to therapy based upon use of various plant and animal products, spiritual practices and ritual behaviours, these frequently overlap and are considered to be broadly similar (Sindiga, 1995c). This observation is also consistent with the suggestion that there exists a broadly generalisable African social system south of the Sahara (Caldwell, Caldwell, and Quiggin, 1989). Therefore, whilst recognising that Africa is a richly diverse continent, in this thesis the generalised notion of a traditional African medical system is used. In so doing, the definition of traditional medicine of the World Health Organisation (WHO) is adopted here. This is as follows:

*“The sum total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures that are used to maintain health, as well as to prevent, diagnose, improve or treat physical and mental illnesses” (World Health Organisation, 2008).*

The significance of traditional health products and medical systems must not be underestimated. It is believed that traditional healers provide 80 per cent of health care services used worldwide (Handwerker, 1999), including Africa (Elujoba, Odeleye, and Ogunyemi, 2005). Globally, between 50,000 and 75,000 different species of plants are used on a regular basis for medicinal purposes (Dharani and Yenesew, 2010). Not only are herbal medicines the most widely used type of traditional medicine but they are also the most financially lucrative form (World Health Organisation, 2008). This popularity may be with good reason given that about a quarter of modern medicines contain active ingredients from plants (Adimoelja, 2000). Such products include quinine and artemisin (both used in malaria treatment) as well as the analgesics morphine, aspirin and codeine. Products from Africa also have a role in modern biomedical treatment - for example, the Madagascan periwinkle plant is the source of vincristine, an anti-cancer drug (Dharani and Yenesew, 2010). Importantly, traditional approaches to treatment are not confined solely to the primary health care of poor people in developing countries. This is illustrated in data from the UK where herbal medicine use is rising such that more than 120 million pounds (GB) are spent annually (Cobweb Information Ltd, 2008). Such popularity of traditional treatment, even in the presence of a nationalised western health care system, underlines the way in which people across much of the world frequently turn to non-biomedical approaches to therapy.

When examining African traditional medicine, it is necessary to consider two underpinning categories of traditional medicine: explicable and inexplicable forms (World Health Organization, 2000). The former includes herbal medicines and has been defined as below:

*“The simplified, scientific and the direct application of plant, animal or mineral materials for healing purposes and which can be investigated, rationalized and explained scientifically” (Elujoba, Odeleye, and Ogunyemi, 2005).*

Inexplicable traditional medicine, by contrast, lies beyond scientific explanation and consists of the following:

*“The spiritual, supernatural, magical, occultic, mystical, or metaphysical form that cannot be easily investigated, rationalized or explained scientifically e.g. the use of incantations for healing purposes or oracular consultation in diagnosis and treatment of diseases” (Elujoba, Odeleye, and Ogunyemi, 2005).*

In the African context, these approaches are by no means totally separate ones. The role for inexplicable traditional treatment in Africa is considered to be based upon a desire to discover the deep-seated cause of a person's illness (Green, 1999), particularly in the presence of symptoms considered to indicate an 'African' illness such as epilepsy (Bibeau, Corin, Buganza et al., 1980)<sup>11</sup>. Central to this is the notion in Africa that healing is not a “thing” but a process that is enacted and often manifested in the form of ritualistic behaviour (Rasmussen, 2008). As part of treatment, specific rituals can also be used to “seal off” an illness (Asuni, 1979), a behaviour which may serve to increase patients' expectation of a cure.

Medical services exist in most African nations in the form of hospitals and clinics. Nevertheless, it is estimated that over 480 million people in that continent depend entirely upon traditional forms of treatment, both explicable and inexplicable (Dharani and Yenesew, 2010). Despite this, formal consensus is often lacking as to the value and role of traditional medicine. Perceptions of its status range from “uncritical enthusiasm to uninformed scepticism” (World Health Organization, 2002). People with faith in African traditional experience point not only to personal experience of cures but also to objective evidence for many herbal products. Although large-scale controlled clinical trials of traditional African remedies in humans are few, evidence of efficacy of a range of herbal products exists from *in vitro* studies and in animals. Recently published examples include the following: efficacy against helminth infections in ruminants (Gathuma, Mbaria, Wanyama et al., 2004), *in vitro* inhibition of HIV-1 (Leteane, Ngwenya, Muzila et al., 2012), and anti-malarial effects in mice (Yerbanga, Lucantoni, Lupidi et al., 2012). There is also some evidence of efficacy of herbal products in chronic disease; for example, roots/leaves from the Congo have been found to reduce blood pressure in hypertensive rats (Nsuadi Manga, El Khattabi, Fontaine et al., 2012).

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<sup>11</sup> The authors do not provide details about what characteristics render an illness typically African but cite “delirious fits” as another example. It is likely that the label “African” is attributed to illness of a sudden, unexplained and serious nature.

There are also concerns over the use of traditional medicines in Africa. Despite widespread popularity and its use across history, traditional medicine has not been officially recognized in most countries (World Health Organization, 2000). Traditional African medicine has suffered from official discrimination at the hands of governments during and since the colonial period (Amutabi, 2008; Elujoba, Odeleye, and Ogunyemi, 2005) due to belief that it was a manifestation of superstitious folk beliefs (Bruschi, Morganti, Mancini et al., 2011), thus limiting education and research in this area (World Health Organization, 2000). Reasons for concern over traditional medicine include evidence of toxic heavy metals in certain herbal products – including African ones (Okatch, Ngwenya, Raletamo et al., 2012). Similarly, concern has arisen from reports of serious side-effects. Again, this includes African products, for example herbal products from Uganda linked to liver fibrosis (Auerbach, Reynolds, Lamorde et al., 2012) and from the Congo associated with gastrointestinal erosion (Ibara, Atipo-Ibara, Boloko et al., 2007). An associated issue is that use of traditional medicine is common in pregnancy in Africa (Malan and Neuba, 2011) and such behaviour risks exposing the fetus during development to potentially harmful substances. Use of traditional medicines in Africa has been associated with wider health risks, for example increased alcohol intake and poor compliance with HIV medication (Banda, Chapman, Goldenberg et al., 2007). Additional concern exists over dosage in traditional medicines and one reason for this is the variable quality and quantity of phytochemical compounds in herbal products that can arise as a result of different soil types (World Health Organization, 2002).

Behind the divergent beliefs about the status and role of traditional medicines lies inconsistent legislation. Whilst some registration of healers exists in Africa (Amutabi, 2008), herbal products often remain unlicensed. This issue, however, is not confined to Africa. Even in the European Community the legal framework for the sale of traditional medicine does not – at present - demand formal testing of products. Instead, their historical use as a traditional remedy remains sufficient for sale:

*“Under Directive 2004/24/EC on traditional herbal medicinal products, it is not required for companies to prove efficacy. Any pharmacological effect is considered plausible based on traditional use only (traditional use is defined here as at least 30 years of medical use, at least 15 of which must be within the EU)”(Murphy, 2012)*

### **3.1.1 Patterns of traditional medicine use in Africa**

The taking of traditional medicine in Africa may be either through self-administration or by consulting a healer. The present literature search identified only one published survey of the extent of self-medication in Africa. That study, from rural Nigeria, found that self-medication was the dominant method (more than 99%) reported amongst more than 700 participants (Arikpo, Eja, and Enyi-Idoh, 2010). The authors of that study attribute this widespread use to poverty and limited access to western medication. What is not clear, however, is the extent to which traditional healers played a role in participants' obtaining access to treatment. This is important because traditional medicine in Africa is associated with, and often delivered through, a variety of local healers.

In contrast to modern Europe, where medical training is formalised, healers in Africa often acquire their skills or talent in diverse ways. This includes inheriting the vocation through their family line (Redmayne, 1969; Sindiga, 1995a) as well as claiming to be born with traits that comprise a healer's nature (Armah, 1979) or receiving this through divine revelation (Redmayne, 1969; Sindiga, 1995a; Sindiga, 1995b). Traditional African healers may adopt a range of approaches to treatment. One useful way to categorise African healers is utilising the following groups: 'pure herbalists', 'herbalist-ritualists', 'ritualist-herbalists', and 'spiritualists', where the middle two categories describe practitioners who use both plants and rituals but with different levels of emphasis on the two (Bibeau, Corin, Buganza et al., 1980). Within each of these categories healers may also be considered generalist or to specialise in treating particular conditions (Sindiga, 1995a). In addition, certain traditional African healers may identify themselves as possessing surgical skills - for example, dentists, bone-setters, circumcision practitioners and birth attendants (Sindiga, 1995b).

Patients are often very satisfied with traditional African medicine and healers are held in high esteem. Indeed, there is often expectation of an "instant cure" (Yebei, 2000). That expectation, however, is also reported for biomedicines and amongst members of other ethnic groups, for example Asian patients (Iqbal, Wahed, Manzoor et al, 2013). Use of African traditional healers is driven by a belief that they will not just be competent, but also accessible and affordable (Mbiti, 2008). Little is known about the modern popularity of traditional African treatments compared with biomedical approaches. One recent study from urban and rural parts of Ghana suggests that, although patients are highly satisfied with traditional African treatment, it is usually the treatment of second choice due to a

primary preference for western medicine (Sato, 2011). This observation concurs with earlier evidence that the most commonly reported reason (in 25-50% of users) for taking traditional African medicine is the failure of western medicine to treat an illness effectively (Bibeau, Corin, Buganza et al., 1980). That study also found that an important factor in patients' choice of healer (and, thus, treatment type) was largely determined by belonging to the same ethnic group. The particular reasons for this were not presented but are likely to lie in a common language and shared beliefs about the causation and treatment of illness. This would be consistent with evidence that the choice to use traditional medicine is closely related to deep-rooted social, cultural, and personal factors (Lebeau, 1999).

Wider reasons reported for choosing traditional medicine in Africa include its cost-effectiveness, accessibility as well as perceived therapeutic benefits (Yinegar, Yewhalaw, and Teketay, 2008). Clearly, the affordability of herbal treatment is likely to render it particularly attractive for the poor and for rural populations, where resources or access to services may be limited. Africans' choice of herbal remedies is not, however, simply the result of poverty or lack of access to modern health care facilities. Additional factors also render biomedical approaches less preferable to traditional medicine. One reason for this is the 'cultural distance' of western medicine from lay health beliefs and practices, leading to suspicion and under-use of formal health care (Pillsbury, 1979). A further, recently reported, reason for the popularity of herbal remedies in Africa is fear over the "chemicalisation" of western medicine and associated side effects (Amutabi, 2008).

Traditional African medicine is used to treat a wide range of problems; however, important conditions for which traditional medicines have long been sought include impotence and sterility (Redmayne, 1969). There is some recent evidence that conditions believed to have an infectious origin dominate the list of diseases for which traditional medicines are used, in particular malaria and bacterial infections (Moshi, Otieno, and Weisheit, 2012). There is also evidence of their use for chronic disease: for example, one study from Kenya identified 39 different species of plant being used to treat diabetes (Keter and Mutiso, 2012). Chronic disease treatment, however, should not be perceived as being confined to herbal products. The following traditional treatments have been reported for epilepsy in east Africa (Tanzania): herbal products, scarification, and Christian spiritual healing (Winkler, Mayer, Ombay et al., 2010). Similar findings from west Africa (Ghana) also illustrate the diversity of treatment to which diabetic patients resort. In this study, participants reported using biomedical treatments as well as turning to ethnomedical



healers and spiritual interventions (Aikins, 2005). The decision of diabetics' to turn from biomedical treatment to traditional medicine was principally driven by the high cost of western medication and through following prescribed dietary advice.

It was originally believed that as migrant Africans became increasingly "westernised" they would abandon cultural health practices such as traditional medicine, particularly in urban areas (Twumasi, 1975). This assumption was expected to be closely associated with the rise of mass education and exposure to western health care systems. Nevertheless, there is increasing evidence for the use of traditional medicines in African cities (Mazaza, 2009). A further dimension to the modern picture of traditional medicine uptake in Africa is that many people use local treatments and rituals *as well as* western medicines, either simultaneously or in sequence (Asuni, 1979; Rasmussen, 2008), particularly in rural areas of Africa (Parry, 2004). There is also evidence that, in Africa, traditional healers are responsible for combining traditional herbal remedies with modern medicines (Parish, 2011).

The manner in which treatment is sought from diverse sources has been described as "therapy resort" (Green, 1999) or "healer shopping" (Kroeger, 1983) and the chosen pathways are dependent upon available treatment options. Behind this approach, a general progression is reported to operate from simple, "empirical" treatments to more serious ones, including "magical" intervention (Janzen, 1981). For some, these basic approaches may start with cheap or home-prepared remedies, progressing to more expensive ones as an illness progresses and is perceived to be more serious (Green, 1999). It is reported that such treatment quests not only involve multiple resorts but can be lengthy and pursued until an illness is cured (Sindiga, 1995a). Central to this is an acceptance of a wide range of therapies. This is despite the fact that to a non-African such an approach may appear to lack consistency and is likely to incur increased risks. Nevertheless, this mixing of medical systems is considered routine in Africa, even within the domain of western medicine:

*"The [western] doctor is usually not the first person to be consulted when a person is sick. This is particularly true for those living in suburban and rural areas.... The fetish priest, soothsayer, spiritualist, or herbalist is always consulted... The physician is hardly the only one administering medication and monitoring the progress of the patient. Food, water, and body lotions usually containing herbs, oils, and others, either from the prayer house or the fetish, continue to arrive at the patient's bedside in spite of the sharp cultural conflicts that openly exist between orthodox medicine and traditional healing" (Mensah, 2008a)*

A key dimension to the issue of pluralism in treatment choice is the effect of the reported direct access to certain western medicines in parts of Africa without consulting a clinician - for example, for antibiotics (Nsimba, 2007) as well as antimalarials and other products to treat fever (Goodman, Brieger, Unwin et al., 2007). Self-medication with antibiotics is known to take place for certain common symptoms and signs that are not usually managed in Europe in this way, for example, treatment of menstrual symptoms. In one study of students at four Nigerian universities it was reported that nearly a quarter had self-medicated with antibiotics for menstrual symptoms (Sapkota, Coker, Rosenberg Goldstein et al., 2010). Clearly this has implications for patient safety, reduction of drug resistance and the likely expectations of African migrants who experience similar symptoms.

## **3.2 Use of western health care by migrants**

### ***3.2.1 Challenges of definition and to searching the literature***

A key aspect of the present study was developing an understanding of how migrants use western systems of health care, particularly in relation to the NHS. Significant challenges exist, however, to the examination of the published evidence relating to how migrants access and use health care in the UK. First, the literature on access to health care is extensive, diverse and complex. As a result, it is recognised that routine database searches do not identify all relevant publications and are likely to produce a volume of potential data that is too great for even a study team to investigate in full (Dixon-Woods, Cavers, Agarwal et al., 2006). A further challenge is that most research relating to the health-seeking behaviour of migrants are derived from small scale, local and qualitative studies (Jayaweera, 2011). Thus, findings may not be generalisable to – or comparative with – different geographical or clinical settings. Such diversity in the delivery of health services may exist in many forms. One example is that health care for asylum seeker services may be provided in separate clinics or (as in the location where the present study was conducted) as part of routine GP surgeries. A further challenge to identifying relevant studies is that - in contrast to quantitative research - no single accepted hierarchy of study designs appears to exist for qualitative data that can be used rapidly to identify evidence of higher quality or relevance (Dixon-Woods, Cavers, Agarwal et al., 2006).

A broader problem with comparing and contrasting studies is that there is inconsistency over use of terms to define major demographic categories, in particular Black Minority

Ethnic (BME) populations, migrants, refugees and asylum seekers. The term Black and Minority Ethnic is the term normally used in the UK to describe people of non-white descent (Institute of Race Relations, 2013). This category at times overlaps with the term “migrant” for which no international consensus on its definition exists (Anderson and Blinder, 2012). In the context of the UK, definitions of the term migrant have included “foreign-born”, “foreign-nationals” and people who moved to the country for a year or more (Health Protection Agency 2011). Within such definitions lie two distinct categories of migrants who constitute a significant number of the participants in the present study, namely refugees and asylum seekers. A formal definition exists for a refugee which was enshrined in the United Nations 1951 Convention relating to the Status of Refugees, in particular as someone who:

*“owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country...” (United Nations High Commissioner for Refugees, 2012)*

In reality, within the UK the term “refugee” is normally applied to someone who has been granted refugee status (or, at least, leave to remain in the country) while an asylum seeker is someone who has submitted a claim to become a refugee and is waiting for that request to be accepted or rejected (Institute of Race Relations, 2013).

Careful consideration of such definitions is important not only because terms overlap but because they also fail to capture important demographic variables about peoples' heritage and personal migration histories. For example, these categories can also fail to embrace the possibility that the children of people born overseas may identify with and retain beliefs and practices from their parents' culture or country of origin. These identities and affiliations can last multiple generations; for example, black people of African descent from other continents (for example, people from the Caribbean and United States) may identify themselves as African<sup>12</sup>. One solution to this has been to incorporate these into one group under the title ‘Migrants and Minority Ethnic (MEM) people (Ingleby, 2009). In terms of policy-making the value of such a definition is limited because of the significant demographic diversity therein. This is particularly important in health care because this group includes wide differences in health needs (Health Protection Agency, 2010) and in their use of health services (Norredam, Nielsen, and Krasnik, 2010).

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<sup>12</sup> In this thesis the term ‘African’ is defined as someone born in sub-Saharan Africa

Challenges to reviewing and contrasting studies of migrants' use of health care extend beyond problems with definitions. Even where researchers and reports clearly identify relevant categories, there remains significant inconsistency in data collection methods used between studies. For example, there is frequently failure to record key migration variables such as country of birth, duration of stay in the UK or immigration status (Jayaweera, 2011). The evidence base for studies of access to and use of care is also restricted by the failure of NHS institutions to collect ethnicity data on patients both at hospital and at primary care level (King's Fund, 2006), including routine coding of migrant status.

As a result of these practical challenges, the present study undertook a pragmatic approach to identifying literature relating to migrant access and use of health care. Instead of a single, overarching and systematic approach using literature databases, the evidence below is derived from a range of separate sources. These included sources identified during the development of the present study through background reading, consulting colleagues, citation chains from recognised studies as well as targeted database searches. Targeted searches were conducted for major themes in this section, in particular migrant access to health care, use of interpreters and medically unexplained symptoms in migrants. This broad approach to gathering data is consistent with recognition that methods distinct from conventional systematic review have been advocated for enquiries into health care service use by vulnerable populations in the UK (Dixon-Woods, Cavers, Agarwal et al., 2006).

A final limitation to the quality of the literature search presented in this thesis lay in the challenges of reporting qualitative studies that were diverse in their methodology, geographical location and the demographic characteristics of participants. Synthesising findings from a range of qualitative studies is a recognised methodological challenge. Perhaps for that reason there exist various approaches to undertake this, including the following eight methods: meta-ethnography, meta-study, meta-summary, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, meta-interpretation, and cross-case analysis (Ring, Jepson & Ritchie et al., 2011). A key part of this process is undertaking a critical analysis of the information extracted (Bhui, McCabe, Welch, et al. 2013). That involves a systematic examination of research evidence in order to assess its validity, results and relevance prior to using its findings to inform policy, practice or other decisions (Hill & Spittlehouse, 2003). In the context of healthcare, an important motivation for undertaking this is to provide a means to promote recognition of the needs, preferences, and experiences of patients for service providers and policy makers (Ring et

al., 2011). It can also serve to identify key underlying principles from evidence for healthcare interventions in one domain in order to assess how the findings may be applicable to other patient groups (Netto, Bhopal, Lederle et al., 2010). Despite potential benefits of appraising qualitative data, there has also been concern over lack of consensus in how this should be undertaken, the need for subjective judgements and that prescriptive approaches to assessing quality may ultimately stifle research creativity (Dixon-Woods, Shaw, Agarwal et al., 2004). A further challenge to using methods of synthesis and quality assessment is that methods may not be explicitly articulated by authors and terminology applied inconsistently (Ring et al, 2011). For these reasons, whilst seeking to critique and summarise qualitative studies, the literature reviews included in this thesis did not adopt a *formal* method of synthesis or quality assessment.

### **3.2.2 Ethnic inequality in primary health care access and use**

Ethnic inequalities in access<sup>13</sup> to, and quality of, health care have been consistently documented in the USA and, to a limited extent, in the UK (Nazroo, Falaschetti, Pierce et al., 2009). A number of studies has looked at ethnicity and use of general practice in the UK, but this has led to a mixed picture. The complexity of the ways in which different migrant groups use health care in the UK is presented in the passage below, which was commenting upon data from the General Household Surveys of 1984–1991:

*“[Findings] do not suggest there is any gross pattern of inequity between ethnic groups, except perhaps with respect to the Chinese population which displays consistently low levels of utilisation. However, while use of GP services by minority ethnic groups is in general as high or higher than the white population, use of outpatient services is low.”(Smaje and Le Grand, 1997).*

This finding is broadly consistent with evidence from other studies that show greater numbers of consultations with general practitioners amongst migrant patients than the indigenous white population in Europe (Norredam, Nielsen, and Krasnik, 2010).

Similarly, analysis of later General Household Surveys (1998-2004) concluded that ethnic minority respondents were more likely to use GP services and that adjusted odds ratios for use according to ethnic group compared with white respondents were as follows: Indian 1.29 (95% Confidence Intervals 1.07-1.54), Pakistani 1.32 (1.10-1.58) and Bangladeshi

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<sup>13</sup> Access to healthcare has been defined in the context of ethnicity as: ‘the ability to have health needs met through existing channels or care pathways designed specifically to meet those needs’ (Suresh and Bhui, 2006)

1.35 (1.10-1.65) (Nazroo, Falaschetti, Pierce et al., 2009). This study also reported that ethnic inequalities existed for access to hospital services as well as marked inequalities in use of dental care. One explanation for increased use of GP services by minority ethnic groups is that this may be associated with greater need (Smaje and Le Grand, 1997). This is important because failure to take into account variations in need of different populations may render the findings about the appropriate level of access inconclusive (Szczepura, 2005).

Other factors may mean that conclusions about ethnic minority use of health care cannot be generalised across patient groups or across time. First, findings in favour of uncomplicated access to care may relate to migrants from anglophone countries or migrants of higher socio-economic status. Second, significant migration (including from Africa) to the UK has continued since the 1990s and migrants in earlier studies may have received different services from the NHS compared with more recently arrived individuals. This is important in the context of “super-diversity” in Britain as it means that generalisations based upon long-established categories of minority ethnic groups may fail to capture the behaviour and experiences of other smaller and more recently arrived populations. Further issues may cloud the picture of African migrant health care access. For example, it is known that African migrants may actively seek help for their problems outside the health service - for example, by consulting clergy and traditional healers (Knipscheer, de Jong, Kleber et al., 2000). The effect of such behaviour upon health and health service use remains largely unstudied.

Three overarching explanations may account for such differential health care use between ethnic groups: racial differences in need, bias in the way that health care workers care for minority ethnic patients and the choices and decisions made that result from patient preferences. Patient preference has long been believed to be the dominant driver of reduced health care use amongst migrants to the USA and attributed there to low health literacy and scepticism of western medicine (Suchman, 1964). A further factor that contributes to patient preferences consists of the expectations and behaviours that arise from the cultural beliefs and practices of minority ethnic patients. Issues relating to the latter factor – patient preference and satisfaction – will now be considered in more detail.

### **2.3.3 Minority ethnic patients and the NHS: a “satisfaction gap”**

One factor that influences people's decision to use the health service is their previous satisfaction with it. Whilst patient satisfaction with UK general practice as a whole has generally been considered to be high, this appreciation is not universal. For example, it is known that Africans are less satisfied with their experience of NHS care than are white British people (Commission for Health Improvement, 2004). In that survey, south Asian people (Indian, Pakistani and Bangladeshi) were found to be the least satisfied of all groups with their care. The difference between satisfaction amongst minority ethnic people and that of the majority white British population has been called a “satisfaction gap” (King's Fund, 2006).

In addition, there is evidence from qualitative research of dissatisfaction with UK general practice amongst certain migrants - for example, asylum seekers and refugees in Glasgow, in particular those from countries with more hospital-based models of health care (O'Donnell, Higgins, Chauhan et al., 2007). What is more, deeper concern amongst migrants about quality of care may pass under-reported, particularly in the context of face-to-face encounters with health care staff. This belief arises from evidence that it is considered less acceptable by some minority ethnic groups to report criticism of interactions with staff and, instead, this may lead to the focus of criticism being placed upon organisational aspects of care, such as waiting times (Patel, 1995). Thus, dissatisfaction with the NHS amongst migrants and other minority ethnic groups may lie in a reluctance or linguistic inability to articulate their concerns.

Other factors are likely to contribute to a perception of poor satisfaction amongst minority ethnic groups. First, is the background rate of poor health amongst any given population. This is because migrants who describe their general health as “poor” have been found to report the greatest dissatisfaction with general practice (Lien, Nafstad, and Rosvold, 2008). This is important because there is evidence that the prevalence of long-term illness is higher in most black and minority ethnic groups in the UK than in the general population, in particular for older age groups (Szczepura, 2005). This is important because central to patient satisfaction with health care services is trust. It is believed that migrants to the UK tend to mistrust formal medical advice, medication, and services (Brown, Avis, and Hubbard, 2007) and there is evidence that refugees and asylum seekers report greater trust in specialists than in general practitioners (O'Donnell, Higgins, Chauhan et al., 2008). Clearly this has implications for African migrants to the UK who – as reported in Chapter

One – experience increased rates of chronic diseases for which diagnosis, prevention and treatment typically take place in primary care.

### **3.2.4 Migrant access and use of health care**

The British NHS has a legal and moral duty to provide services to all people who need them, regardless of gender, age or ethnic background (King's Fund, 2006). In addition to free care for urgent health problems and antenatal care, migrants to the UK are eligible for NHS treatment (including registration with a GP) if they are “ordinarily resident”, i.e. entitled to stay for six months or more (English, 2005). In contrast to the situation in many other nations, in the UK there is no charge for care received from the NHS. Despite this, there is evidence that general practice registration rates for migrants vary significantly according to continent of origin (Stagg, Jones, Bickler et al., 2012). For example, Stagg et al. (2012) found that characteristics of migrants less likely to be registered with a GP included origin from Africa or the Americas, male gender and status as a student or asylum seeker. Behind this observation is evidence that migration has a significant effect upon the way in which people use formal health care services (Van der Stuyft, De Muyunck, Schillemans et al., 1989). A commonly reported finding is that migrants often wait until problems become acute before seeking health care (Morris, Popper, Rodwell et al., 2009; Mullen, Chauhan, Gardee et al., 2007). This phenomenon is, perhaps, most evident for African migrants in the context of HIV testing. Delay in HIV diagnosis amongst Africans in the UK remains an important problem and has been attributed to the multiple social problems that face African migrants. As a result, they have been found to tend to seek treatment at a time of crisis, specifically when “you’re very, very, sick” (Burns, Imrie, Nazroo et al., 2007). This is consistent with evidence that a wide range of social factors influence African migrants’ treatment-seeking behaviour, indeed that this is ultimately determined by factors of circumstance rather than ease of service access (Thomas, 2010). For this reason, most research on migrant access to health care in the UK has focused upon practical barriers to access. Some evidence relating to this is now considered.



### **3.2.5 Practical barriers to accessing health care**

A range of patient factors is recognised as serving as barriers to access of health care by migrants in the UK. For asylum seekers this is known to include problems locating health centres and understanding the registration process (Bhatia and Wallace, 2007). It is also recognised that asylum seekers experience difficulty understanding and engaging with an appointment-based health service and understanding the generalist role of a GP (O'Donnell, Higgins, Chauhan et al., 2008). Alongside migrants' knowledge of the health care system of their host country, an important determinant of access is the perceptions of such people of its efficiency and quality (Boateng, Nicalaou, Dijkshoom et al., 2012). A further factor for migrants – in particular, failed asylum seekers and undocumented migrants - is concern that engaging with formal healthcare may make them vulnerable to having their illegal status identified and, thereby, possibly lead to deportation. Finally, there exist particular barriers to registration with a GP. The following barriers associated with health care providers have been reported by Medecins du Monde, with regard to vulnerable people in the UK, including migrants (Medecins du Monde UK, 2007):

- barriers caused by surgery staff's lack of knowledge and understanding of the regulations
- barriers caused by inhospitable and sometimes hostile GP surgery staff
- barriers caused by misunderstandings
- barriers caused by language

This is important because there is evidence that migrant patients are more likely to be declined registration with a GP than their white British counterparts (Delamothe, 2012). It has been suggested that this may be the result of concern by GPs over reaching pay-related performance targets (Hargreaves, Friedland, Gothard et al., 2006). There are even cases cited by researchers (Thomas, Aggleton, and Anderson, 2010b) and media sources (Adams, 2012) indicating that African migrants may be charged to register with or access care through an NHS GP in the UK. Whatever the cause, failure to register is known to restrict not only access to GP treatment but also onward referral to other health care services and wider exposure to health promotion (Stagg, Jones, Bickler et al., 2012). In particular, this may lead to reduced attendance at preventive services such as mammography and cervical cancer screening (Norredam, Nielsen, and Krasnik, 2010).

### **3.2.6 Language barriers and use of interpreters**

Language is fundamental to effective communication between patients and health care workers, in both the administrative and clinical context. Language barriers can result in misdiagnosis, medication prescription errors and inappropriate hospitalisation (Flores, 1998). Associated with this is reduced understanding by patients of diagnoses and treatment plans and a wish that the clinician had offered greater explanation about the illness (Flores, 2005). Clearly these issues have implications for chronic disease, for which studies show evidence of reduced adherence with medication and follow-up attendance (Karlner, Jacobs, Chen et al., 2007). These observations are also particularly pertinent to patients with mental health problems, where case reports suggest that language barriers lead clinicians to emphasise psychotic features and to underestimate emotional distress and suicide risk (Sabin, 1975). A final area where language issues have additional relevance is the health and social welfare of asylum seekers. This is because the latter may struggle not just with medical language but also to communicate practical facts to officials who are assessing their immigration case, including medical examiners (MacFarlane, Glynn, Mosinkie et al., 2008).

Given these issues, it is unsurprising that language barriers are predictive of poor satisfaction with clinical consultations (Wiener and Rivera, 2004). Nevertheless, language barriers should not be viewed as only having a negative effect upon individual patients or clinical consultations. Indeed, there is evidence that language is *the* most important determinant of ethnic health disparity (Fiscella, Franks, Doescher et al., 2002). Thus, linguistically appropriate communication and services are required not only to improve migrant satisfaction with care but also to identify and tackle underlying inequalities in health. In the context of African migrants this calls for strategies for both infectious diseases and for those chronic conditions that are more common in this population. In each case it is essential that messages be communicated in a way that avoids allegations of discrimination through ethnically-targeted health promotion and screening. Central to this is the need to empower migrants to make informed decisions about their own health care choices (Kreps and Sparks, 2008). A further dimension is the wider role of language knowledge in the well-being of migrants. This is because promoting language skills and tackling linguistic barriers is linked to the critical health literacy of migrants. Such steps

are essential if the wider social and political change required to improve migrant health care services is to be achieved (Sykes, Wills, Rowlands et al., 2013). This is not least because being able to communicate effectively is a core component of any individual's ability to exist as a genuine and active member of the society in which they live (Berry, 2007).

In the clinical context a number of solutions exist to language barriers with patients. One is for patients to seek out a doctor who speaks their own language. The value of a shared language in clinical communication is attested to by evidence that some refugees prioritise a shared language with their physician above the perceived clinical competence of that doctor (Morris, Popper, Rodwell et al., 2009). This approach may be possible in parts of the UK with large black and minority ethnic populations who share a common tongue. The importance of language concordant physicians is illustrated in one study from Birmingham, England. In that study of 290 consultations with non-English speakers, 222 were in the patient's own language, in 57 a relative or friend interpreted, six used a professional interpreter and in six another bilingual health care worker or community worker was employed (Gill, Beavan, Calvert et al., 2011). This study also highlights that for some GPs in Britain, speaking languages other than English is a routine feature of their consultations. Many GPs included in this survey had trained outside the UK, principally in south east Asia, and therefore this may not be representative of other geographical areas. Language-concordant GPs are unlikely to be a solution in areas of the UK that have recently arrived and diverse migrant populations.

Although it is known that use of bilingual health professionals is an effective way of reducing errors in language interpretation (Flores, 2005), this may have a negative effect on other aspects of clinical care. For example, use of language-concordant (Spanish-speaking) primary care physicians in the USA has been found to lead to a divergent picture in screening recommendations (Eamranond, Davis, Phillips et al., 2011). In that study, Hispanic patients were more likely to receive recommended screening for cardiovascular risk factors and most cancers. Language concordance, however, was associated with *lower* likelihood of patients receiving colorectal cancer screening. Two important reasons for this are suggested by the authors. First, doctors may experience increased discomfort discussing colonoscopy with someone from a similar background to their own. Second, Spanish-speaking doctors may have had less time to address screening as a result of evidence that in language-concordant consultations they are more likely to discuss broader

health topics, for instance diet or exercise.

In many situations it is unlikely that a GP and a non-English-speaking migrant patient will have knowledge of a shared language. This is particularly likely in the context of surgeries that care for asylum seeker and refugee populations because these patients come from a wide range of countries and, therefore, multiple languages may be required for a single clinic. In these situations an interpreter of some form is essential. Four categories of interpreter commonly used in clinical practice exist:

- Formal interpreters (i.e. professionals who may be unknown to clinician and patient)
- Informal interpreters (family members and friends)
- Interpretation by other members of the health care staff
- Telephone interpreters

The use of professional interpreters is normally advocated in clinical practice, including in Glasgow, the location of the present study (NHS Greater Glasgow and Clyde, 2012). This is because there is evidence that professional interpreters lead to improved clinical outcomes and patient satisfaction by reducing communication errors, increasing patient comprehension and leading to more appropriate use of health care services (Karliner, Jacobs, Chen et al., 2007). Further advantages may include their understanding of key medical terminology (Jensen, Norredam, Priebe et al., 2013) as well as local knowledge about accessing health services and other agencies (Berry, 2007). Nevertheless, even with the assistance of a professional interpreter, GPs and patients may encounter frustration in achieving effective communication. For example, certain African languages lack terms to describe important medical concepts, such as names for mental health states and conditions (Warfa, Bhui, Craig et al., 2006) or patients may be reluctant to express themselves through interpreters where there are inter-communal tensions in the country of origin (Bhatia and Wallace, 2007).

Although the British NHS has a commitment to provide a professional interpreter to any patient if required (Department of Health, 2004), there is evidence of underuse of professional interpreters by primary care clinicians across a range of countries, including Australia (Bird, 2008), the Republic of Ireland (MacFarlane, Glynn, Mosinkie et al., 2008)

and the UK (Gill, Beavan, Calvert et al., 2011). A number of reasons has been suggested to account for this. First, doctors may lack knowledge about gaining access to interpreters or fail to understand of the importance of using one (Berry, 2007). Second, clinicians often report concern over time pressures, breaches of patient confidentiality and of cost (Wiener and Rivera, 2004). This situation is further complicated by evidence that interpreter use is influenced by broader organisational factors, such as the particular culture of the clinic and the work patterns of individual doctors and receptionists (Greenhalgh, Robb, and Scambler, 2006).

A common alternative to a professional interpreter is the use of a family member or friend. Research from Australia and New Zealand suggests that use of informal interpreters is more common for “on the day consultations” than for ones booked in advance (Gray, Hilder, and Donaldson, 2011). That study also reported that clinicians rated informal interpreters as “working well” in 88% of “on the day consultations and 36% of the time in consultations booked in advance. The choice of an informal interpreter is considered to be influenced by multiple factors, including deficiencies in interpreting services and patient choice. For example, Danish GPs reported that they only use family members where they believe that patients insist on this (Jensen, Norredam, Priebe et al., 2013). Despite this, it is possible that the desire of a patient to use a family member or friend may arise from other factors, including concern over confidentiality or possible additional financial cost. Beyond this, ethnic minority patients have been found to be unaware that health care professionals can obtain the services of interpreters for their primary health care consultations in the UK (Barron, Holterman, Shipster et al., 2010). This observation suggests that the choice of a professional or informal interpreter is a complex one that results from both personal preferences of the doctor as well as practical issues arising from his/her workload.

Evidence from bilingual children belonging to a range of migrant communities in the UK found that that most consultations with an informal interpreter were straightforward (Free, Green, Bhavnani et al., 2003). Nevertheless, issues were reported to arise with health professionals or patients whose communication skills were poor, where the informal interpreter lacked knowledge or where medical problems were of a sensitive nature. This is consistent with evidence elsewhere that family members may struggle due to the following reasons: a) embarrassment, b) concern over revealing information that they believe should be retained within the family and c) a reluctance to convey bad news

(Berry, 2007). A further risk is that where a child interprets in the context of a stressful condition or encounter, they may be left with long-term physical or psychological problems (Jacobs, Kroll, Green et al., 1995). The complex picture is also highlighted by research from Sweden showing diverse experiences of using interpreters in health care consultations, suggesting that choice of an interpreter should be individually and situationally adapted (Hadziabdic, Albin, Heikkila et al., 2013).

A final option is telephone interpretation and this may be undertaken by either a professional or by an informal contact of the patient. Formal telephone interpreters have been indicated for use in geographically isolated or “low demand” areas (Department of Health, 2004). Further potential advantages of telephone interpreting services are that they can offer a wide range of languages and reduce cost. However, disadvantages include the absence of non-verbal cues and concern over anonymity. The use of telephone interpreters remains poorly studied in the UK context.

### ***3.2.7 Discordant expectations of health care***

It is known that migrants possess different expectations of health care and that these are often framed in comparison with those experienced in their original country (O'Donnell, Higgins, Chauhan et al., 2008). At the same time, research suggests that African migrants value free access to health care in the UK (Thomas, 2010) and this is likely to be a result of personal experience of paying for health services in Africa. Given that migrants originate from a range of countries with diverse forms of health care, it is difficult to draw a generalised conclusion over the effect of previous experience of care upon Africans' expectations once in the UK. Certain findings can, however, be identified. For instance, the preferred consultation style of the treating clinician may differ from that normally encountered in general practice. Evidence for this comes from qualitative research with asylum seekers and refugees in Scotland who reported difficulty adapting to doctors with a consultation style that was patient-centred (O'Donnell, Higgins, Chauhan et al., 2008). Beyond this, Africans in the Netherlands describe frustration with what they perceive as dispassionate and negative consultation styles and GPs who do not undertake clinical examination (Feldmann, Bensing, and de Ruijter, 2007). There is also evidence that migrants react to conflict over expectations of health care by seeking treatment elsewhere.

For example, Ghanaian women in the Netherlands with infertility who feel frustrated with their doctors' approach to their problem have been found to travel to Africa seeking "more understanding doctors" (Yebei, 2000).

A common underlying issue in divergent expectations is dissonance between patient and clinician in their understanding of health and illness aetiology (Palinkas, Pickwell, Brandstein et al., 2003; Pavlish, Noor, and Brandt, 2010). Conflicting health beliefs are considered to be an important cause of miscommunication with migrant patients and poor adherence to treatment (Kurdahi Zahr and Hattar-Pollara, 1998). It is known that western concepts of disease may not be understood by African immigrants or, alternatively, may be poorly communicated to them by their clinicians (Ventners and Gany, 2009). Clinicians are often unaware of their patients' explanatory models, especially those patients with lower educational backgrounds (Helman, 1985). They may, thus, dismiss traditional sickness explanations as 'unscientific' (Blaxter, 1990; Calnan, 1987) or simply 'wrong' (Freeman and Motsei, 1992). What is more, traditional explanatory models may be perceived not just as ignorance but as sheer obstructionism (Curren and Stacey, 1986). Such misunderstanding between African patients and clinicians has been reported to have adverse effects on the doctor-patient relationship and to discourage patient attendance - for example, in this African migrant's account from the USA:

*"[We] Somali women never go to the doctor, because we go and the doctor believes we are crazy or psychotic, and we say that makes us more crazy so we don't go" (Pavlish, Noor, and Brandt, 2010)<sup>14</sup>*

Clinicians and patients alike must, thus, mediate between biomedical and folk models of illness (Eisenberg, 1977). For this reason, clinicians' knowledge of their patients' explanatory models of illness is an important measure and predictor of successful communication (Helman, 1985). Conceptualisation and communication issues are particularly acute in general practice where the nature of many symptoms may be uncertain. The general practitioner is, therefore, recognised to be the main interface between the biomedical paradigm and lay health beliefs (Helman, 1978). GPs are only too well aware of the limitations of the biomedical model to account for the range of non-specific symptoms and problems encountered on a daily basis in their clinical work (Bower, Gask, May et al., 2001). Nevertheless, this issue is not purely confined to general

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<sup>14</sup> This phenomenon is not, of course, confined to migrant patients and has been summed-up in the British context as follows: "If patients who can't make sense of their world find no help from their doctors, eventually they no longer ask for it [help]" (Tudor Hart, 2008)

practice: other health professionals should also be aware of, and engage with, lay health beliefs as they are a well-recognised barrier to wider public health promotion (Allmark and Tod, 2006).

It is inevitable that patient frustration will arise when treatment fails to resolve symptoms. Central to dissonant expectations and dissatisfaction is Africans' belief that they are not being taken seriously by their doctors, particularly where GPs fail to investigate problems or prescribe medication (Yebei, 2000). A further area is failure to undertake specialist referral (Feldmann, Bensing, and de Ruijter, 2007). It is also recognised that some asylum seekers and refugees report unrealistic expectations of the role of high-tech services (such as body scans) in their treatment (O'Donnell, Higgins, Chauhan et al., 2008). Similarly, there is evidence that refugees to the UK may feel disappointed when they do not receive antibiotics in certain GP consultations (O'Donnell, Higgins, Chauhan et al., 2007). For Somali refugees in the Netherlands this feeling has been described as a general narrative amongst their community, such that the term "paracetamol" had come to represent having one's health problems dismissed by their doctor (Feldmann, Bensing, and de Ruijter, 2007).

Such medical gossip and wider rumour have an important impact upon people's expectations of health care and the way in which individuals interact with health care services. This may take a number of forms. First, is that family, friends and other non-health professionals are a common source of information about when and how to access health care systems as part of lay referral systems (Suls and Goodkin, 1994). Second, medical gossip can shape beliefs about illnesses and their severity. For African migrants, for example, disease awareness is often rooted in widely circulated accounts of illness amongst members of their community, especially reports of patients with more dramatic or serious outcomes (Boateng, Nicalaou, Dijkshoom et al., 2012). Such medical gossip amongst African migrants may, at times, contain serious allegations. For example, in Australia stories have been reported to include accounts of "pork injections" and "rejection of black babies" by health professionals (Manderson and Allotey, 2003). Clearly, these lay information sources are likely to have an effect upon migrants' expectations of health care services. They also offer benefits, for example familiarising newly arrived migrants with an unfamiliar health care system (Manderson and Allotey, 2003).



### **3.2.8 Symptom interpretation: the example of medically unexplained symptoms**

One area where conflicting expectations of health care between doctors and patients often arise is in the area of interpreting and negotiating the meaning of symptoms. This is particularly challenging for symptoms where the clinician is unable to identify an underlying biomedical cause. Such 'Medically Unexplained Symptoms' (MUS) are a worldwide phenomenon (Escobar and Gureje, 2007; Sumathipala, Siribaddana, Hewege et al., 2008) and typically include abdominal pain, dyspepsia, headache, backache, joint pain, chest pain, palpitations and fatigue (Mayou, 1991). Alongside this, there is evidence that Africans may report culturally distinct patterns of unexplained physical symptoms. Common somatic symptoms amongst African patients are reported to include "of heat" and "peppery and crawling sensations" (Escobar and Gureje, 2007; Escobar, 1995), in particular in relation to the head (Okulate, Olayinka, and Jones, 2004). In west and east Africa such symptoms may also form part of broader culture-bound syndromes, for example "Brain Fag syndrome" amongst students (Aina & Morakinyo, 2011). These syndromes are closely related to – and typically only found within – specific cultures or societies and are frequently shaped by religious beliefs<sup>15</sup>.

In Europe, MUS are common in both primary and secondary care (Bass, 1990) and it is estimated that between 13 (van der Weijden, van Velsen, Dinant et al., 2003) and 40 (Thomas, 1974) percent of consultations in primary care involve complaints considered unexplained by GPs. MUS are often self-limiting in their duration but some may last months and years. One reason why MUS are challenging for GPs is because doctors are trained to expect an organic cause for physical symptoms (Peveler, Kilkenny, and Kinmonth, 1997). Although they retain negative views of MUS patients, GPs still consider general practice to be the most appropriate and effective clinical service for providing care for patients with such symptoms (Wileman, May, and Chew-Graham, 2002).

The aetiology of MUS is, by definition, unknown. In some cases somatic symptoms are associated with depression (Simon, Von Korff, Piccinelli et al., 1999), including amongst MUS sufferers in Africa (Okulate, Olayinka, and Jones, 2004). MUS may also be related to previous sexual or physical abuse and neglect in childhood (Guthrie, 2008). Traumatic

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<sup>15</sup> Only two culture bound syndromes were identified during the writing of this literature review were from the central belt of Africa (i.e. where the study participants originated). These were "penis theft" in the DRC (Bavier, 2008) and an epidemic of laughing in Tanganyika (Ranking & Philip, 1963).

changes in social status can also play a role in the development of symptoms, for example amongst refugees whose social situation changes dramatically upon reaching a new country (Woivalin, Krantz, Mantyranta et al., 2004). Due to their association with trauma and loss, MUS are considered to be “epidemic” amongst refugees (Van Ommeren, Sharma, Sharma et al., 2001) and are sometimes summed up under the lay notion of “traveling [*sic*] pains” (Coker, 2004).

MUS are particularly challenging in cross-cultural contexts on account of conflict between patient and clinician about their causation and treatment (Perron and Hudelson, 2006). GPs recognise that MUS form a significant part of illnesses presented by refugee patients, including Africans (Feldmann, Bensing, and de Ruijter, 2007). One consequence of this belief is that migrant patients may feel that their problems are being quickly dismissed by their doctor. For example, Feldmann et al (2007) found that Somali participants perceived their GPs to be presumptuous in their rapid conclusion that traumatic personal backgrounds accounted for their illness. This typically leads to conflict because most sufferers of unexplained symptoms consider their complaint to be an indicator of an underlying serious health problem (Sumathipala, Siribaddana, Hewege et al., 2008). It also presents a dilemma to clinicians because the patients' desire to determine an organic cause of their problem is known to lead to inappropriate diagnostic investigations and treatment (Smith, Lein, Collins et al., 2003). Clinicians also have their own concerns over missing an underlying serious diagnosis, either in its early stages or because it is rare and unfamiliar. As a result the management of MUS has important implications for the use of health care resources. For example, one Dutch study in general practice found that (compared with consultations with an agreed diagnosis) the odds of investigative tests being ordered was 2.4 times higher in consultations involving unexplained complaints and that this rose to 4.1 where the patients stated that they expected some such tests (van der Weijden, van Velsen, Dinant et al., 2003). This illustrates the effect of uncertainty on the part of both doctor and patient upon clinical behaviour.

Faced with this clinical uncertainty on a daily basis, GPs feel ill-equipped to deal with MUS patients and may perceive such problems to be “inappropriate”, a “manifestation of emotional or social distress” and feel uncomfortable allowing patients to hold the balance of power in such consultations (Wileman, May, and Chew-Graham, 2002). Wileman et al (2002) describe two ways in which GPs are likely to respond in this situation. First, is the establishment of a positive doctor-patient relationship, using empathy to gain trust in order

to increase the likelihood of patients accepting a psychological explanation for their symptoms. This approach was consistent with evidence that patients can be transparent in indicating a wish for emotional support (Salmon, Ring, Humphris et al., 2009). Second, was a more confrontational approach, establishing agreement with the patient about the time pressures in GP consultations in order to focus on only certain parts of the presenting problem:

*“I explain how the practice works, explain how I work as a doctor, how I come to a diagnosis, I explain how much time they have with me, and I ask them what they think it would be reasonable to do in ten minutes. So, for example, if they had a headache, bowel pain, toe-nail ingrowing, and a problem with your piles, is it reasonable that in ten minutes I address and examine you for all those issues? To which they always reply ‘No, it's not reasonable’, so I say . . . ‘Whatever is worrying you most we will address thoroughly, and then the other things will have to wait until next time you come’”(Wileman, May, and Chew-Graham, 2002).*

This suggests that there is diversity in practice in the way in which GPs manage clinical uncertainty in the context of medically unexplained symptoms. It does, however, point towards the notion that doctors tend to adopt either a patient- or a doctor-centred approach in such consultations. The reasons for this choice remain unexplored in the context of migrant patients, as well as the long-term impact upon the patient and doctor.

### 3.3 Summary

People in sub-Saharan Africa grow up in the context of complex medical systems that embrace both the modern and traditional. Africans' choices of treatment are influenced by diverse factors, including their place of residence, socio-economic status, and ethnic background. Associated with this are deep-rooted cultural beliefs about the origin and treatment of illness, which often recognise a powerful role for religious and other unseen forces. These health beliefs and peoples' experiences of health care systems in Africa are considered to affect how migrants to the UK use the NHS.

These factors present a challenge to clinicians caring for migrants, particularly in the context of negotiating discordant expectations of health care and disagreement over the interpretation of symptoms. The evidence available to date suggests that doctors use different strategies to manage discordant beliefs about the meaning of symptoms, but little is known about this in the context of chronic disease in African migrants. Similarly, it is unknown what action African migrants undertake when their expectations of treatment are

not fulfilled by their GP. The following chapter considers two aspects of this. First, is what is known about African migrants' explanatory models of illness, with particular reference to major chronic diseases. Second, is the use of – and beliefs about - traditional medicines amongst African migrants in western countries.

# Literature review

## 4) Africans' explanatory models of chronic disease and migrant Africans' use of traditional medicine

The present chapter describes the results of two focused literature searches that consider existing knowledge in two areas that form the basis of the present study. These areas exist respectively within the popular and folk sector of Kleinman's 1978 model of cultural health systems. First, are explanatory models for chronic disease causation reported by Africans. This section reports studies from both Africa and amongst migrants from there to western nations. Second, the chapter then considers use of traditional medicines by African migrants in western countries. Given the extensive use of traditional medicine in Africa, only studies relating to migrants are presented here.

### 4.1 Explanatory models of chronic disease in Africa

As outlined in Chapter One, societies in Africa are diverse and undergoing rapid transformation as a result of social, economic and technological changes. This renders it difficult to generalise about explanatory models of illness in Africa. In addition, it is known that explanatory models of disease in Africa may be poorly articulated (Sindiga, 1995b), for example with little differentiation between disease, illness and wider misfortune (Sindiga, 1995a). One survey of studies of theories of illness causation held by 139 societies across the globe (of which 23 were from sub-Saharan Africa) provided the following summary of African explanatory models:

*"Africa ranks very high in theories of mystical retribution, which are reported for all but one of its societies and are important (i.e. either predominant or significant) in half of them. Violations of sex and etiquette taboos are more common as precipitating factors [of illness] than in any other region. Spirit aggression and sorcery are also prevalent theories, and of about equal importance. Africa uses the techniques of contagious magic to cause illness more frequently than do other regions, but the otherwise widespread sorcery technique of spirit possession is very rare. Ancestors are more common as supernatural aggressors than in other regions. Witchcraft is important among about a third of Africa's peoples but is absent in about half of them, and there are only sporadic reports of belief in the evil eye, mainly on the northern fringe of the region" (Murdock, 1980) (page 48)*

Lay knowledge of major chronic diseases in parts of Africa is considered to be scant and existing beliefs are rooted in socio-cultural knowledge systems (Aikins, Boynton, and

Atanga, 2010). The complex nature of this knowledge is evident in the way studies presented below report both traditional and biomedical explanations for chronic conditions. These findings cover four major chronic illnesses: cancer, cardiovascular disease, stroke and diabetes. Although the literature on health beliefs about these conditions amongst Africans is limited, stroke is considered separately from other cardiovascular disease in the present review. This is for two reasons. First, as reported in Chapter One, stroke is a major cause of mortality in Africans. Second, its natural history is largely asymptomatic and, when they do occur, symptoms of stroke are sudden, distinct and often clearly serious.

### **4.1.1 Cancer**

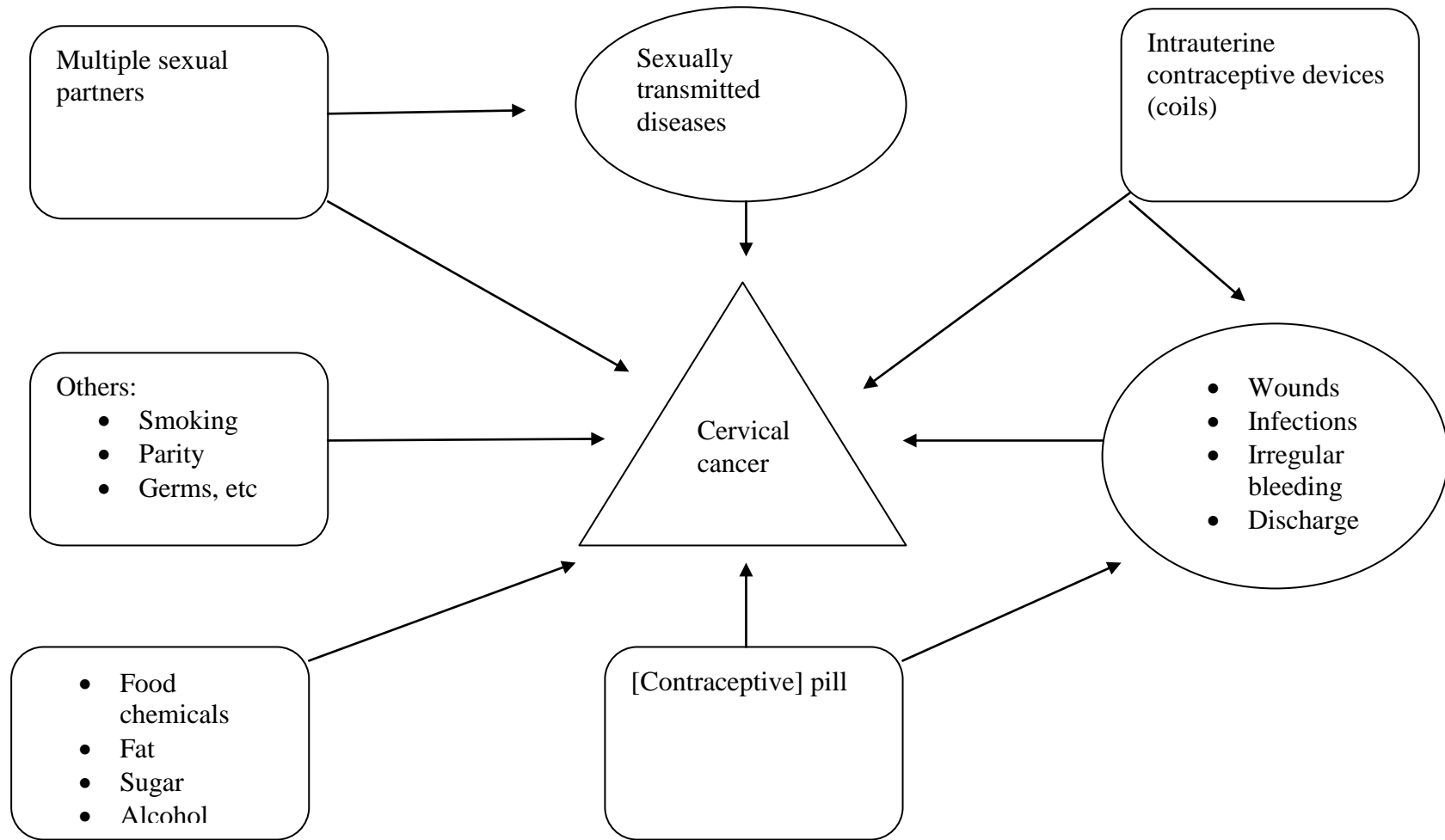
Although cancer incidence in Africa is reported to be increasing, there is evidence that peoples' knowledge of major types, risk factors and signs or symptoms remains limited. This conclusion can be inferred from interview questionnaire studies of knowledge of major cancers in parts of Africa. For example, knowledge and understanding of cervical cancer in Ethiopia (Getahun, Mazengia, Abuhay et al., 2013), breast cancer in South Africa (Maree and Wright, 2010) and prostate cancer in Nigeria (Ajape, Babata, and Abiola, 2010) have been found to be poor and unlikely to promote preventive behaviour. Rather than considering beliefs about the causes of cancer, many interview studies focus upon practical issues relating to cancer such as experiences of screening, treatment and living with cancer. As a result there is a paucity of qualitative studies relating to explanatory models of cancer in Africa. The review below identified three studies that directly considered beliefs about cancer causation.

One study of rural Kenyan women that used semi-structured interviews, focus groups and other qualitative methods found that of 160 interview participants only 40% were aware of cervical cancer (Gatune and Nyamongo, 2005). Of the remainder, 35% had never heard of cervical cancer and 25% were unable to provide any explanation about the nature of the disease. Cervical cancer was principally understood in two ways: wounds on the cervix that did not heal and excessive/irregular vaginal bleeding. One participant, however, described cervical cancer as follows: "a growth that shifts to another part of the body especially on surgery. It relocates and therefore never gets cured". Factors commonly believed to cause the disease included a history of sexually transmitted infection, multiple sexual partners, contraceptive use and complications of childbirth. Other causes cited included smoking, abortion and low standards of hygiene. Four participants suggested that cervical cancer could

be caused by chemical preservatives in food. As a result, the authors proposed a “folk causal model of cervical cancer” for Kenyan women, based upon whether causes were direct or indirect. This model is reproduced below and illustrates the diverse and complex way in which Africans perceive this particular cancer.



**Figure 4. Folk model of cervical cancer among rural Kenyan women (adapted from Gatune and Nyamongo, 2005). Rectangles are direct causes and ovals indicate indirect causes**



Whilst valuable for highlighting the complex way in which Africans understand cancer, two important factors are not included within this framework. First, is a role for cultural beliefs and practices in disease causation and prevention. Second, the model fails to incorporate supernatural beliefs about cancer causation. All these issues are important and known to be prevalent in parts of Africa, for instance as reported in one study of the beliefs of 1100 Zambian women about the cause of cervical cancer (Chirwa, Mwanahamuntu, Kapambwe et al., 2010). This face-to-face interview study was undertaken by peer educators alongside a programme of health promotion about the disease. The findings presented were for women who had never been screened for cervical cancer and reflect the “prevalent myths and misconceptions” surrounding the disease and its prevention. They illustrate the pluralist way in which some Africans understand illness - that is to say, offering explanations that operate at multiple levels. Identified beliefs were broad but included cultural, supernatural and moral explanations:

- Cultural beliefs: “Putting herbs in private parts can cause cancer of the cervix”
- Supernatural beliefs: “When one has cervical cancer that means she was bewitched so I don’t want to know if I have it”
- Religious beliefs: “People think that cervical cancer is not from sex but from a Satanic curse”
- Moral beliefs: “Having sex with a married woman’s husband can give you cervical cancer”
- Stigma beliefs: “People think that if you have cancer, they say you have HIV”
- Heredity beliefs: “Some people think that it’s a family disease”
- Dietary beliefs: “Eating bad food causes cancer of the cervix”
- Hygiene beliefs: “A dirty womb causes cancer so you have to wash yourself out every day”

The above study also illustrated the difficulties of promoting cancer screening in Africa. This is for the following two reasons: the diverse range of causes cited and because certain participants offered a fatalistic view to cervical cancer prevention. Further beliefs reported to be barriers to requesting screening were concern over the quality of the screening (for example, anxiety over hygiene) and possible long-term consequences such as infertility and troublesome menstrual periods. A final challenge reported was that of concern over patient confidentiality in African clinics.

A third, South African study used a questionnaire to explore cancer beliefs amongst teenagers in Africa. This compared the beliefs about cancer causation amongst two participant groups,

described as 338 African and 378 white school pupils (Walker, Rossouw, and Lelake, 1999). The types of cancer that were most widely recognised by both African and white pupils were those of lung, skin and breast. More than 97% of all children recognised smoking as a cause of cancer, but only 42.3% and 52.6% of African and white pupils respectively reported that fruit and vegetables were protective. In this study the authors also considered the effect of other social factors on the children's beliefs about risk. Rather than worrying about future ill-health, both groups were more anxious about unemployment and violence and, for African children, contracting AIDS. This suggests that beliefs about cancer risk should be considered not just in the social context but specifically in terms of a perceived hierarchy of risks, including non-medical ones.

#### **4.1.2 Cardiovascular disease**

One African country where a number of studies has been undertaken to examine beliefs about non-neoplastic chronic disease causation is Ghana. Here cardiovascular disease has been found to be attributed by church members to a variety of causes, including stress, an unhealthy diet, advanced age, and lack of physical activity (Abanilla, Huang, Sinners et al., 2011). Whilst these findings do not appear distant from the biomedical viewpoint, another Ghanaian study found that explanations of hypertension were mostly discordant with the western models of its causation (Spencer, Phillips, and Ogedegbe, 2005). In this study, some participants reported no knowledge of hypertension and others attributed it to the following causes: rapid heart rate, increased blood volume, as well as the product of headache or fatigue. Clearly, these explanations essentially constitute symptoms rather than causes. The relationship between certain symptoms and hypertension was also emphasized by the finding that nearly all participants believed that hypertension caused symptoms, including joint pain, dizziness, and headache. The study illustrates the diverse ways in which Africans explain chronic disease, thus rendering it difficult to generalise people's health beliefs. For example, some participants believed that hypertension had no long-term effects whilst others stated that such symptoms were a sign of imminent death. In this study 58% of patients reported that hypertension was curable, although the authors noted that the Ghanaian language used in the study did not possess a direct translation of the English word "cure".

The type of belief described above is not confined to lay people. Evidence that similar beliefs may be held by medical staff is illustrated in one South Africa study. In this study,

focus groups with community health workers revealed that they had difficulty recognising that individuals without risk factors, such as obesity or having an affected family member, could become hypertensive (Sengwana and Puoane, 2004). Participants reported uncertainty about the causes of hypertension, although they did identify some risk factors such as heredity, lack of physical activity and consumption of lots of salty and fatty food. Many community health workers believed in the effectiveness of traditional medicines for hypertension and, more concerningly, that home-brewed beer was the best treatment. What is more, participants reported a belief that medical treatment made patients sicker, leading to a more rapid deterioration in their health. The study suggests that explanatory models of chronic disease pertain not only to lay members of society but are likely to be closely linked to the beliefs and practices of local health professionals. This scenario clearly calls for interventions that reach both patients and health workers.

### **4.1.3 Stroke**

Little evidence exists for Africans' beliefs about stroke and this literature search only identified two papers that addressed the issue. First, one urban study from Benin (west Africa) found that awareness of stroke and knowledge of its risk factors and symptoms were low (Cossi, Preux, Chabriat et al., 2012). In this interview questionnaire study, 14.1% of participants identified the brain as the affected organ, 34.5% that hypertension was a risk factor and 34.4% that paralysis and hemiplegia were signs of stroke. It seems, however, likely that beliefs about the causation of stroke may differ according to people's location of residence. For example, another study from Tanzania (east Africa) compared the beliefs of people in the city of Dar es Salaam (Dar) and in a rural district (Hai) in the Kilimanjaro region (Mshana, Hampshire, Panter-Brick et al., 2008). Participants included 20 patients, 20 relatives, 10 traditional healers, and 30 other local residents. It was in the urban context that supernatural explanations dominated. The authors point out that stroke – as a condition with sudden onset of symptoms resulting in severe loss of function – may be particularly likely to attract explanations associated with a malevolent force. In this study, supernatural explanations were mainly based upon belief in demons and witchcraft. Unlike many other studies, the researchers explored participants' perceptions of witchcraft and came to the following conclusion:

*“Witchcraft allegations involving stroke were mainly associated with conflict and jealousy within the community – conflict for land (between neighbours) or jealousy related to social advancement (e.g. taking children to school)”(Mshana, Hampshire, Panter-Brick et al., 2008)*

Study participants provided additional details about underlying traditional explanatory models for stroke caused by demons. This is notable because stroke was also reported to be inflicted upon sufferers by demons as a result of the patient’s coming into physical contact with a certain insect. This illustrates the way in which traditional models of chronic disease causation in Africa combine both natural and supernatural forces. Although not suggested by the authors, it is possible that such a belief arises from wider public health messages about preventing tropical diseases that are transmitted by insect bites, such as malaria and sleeping sickness. The account of the participant below illustrates how such beliefs could pose a challenge to preventive interventions based upon lifestyle:

*“Stroke cause is similar to convulsions . we say it is mdudu (insect) ... we say it is an animal meaning it is a bad devil (shetani mbaya) or in other formal language it is a demon.. . when it attacks you, it either stays in all your body parts, legs and arms or in one part of your body”(65 year old male)*

In the rural area, conversely, hypertension, fatty foods, stress and “pressure” comprised the main causation beliefs and witchcraft was rarely mentioned. This difference, the authors suggest, may have arisen from the fact that rural Hai had a long history of influence from Christian missionaries.

#### **4.1.4 Diabetes**

Similar explanatory models have been reported for diabetics in Africa. One qualitative study of the beliefs of Ghanaian diabetics identified a number of explanations for the condition, including the following: high sugar diets, heredity, physiological imbalance, toxic foods, and spiritual disruption such as witchcraft and malevolent social actions (Aikins, 2005; Aikins, 2003). Aikins also reported that diabetics identified its origin as being “blood-borne” or lying in internal blockage or pancreatic dysfunction. It was, however, noted by many participants that such physiological upsets could be remedied through the use of (Christian) prayer. The fear of toxic foods arose from a belief that inappropriate agricultural production and storage methods led to food produce of lower quality. Associated with this was concern over processed and canned foods, rapidly ripening of fruit and the use of spraying to promote

rapid growth. Central to this belief was concern over chemicals - for example, from using modern artificial fertilizers and pesticides and employing poisons to catch wild game (Aikins, Anum, Agyemang et al., 2012).

In another study, Shona-speaking Zimbabweans with diabetes volunteered the following causes for the condition: heredity, use of drugs such as anti-hypertensives, problems of the pancreas and eating “wrong” foods (Hjelm and Mufunda, 2010). The notion of “wrong” foods was summed-up by one participant as “especially foods that contain too much sugar”. Participants recognised the following, additional factors from a list of potential causes suggested by the interviewer: obesity, stress, supernatural causes (including punishment from God and witchcraft) and fate. Very similar explanatory models have been reported amongst type two diabetics in Uganda (Hjelm and Nambozi, 2008), although in this group most participants did not know or were unsure of the cause of their diabetes. Findings also pointed to gender differences in understanding. For example, women perceived diabetes to be a life-long condition, whilst men were uncertain how long it would last and talked about living longer and achieving recovery.

The notion of “excessive sugar” as a cause of diabetes has also been reported from one study amongst mainly non-diabetics in Cameroon (west Africa) (Kiawi, Edwards, Shu et al., 2006). This found that not only was obesity considered a cause, but that it was perceived positively as a sign of “good living” and that many participants underestimated the degree to which they were overweight. In certain Cameroonian cultures, slim young girls who had recently married were expected “to fatten up before relocating into the marital homes”. These findings illustrate the cultural context of chronic disease beliefs and point to challenges in health promotion. This study highlights cultural challenges in the context of promoting a healthy Body Mass Index (BMI). This is because not only was low bodyweight perceived negatively, but it was reported to be a sign of poverty, malnutrition, ill-health and HIV infection.

Finally, one focus group study from rural Uganda identified a range of other causes for diabetes (Rutebemberwa, Katureebe, Gitta et al., 2013). Like the studies reported above, participants stated that diabetes could result from excessive intake of sugar or fatty food. Other explanations included its origin as an airborne disease (from diabetics who cough or spit), from a contagious virus spread by sitting too close to diabetics and by the sharing of utensils, such as cups and plates. Such causes were reported to lead to stigmatisation of

diabetics and to hinder their search for treatment. The study identified other beliefs that could lead to further stigmatisation of sufferers, in particular mistaking diabetes for HIV infection or believing it to be the result of witchcraft. Finally, there were mixed views on the natural history of diabetes. Most participants believed diabetes to be incurable and, ultimately, fatal even with medication. Conversely, in one focus group it was suggested that diabetes was curable, in particular through early diagnosis at hospital. This study is also important because it provided the only evidence identified in this literature review of a belief in diabetes as a contagious disease and indicates some of the effects of such beliefs. The evidence that villagers mistook diabetes for HIV calls for culturally sensitive health promotion for rural east African communities, in particular with regard to interpreting weight loss and the symptoms and signs of different types of diabetes

## **4.2 African migrants' explanatory models of illness and of chronic physical disease**

The explanatory models of African migrants are considered separately here as it is likely that these populations will have been exposed to different health messages and experiences of illness from those who do not migrate. Evidence was sought using the strategy outlined in Chapter One. Additional sources were found by examining citations within identified sources and consultation with colleagues. The literature available was substantially smaller than that identified for explanatory models of Africans still living in Africa. As a result, this section is not divided according to disease group.

Three studies were identified that addressed what can be considered to be general explanatory models amongst African migrants: that is, without specific reference to a single condition. These studies all concerned sub-Saharan Africans migrating to countries in the northern hemisphere. First, Ethiopian migrants to Israel were said to believe that health resulted from “a state of equilibrium within the body and between the body and the outside world” and that illness could arise from physical factors such as heat, cold, drink, worms and sun (Hodes, 1997). Similar general causes of illness are described by Somali migrants in the Netherlands (Feldmann, Bensing, and de Ruijter, 2007). Finally, a more detailed typology of explanations has been described amongst Ethiopian migrants in the UK (Papadopoulos, Lees, Lay et al., 2004). These findings resemble the multifactorial nature of explanatory models described in Africa (Green, 1999), including physical, psychosocial and spiritual causation. Papadopoulos

et al. (2004) found that illness was reported to be mediated via the following causes:

- Germs e.g. through blood, air, food and water; poor cleanliness
- Diet, e.g. eating the wrong foods
- Climate and environment (pollution, flooding, weather changes, cold weather, too much sun)<sup>16</sup>
- Accidents
- Poor socio-economic conditions (inability to afford to eat a balanced diet, keep clean and find suitable shelter)
- Depression and stress
- Unhealthy behaviours (unprotected sex, alcohol/drugs, smoking cigarettes, lack of exercise)
- Social isolation/loneliness
- Supernatural causes (God, Satan or evil spirits, magic, the evil eye)
- Other causes (including self-neglect, inherited disease and iatrogenic causes such as the bad effects of traditional medicines)

Five studies were located that examined African migrants' explanatory models of specific chronic diseases. These findings illustrated a difficulty in that studies of African migrants tend to originate in diverse geographical locations and to consider different populations. One qualitative study compared explanatory models for hypertension amongst Ghanaians, African-Surinamese and native Dutch hypertensive patients in Amsterdam (Beune, Haafkens, Suchuster et al., 2006). Ghanaians and African-Surinamese perceived hypertension as a disease with immediate effects resulting mainly from stress as well as migration-related factors such as adapting to dietary and climate change. Many participants felt a return to their homeland could cure their hypertension and few associated hypertension with obesity, despite many being overweight. It was also noted that some Ghanaians held reservations about sharing their diagnosis with other community members as hypertension was considered as a sign of domestic problems or an inability to fulfil social obligations.

Similar findings for hypertension were found amongst 22 first generation Zambian migrants to Indiana, USA (Siangonya, 2010). For example, stressors such as time pressures, paying bills, raising children in the USA and fulfilling extended family commitments were suggested as causes of hypertension. In addition, the study found that women were perceived to be at a higher risk of hypertension due to the menopause, worry about children and family as well as

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<sup>16</sup> Such folk models of illness are not confined to Africa or to Africans. Similar models have been reported amongst Europeans, most notably in Cecil Helman's (1978) study of the health beliefs of suburban English people in London. This found that body temperature was considered a cause of common illnesses and that these beliefs were *reinforced* by knowledge of modern germ theory.



having to carry greater social responsibilities than men. Some participants showed considerable knowledge of hypertension, for example using terms such as “systolic” and providing figures consistent with a formal diagnosis of the condition. Nevertheless, in these cases it was unclear whether these were participants who had previously been diagnosed with hypertension. Other causative factors described included heredity, older age, excessively strong emotions as well as both lack of rest and insufficient physical exercise. Some participants pointed to a role for salt intake in hypertension causation and one female participant reported concern over the perceived unnatural origin of American foods:

*“No not food from Zambia, that food is natural. The only food that has starch is potatoes, otherwise most of the food, you know they are not processed food. They are natural. Especially vegetables, dried vegetables. They are good”. “Here it’s the chicken, beef, pork, mashed potatoes. Those are the regular foods we eat here.”(Siangonya, 2010)*

Siangonya also reports that participants considered the major consequences of hypertension to be collapse, heart attack, stroke, paralysis, “bursting” of blood vessels and death. A “stress-free mindset” was reported to be an important part of tackling hypertension and a further coping method lay in wider social networks to which Africans belonged. Some participants raised anxiety over taking prescribed medication, including side-effects. Additional concerns were the cost of medication and becoming dependent upon treatment. One male participant offered the following illustration of this:

*“I think that is, they [doctors] quickly, they are trying to solve a problem in a tertiary stage than looking at the cause. What am trying to say is if they can spell out and tell you outright, you know what is causing this is this, then maybe we would avoid these medications so that we don't get hooked on these medications...I spend so much money buying these medications. I was not dependent on them, now am dependent them. I can't do without it. If I don't take it, my blood pressure is high” (Siangonya, 2010)*

A further study looking at ongoing infertility in Ghanaian women in Amsterdam reported a range of explanations for their infertility (Yebei, 2000). Sufferers gave three types of explanations for their misfortune. First, some participants pointed towards physiological processes such as irregular menstruation, ovulation problems and “tubal factors”. Second, others suggested health-related factors, for example high blood pressure, physical stress and excessive weight. It was notable that, although half of the respondents were aged over 40, only one believed that her advancing age was related to her infertility. A third explanation for infertility was based upon supernatural or moral causation of disease, as below:

*“[Some women with infertility] mentioned non-biomedical causes, including witchcraft and beliefs in predestination by God. Other causes mentioned by the women and some informants were misconduct, incompatibility and conflicts in social networks” (Yebei, 2000).*

Only three studies from the UK of African migrants' beliefs about chronic disease were located. One examined health beliefs about hypertension amongst 312 black attendees of a Seventh Day Adventist church in London, ten percent of whom had been born in Africa (Newell, Modeste, Marshak et al., 2009). The authors reported an understanding amongst black participants of the causes and consequences (for example, heart attack and stroke) of hypertension, but no specific recognition of increased risk of hypertension amongst black people. Similarly, the general perception of the condition was that the consequences were not severe. Although a quarter of participants were already hypertensive and a further two thirds found to be at increased risk of developing the condition, there was little sign that behavioural changes were being pursued in order to reduce personal risk. The second study from the UK examined the beliefs of African and black Caribbean origin survivors of cancer in London (Bache et al 2012). This suggested a pessimistic view of cancer outcomes coupled with only limited knowledge of risk factors, based upon diet, alcohol intake, travel history, place of residence and smoking status. In the study by Bache et al, cancer was believed to result from complex and diverse factors, again including stress, as well as genetic and divine causes.

Finally, a third study found limited knowledge of cancer amongst Ghanaian and Nigerian migrants in England (Ehiwe, McGee, Filby et al., 2013). The authors identified similarities in cancer beliefs that are shared with other populations, including different ethnic minorities in England. In particular, secrecy, stigma and fear were common and reported to limit participants' access to diagnosis and treatment. One reason for this was the perception that cancer was contagious, shameful and (particularly for genital or gynaecological neoplasms) embarrassing to disclose to their doctors. That denial, embarrassment and fear serve as barriers is consistent with stepwise models of how in order to access appropriate care vulnerable populations must recognise an illness as requiring treatment, understand how to navigate services and negotiate their need for treatment with front line health service staff, often through face to face interactions (Dixon-woods et al., 2005).

Although the studies outlined above are limited in number and each only considered a small population of African migrants, they suggest that explanatory models for chronic disease are likely to have an effect upon the adoption or otherwise of lifestyle changes. This is because

these models consist of diverse causes rooted in biological, social, moral and supernatural beliefs. In accordance with Kleinman's theory of explanatory models, these findings also have implications for clinical care. One way in which explanatory models influence chronic disease care is through medication adherence. This is important because there is evidence that poor medication adherence is an issue for both black minority patients and African migrants. For example, one cross-sectional survey of black Americans in the USA (including participants recruited at migrant health centres) found that self-reported adherence to medication for hypertension was sub-optimal in one half of those investigated (Lewis, Schoenthaler, and Ogedegbe, 2012). The study only included English-speaking participants and thus it is possible that adherence problems were even greater for African migrants with limited English language skills.

A number of factors may underlie African migrants' poor adherence to medication in chronic disease. First, is a belief amongst many migrants that doctors should *cure* health problems rather than keep them under control (Morris, Popper, Rodwell et al., 2009). Associated with this a notion amongst African migrants that their symptoms themselves may come to represent the illness (Pavlish, Noor, and Brandt, 2010). Thus, it becomes the doctor's duty simply to provide symptom relief rather than tackling a larger, underlying disease process. This is likely to reflect lack of awareness of the chronic nature of some diseases and is consistent with evidence that chronicity is not recognised as a concept by some African societies (Aikins, Boynton, and Atanga, 2010). Chronicity has also been reported to be defined in terms of conditions that are incurable by being unresponsive to both biomedical and traditional treatment (Aikins, Anum, Agyemang et al., 2012). This implies that such diseases are not recognised to be treatable even through *long term* lifestyle change and medication adherence. Further factors that are likely to affect this are a fatalistic view of illness (Vaughn and Holloway, 2009) and concern over side effects from drugs (Nnoaham, Pool, Bothamley et al., 2006).

### **4.3 The use of traditional medicines by African migrants**

A literature search was undertaken to locate studies on the use of traditional medicines by African migrants and is outlined in Chapter One. Although it is recognised that there are few detailed studies on the use of traditional medicines by African migrants (Ventners and Gany, 2009), thirteen such studies were identified. These included a wide range of study types, as

well as diverse participant groups and geographical locations. As a result of this diversity, these studies are presented individually in tabular form overleaf. Ten were found following direct database searches and three from wider reading about African migrant health beliefs.

The literature search referred to above did not include the use of the herbal product “Khat”, a practice common in the Horn of Africa. This product - which comes in various forms and under a variety of names – has psychomotor stimulant effects. Khat is important because it has been suggested that use is associated with increased mental disorder and suicidal ideation (Bhui, Craig, Mohamud et al., 2006). Nevertheless, extensive evidence exists about the properties and use of khat, including some studies of its use by east African migrants. It is not believed to be used by populations covered in this thesis and, therefore, it is not considered further here.

| <b>Authors and date</b>          | <b>Study type, participants and location</b>   | <b>Summary of main study findings relating to traditional medicine use</b>  |
|----------------------------------|--|---|
| Yebei (2000)                     | Qualitative study of beliefs about infertility amongst Ghanaian migrants in the Netherlands  | Participants reported using products purchased at African shops in Europe as well as those imported by herbalists returning from visits to Africa. One reason offered by participants for use of traditional medicine was the desire for a rapid cure. Six out of twelve interviewees believed that pursuing several strategies at once would increase the chances of curing their infertility and lead to a more rapid resolution. A key advantage of consulting a traditional healer lay in easy communication through a shared language. |
| Kuo, Hawley, Weiss et al. (2004) | Questionnaire cross-sectional survey of 322 collected at primary care practices in Texas, USA, including 136 African-Americans. Migrants identified through self-identification of “an | Factors associated with herbal use were non-African-American ethnicity, having an immigrant family history and reporting herbal use by other family members. This may be explained by the fact that only 23% of African-American participants had an immigrant family history, compared with 58% of Hispanics and 100% of Asians. Nearly half of herbal users (46%) reported taking herbal medicines and prescription medications concomitantly   |

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|  | immigrant family history”  |   |
| Papadopoulos, Lees, Lay et al. (2004)    | Interviews with Ethiopian refugees in the UK   | The first action in minor illness for Ethiopian migrants to the UK was reported to include turning to certain traditional foods   |
| Fenta, Hyman, and Noh (2006)             | Cross-sectional structured interview survey of Ethiopians in Toronto, Canada                     | Ethiopians were more likely to consult traditional healers than health care professionals for mental health problems (18.8% vs 12.5%)   |
| Carroll, Epstein, Fiscella et al. (2007) | Interviews with 34 resettled Somali (Somali and Bantu) refugee women in Rochester, New York, USA | <p>Several participants reported using traditional healers and healing ceremonies, prayer, and various foods and home remedies for treating or preventing illness. Some women reported that by using traditional treatments they could avoid having to turn to additional (presumably formal) medical care. A role identified for traditional medicine in preventing the development of early symptoms into a more serious illness. For these reasons, traditional ceremonies, healers, or remedies often used prior to accessing the health care system in the USA.</p> <p>A 20-year-old English-speaking Somali woman provided the following description of the role of a traditional healer: “They [traditional healers] give out medications or treat people in different ways. They read in the Koran and they help you when you are sick.</p> |

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|                                   |  | <p>They read the Koran and help, and things will go away”. Six participants (18%) spoke of healing ceremonies conducted by traditional doctors that are still practised.</p> <p>Out of 34 participants, 13 described traditional remedies for protecting the body against illness and preventing development of more serious illness by treating certain symptoms early.</p> <p>Herbal and nutritional remedies were used to treat a variety of ailments including headaches, gastric problems, body aches, and diarrhoea. One example included treating a child with stomach ache where “no one knows what causes it” by using “herbs, things like garlic, lemon because the stomach ache will go away in a while”</p> |
| Barimah and van Teijlingen (2008) | Questionnaire survey of Ghanaians in Toronto, Canada | <p>Amongst participants, 73% exhibited a positive attitude towards Ghanaian traditional products. This faith appeared to be an enduring one: being born in Ghana or Canada had no effect on attitude towards use. Nevertheless, certain participants did express concern over both the hygienic nature of herbal remedies, including the absence of “expiry dates” on products. This study also found a “mix-and-match” approach to treatment, whereby Ghanaians selected traditional or western medication according to the nature of the illness. Ghanaian healers practising in Canada were reported to exaggerate the efficacy of their treatments</p>  |

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| Knipscheer and Kleber (2008) | Focus groups, in-depth interviews and questionnaires of Ghanaian migrants in the Netherlands | This questionnaire study found that nearly a quarter (23/90) of participants had consulted a herbalist, priest or traditional healer regarding their problem and for one fifth (9/50) this was their first port of call. On the other hand, the authors note that this proportion was less than in Africa and for certain other migrant groups to western countries. One reason advanced to account for this was the predominance in their study of younger, urban-raised, participants. This appeared to account for low use because rural origin and older age were associated with a higher rate of use of traditional services. These findings suggest that the decision to turn to a traditional form of healing is influenced by multiple factors and that the health-seeking trajectories of African migrants should not be seen as simplistic behaviours. |
| Krause (2008)                | Interviews with Ghanaians in London, UK  | Herbal medicines used by Ghanaians in the UK mainly imported from Africa by traders and sold through shops. Some shops have links with herbalists in Ghana who can be consulted by telephone and specific medication then sent across. A few Ghanaian herbalists work in London. Other healers include Christian prophets, Muslim marabouts and fortune-tellers. There is competition between healers who seek to delegitimise other approaches. Medical reasons for consulting include infertility, to improve sexual performance (for men), joint problems and piles. Medication cost is considerably more expensive in UK than Ghana and products are circulated only amongst trusted networks.  |
| Thomas (2010)                | Interview study of   | Participants described personal carriage of traditional products when returning from  |



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|  | southern African migrants in London, UK           | Africa. Traditional medicines also reported to be imported by being shipped from trusted contacts in Africa. For directly imported items, carriage by or from a trusted contact was considered important to ensure that they were genuine. Reasons for preferring traditional medicines included not just faith in their therapeutic efficacy but also a desire to affirm cultural identity. A further indication reported was for the treatment of conditions that eluded the biomedical model  |
| Thomas, Aggleton, and Anderson (2010b) | African migrants with HIV infection in London, UK | A key finding of this study was the absence of disclosure of traditional medicine use to the patients' HIV physician. Such concealed use was sometimes attributed to the physician's failure to take an alternative medicine history but also fear on the part of the patient that the clinician would disapprove of traditional medicine use. Certain traditional products (for example, the plant "aloe vera") were believed to be so natural that they posed no health risk to users and, as a result, some declared a temptation to consume such items in large amounts to ensure their efficacy. The fact that certain herbal remedies were also available in tablet form appeared to lend legitimacy to their use as it suggested that they had been "measured" or officially "approved" |
| Parish (2011)                          | Akan (Ghanaians) in Paris, France                 | Ghanaian Akan shrine priests in France are known to offer treatment through divinatory techniques, ritual use of over-the-counter medication (for example, placing paracetamol tablets inside clothing) and traditional means of promoting positive thinking.  |

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| Ellena, Quave, and Pieroni (2012)        | Senegalese in Turin, Italy. Interview study compared use in Turin with that in a city in southern Senegal                               | <p>In Turin a total of 41 types of medicinal plant was identified during interviews with Senegalese migrants compared with 71 in Senegal. The majority of the medicinal plants recorded in Turin were also used in Senegal. A number of factors was recognised as influencing Africans' use of traditional medicines in Europe. These are dynamic and depend upon the particular individual and their personal situation, including the following:</p> <ul style="list-style-type: none"> <li>• The nature of culture-bound perceptions of herbal products</li> <li>• The existence of transnational networks between Africans and their home country</li> <li>• The availability of traditional practitioners and/or herbal products in food shops in the host country</li> <li>• Legislative restraints on importation and use</li> <li>• The impact of cross-cultural health services in the host country</li> </ul> |
| Simmelink, Lightfoot, Dube et al. (2013) | Two focus groups with a total of 15 East African participants in Minneapolis, USA, including community leaders and health professionals | <p>Many east Africans continue to use certain types of herbal medications to both treat and prevent illness. Participants described types of foods that are used to treat or prevent illnesses such as tapeworm infestation, sore throats, and measles.</p> <p>Growing concern amongst participants was reported over the efficacy of herbal medications. Medically trained participants expressed worry about appropriate dosage of herbal products. Participants discussed the lack of scientific evidence for traditional medicine, but also cited examples of people who had experienced apparent cures of</p>  |

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|  |  | <p>conditions such as cancer and liver disease by using such products. One participant reported that traditional medicines could also offer a psychological or placebo benefit where they were considered to be “trusted and culturally relevant”. Mental illness was believed to be cured by religious leaders using prayer.</p> |
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The studies included in the literature review above echo Kleinman's (1978) call for cross-cultural studies to examine health behaviours in their *local* setting. This is increasingly important because of the scale and multi-ethnic nature of migration from Africa to Europe. Clearly, this situation presents a challenge both to conducting research into traditional medicine use and to generalising findings. These studies do, however, illustrate that traditional African medicines and healers are a highly valued resource for some African migrants. This appears to lie in a desire to affirm cultural identity and demonstrates a deep belief in the therapeutic efficacy of traditional products. The choice to take these appears to be influenced by certain demographic factors - for example, evidence from Africa that use is more prevalent amongst older people and those originally from rural areas. The studies presented above display wide diversity of use, for instance in type of product or healer and ways in which remedies are obtained. Given the location of these studies, such behaviour indicates significant cultural resilience in the maintenance of traditional health beliefs and practices. The transnational dimension to accessing traditional medicines affirms the notion that the "health-seeking trajectories" of African migrants are complex (Knipscheer and Kleber, 2008) and should be considered to be transnational – rather than local - ones. Despite this, the factors that determine the nature of such trajectories remain poorly studied.

The literature reviewed above also points to ambiguity amongst some African migrants over aspects of traditional African medicine, specifically concern over side-effects and dosage. This is consistent with evidence of the variable quality and quantity of phytochemical compounds in herbal products that can result from different soil types (World Health Organization, 2002). A further factor might lie in awareness of possible contamination associated with certain traditional products, for example lead and arsenic poisoning from "calabash clay" that is taken in various parts of Africa during pregnancy (Farley, 2012). Although not discussed in the studies described above, a final reason for uncertainty about the role of traditional products could have arisen from a lack of clarity about the legal status of such products, in both Africa and Europe. This would suggest a need for further research amongst both Africans and western officials over the how African traditional medicines should be regulated in order to protect patients' health and to promote registration of practitioners.

A further aspect of this ambiguity with implications for patient care is evidence from the present literature review of undisclosed use of traditional medicines alongside prescribed ones – for example, antiretroviral agents used to treat HIV infection. The issue of disclosure is likely to be important to primary care as much as in the hospital setting and requires further investigation in order to prevent undesirable drug interactions, side-effects and poor adherence. Central to this is a need for further research into the extent and type of use of traditional medicines to treat chronic diseases. Such research would be strengthened by examining the perspectives of both patients and health professionals. Although not the focus of the present literature search, there also appears to be a need for future research to consider use of traditional medicine by second and third generation Africans in western countries.

The present review is limited by dint of its small number of studies, many of which are from anglophone Africans living in large, international cities. This highlights the limited number of published studies about traditional medicine use amongst African migrants as well as certain challenges to identifying wider data sources. That is to say that nearly a quarter of the studies were located through informal communication with colleagues rather than as a result of a database search. This is likely to be because traditional medicine use only formed a small part of the findings in some of the studies described above. It is, therefore, probable that additional evidence exists in this area, for instance in theses about other aspects of the lives of African migrants. Such sources may also have been published in foreign languages, most notably French, Portuguese and Arabic which are widely spoken in parts of Africa. A final resource that might provide further information lies in exploring media reports. These, however, were not considered in this chapter because they may tend towards sensational conclusions or events that do not represent the behaviour of most immigrants.

## 4.4 Summary

Studies of the health beliefs of Africans and African migrants about chronic physical disease are few. Existing published research suggests that awareness of chronic disease is low amongst Africans and African migrants and explanatory models for them are constructed using a wide range of biological, social, moral and spiritual factors. Major biological beliefs about chronic disease causation are based upon heredity, diet, ageing and

concerns about exposure to unnatural products. Because they draw upon both biomedical and traditional explanations, the way in which Africans express these health beliefs may appear contradictory to an outsider. The situation described above calls for additional research into Africans' explanatory models of chronic physical disease, not least because these may lead to limited preventive behaviour, delayed diagnosis or poor adherence to long-term medication.

A further area where only limited research has been published is the use of traditional medicines and healers by African migrants to western countries. Where such studies have been undertaken these have tended to examine established African communities in large, international cities. What is known points to a deep attachment to traditional medicine amongst a significant proportion of African migrants and that use is often based upon the existence of transnational networks to supply products. Faith in traditional medicine is not shared by all African migrants and there is concern by some non-users over safety and effectiveness. Traditional African healers are recognised to operate in some western countries but remain poorly studied in the context of many African migrant populations. Finally, little published evidence exists about the use of traditional medicine in migrant African communities in the treatment of chronic disease.

# Methodology

## **5) Methodology**

### **5.1 Choice of qualitative methodology**

There are many forms of methodology that can be used to explore the subjective nature of human experience and these stand alongside experimental ones which seek to measure, predict and control (Brechin and Sidell, 2000). In order to understand and, potentially, explain people's behaviour it is necessary to consider the meanings and interpretations that they attach to their actions. In the study of people's experiences of and beliefs about health - including their explanatory models of illness - a commonly taken approach is through qualitative rather than quantitative methodology (Bhui and Bhugra, 2002; Ogden, 2007). The qualitative approach is also a particularly appropriate method for cross-cultural research because its emphasis on interpretation and its flexibility elicits answers that more authentically represent the perspectives of study participants (Liamputtong, 2010). A further advantage of the qualitative approach is that it considers the place of health beliefs within the context of participants' lives as a whole - for example, their social setting and personal networks (Cornwell, 1984).

At the outset of the present study, consideration was given to undertaking direct observation of consultations between GPs and migrants. This might also have been extended to observing African migrants' health behaviours – for example, self care of illness in their own homes. Such an approach was excluded for two reasons. First, were practical reasons that would render it particularly problematic for a physician to integrate themselves into the world of an African migrant. Such dilemmas might include requests for medical opinions and medication, support with immigration applications and assisting with financial hardship. It would also be difficult for a clinician to observe health behaviours without directly influencing them. Second, observation of behaviour normally forms part of an ethnographic approach to research (Patton, 2002). Such a methodology was not considered appropriate for the present research as it did not seek to study a single “culture-sharing group” (Creswell, 2007). This is because the study participants came from a wide range of ethnic, linguistic and religious backgrounds.



Unlike other methods, the qualitative approach employs a hypothesis-generating method, typically including a repeating cycle of data collection and ongoing analysis (Robson, 1993). The advantage of this inductive approach is that it may generate surprising findings, which can then be explored and further interpreted in subsequent interviews (Bryman, 2008). Nevertheless, qualitative methods are sometimes regarded as “soft” approaches and have been criticised for lacking evidence of scientific rigour such as reliability, representativeness and generalisability (Gomm, Needham, and Bullman, 2000). A further criticism of qualitative research is recognition that the interview itself is an active interaction and one that can provide space for a process of *creating* – rather than reporting – subjective meaning (Holstein and Gubrium, 2004). As a result, the researcher’s interviewing style must uncover participants’ own beliefs rather than eliciting notions constructed through shared knowledge or experience. This is likely to be particularly relevant where the interviewer and participant share similar backgrounds, for example belonging to the same profession.

A number of steps has been advanced in response to such criticisms in order to promote rigour in qualitative research. Foremost amongst these is the need for systematic and self-conscious research design, including during the phases of data interpretation and communication of findings (Mays and Pope, 1995). In addition, the validity of qualitative findings may be appraised using independent criteria which are distinct from quantitative ones. These include the presence of triangulation, respondent validation, attention to negative cases and reflexivity (Mays and Pope, 2000). As part of the latter, the qualitative investigator should be aware of, and attempt to set aside, his/her own personal beliefs and experiences as far as possible. This is in order to adopt an independent perspective on the phenomenon that is being studied (Creswell, 2007). Therefore, across the study the researcher should promote reflexivity by considering the ways in which their own background and demographic characteristics may have influenced the study and its findings. One way to identify and explore such areas is by involving colleagues from different backgrounds in the analysis process and the interpretation of data.

## 5.2 Analytical approach: applied thematic analysis

The present study adopted the approach of applied thematic analysis. Although sometimes unacknowledged, this is a widely-used analytical method in qualitative research (Braun and Clarke, 2006). Whilst some researchers consider thematic analysis simply to be a tool employed within a range of different analytic approaches (Boyatzis, 1998), others define it as a qualitative method in its own right (Braun and Clarke, 2006). The present study adopts the latter perspective, namely that applied thematic analysis is, alone, a sufficient and suitable method for examining interview data. Regardless of one's stance on this matter, thematic analysis can be subjected to measures for examining validity in qualitative research described in the section above.

As the term applied suggests, thematic analysis is an approach that seeks to solve research problems of a practical nature by considering issues in the context of their wider social world, including finding solutions to “real world” problems (Guest, MacQueen, and Namey, 2012). Thematic analysis is a rigorous qualitative technique to ensure that interpretations are supported by actual data that are generated during research. This is often an inductive approach that begins with identification of themes emerging from interviews by:

*“identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail... The process starts when the analyst begins to notice, and look for, patterns of meaning and issues of potential interest in the data – this may be during data collection” (Braun and Clarke, 2006)*

As part of an inductive approach of thematic analysis it is essential that the researcher become immersed in the data through diligent re-reading of interview transcripts. Specific codes may then be developed from emergent themes. These require to be validated, for example through discussion with co-researchers to consider alternative interpretations of the data. Finally, the codes can be applied across the interview data sets.

As well as undertaking an inductive approach to theme identification and code generation, thematic analysis can utilise structural coding (Guest, MacQueen, and Namey, 2012). This situation typically arises where a structured or partly structured approach has been taken to the generation of interview content in a study. This is relevant to the present study where in-depth interviews were undertaken around previously identified topics as well as identifying and developing emergent ones. A combined approach is acceptable in thematic analysis: nevertheless, researchers must pay careful attention when coding participant

responses to apriori questions because these may need to be redefined in the light of unexpected content, including the emergence of wholly novel themes. In thematic analysis, codes may also be generated deductively from theory or from a literature review (Boyatzis, 1998).

Applied thematic analysis was chosen for the present study because of its practical approach to examination of qualitative data. This includes its flexible stance on choice of philosophical perspective, in the present case permitting the adoption of a phenomenological interpretation. This is discussed further in the following section. Second, applied thematic analysis allows for practical steps to facilitate data analysis, for example accepting the use of additional techniques such as word searches across lengthy data sources (Guest, MacQueen, and Namey, 2012). This was important in the present study because its multilingual nature meant that multiple terms were used to describe single themes. For example, the words for heart disease are different in English, French and Swahili and word searches offered a practical solution to confirm that these issues were all identified and appropriately coded.

Other approaches were also considered for the present study, most notably that of grounded theory (Glaser and Strauss, 1967). Before considering why a grounded theory approach was not undertaken, it is important to recognise that applied thematic analysis is closely related to grounded theory in many ways. First, is their overlapping aim to promote rigour by ensuring that interpretations are fully supported by the actual data (Guest, MacQueen, and Namey, 2012). This lies in shared methodological components, for example simultaneous collection and analysis of data and iterative data analysis that includes comparison of themes across interviews (Guest, MacQueen, and Namey, 2012). A grounded theory approach, however, was not undertaken in the present study for a number of reasons. First, is the fact that a core component of grounded theory method is that it should lead to the evolution of theory from the study (Glaser and Strauss, 1967). Although grounded theory methods do not assert that everything that emerges should be novel, that a study will elicit a form of brand new theory to account for what is observed remains a bold claim. This is because it is recognised that whilst qualitative studies are likely to deliver rich data, not all will lead to novel hypotheses (McDermott and Palchanes, 1994). Despite this, research that sets out to present a description of social processes on a local scale is a recognised and valued approach in cross-cultural studies. For example, in the context of African cultural studies, it is recognised that local case studies can reveal

“how the ‘big why questions’ of world history actually manifest themselves to human actors in real life” (Lonsdale, 2000). Thematic analysis was ultimately chosen because it not only permits consideration of rich data but does not *preclude* theoretical development (Guest, MacQueen, and Namey, 2012).

Second, the present study was commenced with certain apriori themes, such as Africans’ awareness and experience of traditional medicines *in their home country*<sup>17</sup>. This contrasts with traditional grounded theory methods where generation of themes should, ideally, arise solely from the interview data. As noted above, the present study included a mixture of apriori and emergent themes, including ones that were totally unexpected. A flexible approach to using emergent and structural codes was thus considered essential for the present study since it combined apriori themes (from the in-depth interview topic guide) in the context of African participants, whose beliefs arose from a non-western perspective and could not be predicted by the researcher. Third, recruitment in the present study was anticipated to be problematic and, therefore, the participant sampling was purposive and opportunistic rather than adopting a theoretical sampling approach that is normally used in grounded theory. A final reason for not adopting a purely grounded theory approach in the present study was the practical issue that it was difficult to ensure that data were fully saturated in certain areas. For example, in this study only one traditional healer was recruited: wider sampling of traditional healers and saturation of themes arising from such interviews was considered an unachievable aim given the practical constraints on the project.

### **5.3 Philosophical basis: a phenomenological perspective**

Research methodology must be founded upon a philosophical framework that permits interpretation of the object under examination in order to consider the nature, scope and limitations of the knowledge generated by the study. The philosophical perspective adopted for the present study is consistent with the way of understanding the world known as phenomenology. This school of thought is founded upon the writings of the German philosopher Edmund Husserl and his French counterpart Maurice Merleau-Ponty. The

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<sup>17</sup> In the present study it was anticipated that African participants would have at least some awareness of traditional medicine from their experience in their home country. Exploring this experience formed an apriori interview theme. Aspects of use in the UK arose as a major *emergent* theme.

philosophy of phenomenology has been called “the study of essences” (Van Manen, 1990) as it seeks to examine the meaning to individuals of their lived experience of a particular phenomenon (Creswell, 2007). Central to this is a shift from examining *things* to understanding the meaning of things (Schwandt, 2001). This phenomenological concept is known as “intentionality” and has been defined as the notion that “every act of consciousness is directed towards an object of some kind” (Sokolowski, 2000). In phenomenology, therefore, the reality of an object or experience is entirely contingent upon an individual’s consciousness of it. The ontological perspective of phenomenology is, therefore, a constructivist one. This is the notion that knowledge and meaning are not discovered but, instead, are socially constructed (Illing, 2007). As a result of this, it is assumed that people’s interpretations of social phenomena are in an ongoing state of revision (Bryman, 2008).

In interview studies the researcher can only gain access to the phenomena under study through their informant. This is in contrast to other data collection techniques, for example where findings may arise from the direct observation of participant behaviour. In addition to practical challenges to eliciting data from participants, this calls into question the philosophical interpretation of data provided by another individual. With regard to the nature and origin of knowledge, the approach of phenomenology adopts an interpretivist perspective. This asserts that it *is*, indeed, possible to garner useful knowledge from what is reported another individual - in the present study, in relation to their health beliefs. This refutes the notion that one’s thoughts and experience can only be known from the perspective of the first person (Rakova, 2006). Thus, the epistemological perspective of the present study is an interpretivist one. Nevertheless, it is important to note that phenomenology recognises that the beliefs that individuals describe are essentially reported ones which may, in fact, not be genuine. This is relevant to the findings of the present study because reported health beliefs may, in practice, not lead directly to predictable health behaviours.

Strictly speaking, the present research is not a phenomenological study, but one that adopts a phenomenological *perspective*. This world view was considered particularly suitable for the present study for following reasons. First, the interview contents of the present study consisted of discrete accounts and unique individual stories, particularly from African participants. Second, African migrants beliefs were considered likely to differ markedly from mainstream western thought. This is because, as reported in Chapter Three, Africans’

health beliefs have historically been perceived to lie outside the biomedical model and supernatural causes of illness are reported from many geographical regions across the continent (Murdock, 1980). It is, thus, important for a study such as this one to have a philosophical approach that embraces non-biomedical beliefs and accepts them as representing reality to the informant. Third, a phenomenological perspective is suitable for research conducted in a cross-lingual context. This is because phenomenology is closely related not just to ideas and understanding but also to language. Phenomenology views language as constructed through an ongoing process of shared meanings, understandings and actions (Brechin and Sidell, 2000) and seeks to understand this deeper perspective on what people say. Finally, in its desire to describe and comprehend people's feelings, thoughts and behaviour within a given social context, phenomenology is consistent with the approach to data analysis used in this study, namely applied thematic analysis (Guest, MacQueen, and Namey, 2012).

## **5.4 Choice of in-depth interviews**

Semi-structured interviews were considered at the outset of the present study but were not ultimately adopted. This was for two reasons. First, the principal researcher's personal experience of conducting semi-structured interviews in Africa highlighted that this model may fail to capture sensitive cultural and religious beliefs, especially those that had not been anticipated during the study design. In contrast to this, open questions had been found to elicit responses that were rich in culturally relevant data. Second, it was anticipated that African participants' experience of consulting a GP or knowledge of certain illnesses was likely to be limited. This was because Africans in the present study were not selected according to their health status; that is to say, individuals did not require a specific diagnosis to participate. As a result, a flexible structure to explore the diverse experiences of participants was considered essential. An in-depth approach offered such a solution by permitting questions in areas that were important for the participants and explored their particular experiences of using traditional and formal health care services. This decision was consistent with others who have advocated avoidance of an excessively structured interview process for eliciting lay health concepts from people belonging to ethnic minorities (Curren, 1986).

Focus groups were not undertaken because of recognised difficulties with asylum seekers, including challenges to organisation and difficulties in establishing trust between participants (Higgins and O'Donnell, 2007). It is also known that transcripts from focus groups with migrants have also been reported to be difficult to transcribe and interpret (Yelland and Gifford, 1995). A further disadvantage of focus groups is that participants with a minority perspective may not be heard and time may limit the depth of responses from individuals (Patton, 2002). This was considered important in the present study, which sought to explore the private beliefs of a whole range of such individuals and not just representatives of community organisations.

## **5.5 Participants**

The present research was undertaken using in-depth interviews with one key informant and two participant groups in the west of Scotland:

- One key informant from the African Muslim community.
- Nineteen Swahili- or French-speaking African migrants aged over 18. Recruitment was not dependent upon health status.
- Thirteen GPs with more than two years' experience working with migrant patients. This experience included caring for refugees and asylum seekers, international students or eastern Europeans.

### ***5.5.1 Defining an African participant group***

At the inception of the present study, a major challenge was defining inclusion criteria for the African participant group. A number of factors made it difficult to identify a single, circumscribed population for this study. Africans in the UK are a very diverse group of people and this study affirms recognition that heterogeneity on all levels renders it very difficult for researchers to make generalisations about Africa and Africans (Karp, 1995). African migrants in the UK represent diversity across ethnic identity, religion, country of origin, language(s) spoken, educational level and socio-economic status. In addition, African migrants belong to a range of immigration categories, including asylum seekers, refugees, economic migrants, and students. As reported elsewhere (Barimah and van

Teijlingen, 2008), it became clear in planning the present study that these distinctions may easily become blurred. For example, people may migrate from Africa to other European nations as asylum seekers and later to the UK as European Union citizens.

A further issue is that changes in global migration undermine demographic categorisation by urban/rural origin, nationality or ethnicity. First, African cities are a “melting pot” of populations due to mass migration from rural areas and, thus, individuals and their parents may have lived in both urban areas and villages. People from a single African city may, therefore, come from a range of provinces or ethnic groups. Second, in parts of Africa large international population shifts have occurred that blur definitions of nationality. Modern examples from Africa include the Great Lakes nations and from the countries in the area of the Horn of Africa. In these regions, significant cross-border population movements have occurred in recent decades as a result of civil unrest, such that study participants from these areas could report affinity with more than one nationality. As a result of this phenomenon (as well as to preserve participant anonymity) in this study only the region of origin of participants is reported.

As a result of these dilemmas, the present study adopted language knowledge as an inclusion criterion: namely, originating from a French- or Swahili-speaking country. This was a pragmatic choice as the principal researcher was familiar with medical consultations in these languages and this would, therefore, remove the need of interpreters. It should be noted, however, that during the present study interviews with African participants were mainly conducted in English in those cases where the participant was clearly competent and desired to express him/herself in English.

### ***5.5.2 Recruitment of African participants***

The present study sought primarily to interview a range of “ordinary” sub-Saharan migrants living in the west of Scotland. This is consistent with what has been called a call to reach “authentic voices” amongst cross-cultural study participants rather than others who speak for them, such as community representatives (MacDougall and Fudge, 2001). Nevertheless, at the inception of the study it was anticipated that such recruitment could be problematic and, therefore, the option of interviewing community leaders as key informants was included in the planned methodology. This approach has been used elsewhere in studies of African migrants to explore sensitive health issues (Burns, Imrie,



Nazroo et al., 2007). Ultimately, in the present study it proved necessary to interview only one key informant from the African community, the first recorded interview of the study.

Africans were recruited from community organisations with members from the African community in the west of Scotland. These organisations were identified by web-based searches and included groups founded upon country of origin, language spoken or religious identity. Ultimately, most participants came from two two protestant churches and five African societies. Group leaders were approached by the principal investigator using email and telephone contact details in the public domain. A meeting was arranged between the principal investigator and individual leaders who responded favourably. Leaders were asked to contact members with the participant information sheet who then responded directly to the principal investigator. A date and a potential interview location were then arranged with those individuals who agreed to participate. Community group leaders and potential participants were provided with the study information sheet (see Appendix) prior to agreeing to participate.

A process of onward chain sampling (“snowballing”) from initial contacts was employed to facilitate the identification of other, potential respondents (Faugier and Sargeant, 1997). It was anticipated that by commencing “contact chains” through individuals in different starting points it would be possible to reach a diverse range of participants. Initially new participants with similar characteristics were accepted in order to facilitate onward chain sampling. This was also because experience had shown that recruitment might not be straightforward (O'Donnell, Higgins, Chauhan et al., 2007).

A purposive sampling strategy was adopted in order to endeavour to recruit a participant group that broadly represented the wider population of French- and Swahili-speaking Africans in Glasgow. For such a diverse population it was evidently not possible to aim for a truly representative sample. Following discussion with supervisors and African community leaders, three overarching criteria were agreed upon for categorising participant characteristics in order to ensure diversity. These variables were: gender, age, and religious tradition (Christian or Muslim). As a result of the limited scale of the present research it was decided not to categorise participants according to other important characteristics such as socio-economic status, duration of stay in the UK or educational level. Nevertheless, additional demographic information was collected in order to consider the effect of these variables. Using the criteria of gender, age, and religious tradition, a target number of twenty four participants was identified (see Table Four in the Appendix).

This figure was also based upon similar qualitative studies investigating health beliefs and primary care consultations (Bhatia and Wallace, 2007; Kokanovic, May, Dowrick et al., 2010; Yebei, 2000). Ultimately, the number of participants was determined by saturation of the themes that comprised the major findings in the study. Data saturation occurs when no new ideas about issues under study are generated by undertaking additional interviews (Creswell, 2007).

### **5.5.3 Interview conduct: African participants**

The development of an interview topic guide was informed by the existing literature on migrant consultations in general practice. In addition, its content was developed through discussion with project supervisors, clinical colleagues and preliminary meetings with leaders of three African community groups. The topic guide used in this study for interviews with African participants is included in Table Seven. In keeping with the nature of in-depth interviews, this was employed as a broad guide in order to explore the individual nature of participants' beliefs and experiences whilst also covering similar material between interviews. Findings from early interviews were used to inform the content of subsequent ones.

Interviews frequently began by asking participants about their knowledge of languages and what was normally spoken at home. Speakers of Swahili were asked how they would construct medical phrases such as "I am ill" as a means of considering cultural and linguistic influences on health beliefs. This approach also served as an "icebreaker" in order to establish rapport and to facilitate later discussion on health topics. The interview then examined participants' experiences of GP consultations, with particular reference to antibiotic prescription as an example of potentially conflicting expectations. Further topics included participants' sources of health information, perceptions of health threats, beliefs about traditional medicines and explanatory models of chronic disease. However, interview content to a large extent focused upon those issues of which an individual had significant personal experience or felt most comfortable discussing. Some of the practical challenges encountered in this approach are considered in the final chapter of this thesis.

#### **5.5.4 Recruitment of GP participants and interview conduct**

An informal network of doctors interested in international health was used to approach GPs working with migrants. GPs were contacted by the principal investigator by email via this network. Potential participants received a copy of the participant information sheet for GPs (see Appendix). A meeting was arranged with GPs who responded favourably, typically in their own home. Signed consent was obtained prior to interviewing. At the end of interviews, further participant contacts were sought using a chain sampling (or “snowball”) technique. As part of this, the direction of recruitment was modified partway through the study in order to obtain the views of two groups of GPs that had not been considered during the planning stage of the project: GPs working with students and GPs of African ethnicity. This was, first, in order to consider migrants who had come to the UK for reasons other than seeking asylum or employment. Second, the perspectives of African GPs were considered valuable in the context of conflicting viewpoints between Africans and European GPs. Demographic data were collected for GP participants and are included in Table Six in the Appendix.

The themes covered with GP participants are included in Table Eight in the Appendix. These were generated through discussion with supervisors, knowledge of the literature and to mirror some of the important contents of interviews with African participants. As with interviews with Africans, issues emerging from GP interviews were used to inform later ones. Topics included experience of differing expectation of health care in consultations with migrants, with particular reference to GPs’ antibiotic-prescribing practice for common symptoms in the absence of clinical signs. Additional areas examined included professional issues encountered in consultations with migrants and beliefs about burnout in this role. Finally, experiences of chronic disease in Africans emerged as an important theme from interviews with African participants and was examined in later interviews with GPs. Throughout these interviews it was considered inevitable that clinicians’ experiences with other (i.e. non-African) ethnic groups would be elicited. This was welcomed but, where possible, examples from African patients were specifically sought.

## 5.6 Conduct of interviews and data analysis

Signed consent was taken prior to every interview (see Appendix). The principal researcher kept informal notes in English across the entire study and these served to inform the content of subsequent interviews, data analysis and discussion of study findings. Interviews lasted from 34 to 82 minutes (mean = 67 minutes) and were conducted at a time and venue chosen by the participant, including their home, Glasgow University teaching rooms and cafés in the city. Of the 19 interviews conducted with Africans seven interviews were in French, three in Swahili and the remainder in English. As many participants were multilingual, interviews often contained words or phrases in the three study languages, as is illustrated in quotations included in the Results chapters of this thesis.

Interviews were recorded using two digital audio-recorders and subsequently transcribed. Most transcription was undertaken by the principal researcher (27 interviews) and six by a professional secretary. Two interviews with English-speaking Africans transcribed by the professional secretary required considerable correction by the principal investigator due to participants' accents. In addition to transcription, all interviews in French (seven) and Swahili (three) were translated by the principal investigator who has experience of conducting qualitative research in French (Cooper, van der Loeff, McConkey et al., 2010) and Swahili (Cooper, 1995) in Africa. Rather than word-for-word translation, interpretation was undertaken with a view to reconstructing the value or meaning of the original term or phrase (Simon, 1996). The accuracy and cultural appropriateness of the translations was assessed by asking native speakers to review randomly selected and anonymised portions of interview transcriptions. In addition, the translation of quotations selected for this thesis were reviewed by, and discussed with, Africans fluent in Swahili or French in order to consider alternative interpretations of the data.

Data analysis was undertaken using applied thematic analysis (Guest, MacQueen, and Namey, 2012), a method informed by the approach of Grounded Theory. Anonymous interview transcripts were imported into the NVIVO software package to facilitate data coding and analysis. Data were coded from early on in the study in order to identify emerging themes from the data and to inform the content and direction of future interviews. Following reading and re-reading of the transcripts, codes were applied to portions of the text by the principal investigator. These were then reviewed and re-ordered

into thematic categories. A sample of interviews was also independently coded by two study supervisors. That was in order to allow for alternate interpretations, typology and hierarchy of themes. In order to establish consistency, emerging codes and themes were reviewed in data clinics by the three coders to review discrepancies and to seek agreement on coding. Where possible this included constant comparison across interviews (Glaser and Strauss, 1967) and across key variables such as gender, educational attainment and religion. The final coding framework was then applied to all the interviews by the principal researcher.

In the Results chapters that follow, quotations were selected to illustrate particular points. Whilst seeking to preserve anonymity, quotations make reference to the participant number, gender, and age. For African participants this includes the original language(s) of the quotation used (e.g. African 3F 40-49 French) or for GPs their country/continent of origin (eg. GP2 30-39 UK). Where these include more than one language they are listed in order, starting with the one which was most frequently used in the quotation. Original quotations in French and Swahili are included as footnotes. It should be noted that many participants used non-standard grammatical forms in all three languages. As these are so numerous they are included uncorrected. Additional words have been included in brackets only where this is required to clarify meaning.

## **5.7 Validation of transcription and translation**

In any qualitative study it is important to strive for authentication of data. It is, however, known that translation between languages can be challenging, particularly where cultural and conceptual differences exist (Bhui, Mohamud, Warfa et al., 2003) such as between European and African languages. What is more, translating health concepts between languages is a recognised problem (Currer and Stacey, 1986). Given these challenges, in this study the principal researcher sought to provide the “best possible sense of the interviewee’s original speech” following Marston, 2005. Importantly, this implied not adopting a word-for-word translation. Instead this approach sought to preserve the meaning and value of the original language.

As part of this process, consideration was given to verifying both translation and transcription in the research process. Direct translation verification (i.e. third party listeners to the interview audio recordings) was not undertaken in the present research.

The decision that only the principal researcher should listen to and undertake transcription of interviews in French and Swahili was for the following reasons. First, in planning discussions with African community organisation leaders it was stated that Africans would be very reluctant to participate if they thought that someone from their own background might listen to the interview and risk identifying the original speaker. Community members raised concern that this might be particularly acute for Swahili speakers who would be aware that any first language interpreter was likely to belong to local networks. It was suggested that this would adversely affect both recruitment and the authenticity of interview data. As a result, the ethics committee application (and approval) did not include permission to use an African to transcribe for Swahili interviews.

A second barrier to the use of professionals for transcription, interpreting, and translation was cost. This was potentially enormous and beyond the means of this postgraduate project. One aspect of this was that the study languages are spoken in Africa using a range of dialects and therefore no single individual interpreter could be expected to be able to translate all interviews in a specific language. As the principal investigator had experience of using Swahili and French with Africans from a range of countries, it was possible to take into account language mixing and dialect use without resorting to multiple interpreters.

A number of solutions exist for verifying translation accuracy. One strategy to promote quality in cross-lingual research is “blind back-translation” where the text is translated back from the target language to its source language by another interpreter for comparison (McDermott and Palchanes, 1994). This was not undertaken in the present study due to the enormous work and financial implications recognised to be necessary in adopting such an approach (Bhui, Mohamud, Warfa et al., 2003). Nevertheless, the quality of the translation in the present study was independently reviewed in two ways. First, for a few participants it was possible to verify certain portions of text from their interviews that were unclear or ambiguous. Second, anonymised random sections of interviews were sent to four non-participant African French and Swahili speakers for review. Translation reviewers did not receive payment for these comments and they were not relatives of the principal researcher. As well as commenting upon the quality of the translation, this approach underlined the diverse ways in which Swahili may be translated into English and suggestions for improving translations were used to inform the final versions. The following opinions of the quality of the principal investigator’s translations were received:

*“I think you have done a really good job. You have captured meaning, but also, and perhaps more importantly from a research perspective, the delivery of the speaker, which at times is quite complex. For the purposes of your research, I would proceed as you are doing, obviously you will probably want to ‘tidy up’ sections for inclusion in your chapters” Professional English-French language interpreter (female)<sup>18</sup>*

*“The translations are perfect apart from the part for the translating ‘the Congolese normally get 60% of it wrong’ - because they pick and drop Kiswahili with French so it sometimes changes the meaning completely” Native Swahili speaker (female)*

*“I had a look at the translation. The overall meaning in English is what is said in French, I could not see any error. But on page 8 there is a translation regarding ‘fissure dans les nerfs de la tete’, I could guess that you translated the hole [sic] context but it's not clear from that short French sentence; you may wish to have a look at it again” French-speaking African health professional (female)*

*“There is no major problem [here]”<sup>19</sup> Native Swahili speaker (male)*

In order to improve accuracy of translation and analysis of qualitative data it has been suggested that interview contents should be both transcribed and analysed in the original language prior to translation (Twinn, 1998). In the present study the principal investigator examined all data in its primary language during analysis and writing up in order to remain grounded in the original interview texts. In pursuit of keeping translated data close to its original form, quotations were maintained in this thesis throughout writing-up as a footnote, rather than an Appendix. This also was in order to help ensure that data in the primary language were readily accessible to future researchers.

## 5.8 Ethical issues and confidentiality

A number of ethical issues was considered in the preparation and implementation of the present study. Although the present study did not intentionally seek to elicit stressful life experiences, this was indeed a possibility in a number of areas. For African participants these included first-hand experience of life-threatening illness, trauma experienced during migration from African to Europe and distressing encounters with health care services in the UK. This risk was exacerbated in the present study due to linguistic and cultural differences that might lead to misunderstanding. Such issues were not confined to African

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<sup>18</sup> MSc in Translation and Interpreting, a Diploma In Public Service Interpreting, and 10 years' professional experience as an interpreter and translator (Working in French and English)

<sup>19</sup> “Hakuna shida mkuu”

participants as there was also potential for stressful accounts to emerge during interviews with GPs. Controversial areas that might have arisen included experience of physical violence with patients, reports of unprofessional behaviour towards patients or accounts of serious allegations against employers. These risks were limited in the present study in two ways. First, was by recruiting Africans from community groups and GPs through informal networks. As these groups were relatively small, such an approach made it unlikely that any individual with a particularly negative experience would come forward to present their case in terms of a grievance. Second, the principal investigator was prepared to keep interviews with GPs focused upon issues relating to the study area and, with Africans, to offer to curtail the interview if participants were to become distressed. In this event, the principal investigator would provide the participant with the contact details of services providing suitable support<sup>20</sup>.

A further ethical issue within the present study arose from the fact that there was a financial incentive for African participants. These people were offered £15 in recognition of their time and travel. The idea of using such a financial acknowledgement arose during a meeting with African community group leaders, who felt it necessary if they were to recruit participants. A further aim was to dissociate study participation from requests for medical advice to the principal investigator. A financial incentive is most likely to have ethical implications for the recruitment of participants from low socio-economic backgrounds, for example asylum seekers and refugees. Despite this, seeking ethical approval for inducement was considered acceptable in the present research as it did not involve the following controversial situations (Grant and Sugarman, 2004):

- where there is a dependency relationship with the researcher
- where risks are particularly high
- where the research is degrading
- where the participant would only consent if the incentive was relatively large

The present study was not considered to fulfil these criteria. A further reason for adopting this approach was evidence that financial payment had recently been used in other community-based work and the sum being offered in the present research was

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<sup>20</sup> For example, the Scottish Centre of the Medical Foundation for the Victims of Torture



commensurate with that in such studies. Examples of the latter include evaluation of the national anticipatory care Keep Well Project (O'Donnell, MacKenzie, Reid et al., 2010) and elsewhere (NIHR, 2010), including research of unmet health care expectations in migrants (Marshall, Wong, Haggerty et al., 2010).

Ethical approval for the present study was not required from an NHS Research Ethics Committee for two reasons. First, Africans were recruited through community organisations and not through the NHS. Second, interviews with health care professionals no longer require NHS approval. That this was the case was verified with the NHS Research and Development Directorate, Western Infirmary, Glasgow. Ethical approval was instead sought from the University of Glasgow Faculty of Medicine Ethics Committee<sup>21</sup> in January 2011. This specifically included permission for a financial incentive. As part of this approval, measures were included to ensure that consent was voluntary and that confidentiality would be preserved. Prior to their interviews, participants were provided with the participant information sheet and the reasons for undertaking the study discussed. Signed consent was obtained from all participants prior to their being interviewed. All participants were assured of anonymity and the process outlined as follows. First, whilst only the principal investigator would listen to the interview recording, anonymised transcriptions were to be read by others involved in the study and portions of these would ultimately be used for publication in scientific journals. In order to preserve anonymity, digital audio-recordings were labelled using an identification code and signed consent forms (see Appendix) were marked with the audio file reference and these were stored separately. Recordings of interviews were kept on password-protected data storage systems and – where possible – in a locked cabinet. Interview recordings were all destroyed at the end of the study.

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<sup>21</sup> This committee has since changed its name to the Ethics Committee of the College of Medical, Veterinary and Life Sciences, University of Glasgow

# Results

## **6) Chronic disease: risk perception and explanatory models**

The Results section below consists of four chapters that consider the following themes: explanatory models of chronic disease, antibiotic beliefs and treatment-seeking, traditional medicine use and, finally, the dynamics of migrant consultations in general practice in the context of street-level bureaucracy theory. These chapters are constructed around major themes emerging from the interview data and are illustrated using participant quotations. During the study it was noted that Africans frequently talked about their beliefs and experiences using short sentences, sometimes in the form of “throw away” comments. As a result, some evidence in this thesis is presented in the form of brief quotations. Before examining the study results, this section begins by presenting demographic characteristics of the participants.

### **6.1 Participant characteristics**

The study ended after interviewing the following number of participants: 1 key informant, 19 Africans and 13 GPs had been interviewed. The characteristics of all these participants are included in Tables One and Two below. This cut-off point was chosen because data saturation was reached in the major study objectives. A limiting factor to further interviews was recognition of the length of time required for recruitment, transcription and translation by the principal investigator.

African participants possessed a broad range of demographic characteristics, with the notable absence of Muslim males (see Table One). Amongst the African participants, nine primary participants were interviewed and onward chain sampling (“snowball”) recruitment resulted in four chains of one additional participant and one of six. Of the nineteen participants in the African group, nine were women of whom three were Muslim. Participants were from a range of countries from Africa’s central belt, including both Congo republics, Burundi, Rwanda, Somalia and Kenya. During interviews it became evident that definitions of nationality were not clear cut. That was because some participants had lived in multiple African countries and tended to identify with either their place of birth or the country of origin of their parents. A similar lack of clarity arose with regard to immigration status: some participants had migrated to other European states as

asylum seekers prior to coming the UK as European Union citizens. For these reasons - and the inclusion of two students in the study - it proved problematic to interpret results according to nationality and immigration status. The health status of participants was not directly sought during recruitment; however, three patients volunteered that they had hypertension (African interviewees 6 and 19), diabetes (6) or asthma (15).

GP participants included individuals with experience of caring for key groups of migrants: asylum seekers and refugees, international students, economic migrants (principally eastern Europeans) and destitute patients, particularly asylum seekers who had been refused leave to remain in the UK.

**Table 1. Characteristics of African participants**

| <b>Id no.</b> | <b>Age</b> | <b>Religion</b> | <b>Languages (main language of interview given first)</b> | <b>Area of Origin</b> | <b>Age of finishing education</b> | <b>Years in UK</b> | <b>Immigration status</b> |
|---------------|------------|-----------------|---|-----------------------|-----------------------------------|--------------------|---------------------------|
| Key Informant | 40-49      | M               | Eng/Arabic  | Sudan                 | >25                               | 5-10               | MWS                       |
| 1F            | 25-29      | C               | Eng/Sw  | EA                    | 17                                | 5-10               | AS/R                      |
| 2F            | 30-39      | C               | Eng/Sw/OA   | EA                    | 17                                | 5-10               | MWS                       |
| 3F            | 30-39      | C               | Fr/Eng/OA/OE  | Congo                 | 27                                | 5-10               | MWS                       |
| 4F            | 40-49      | C               | Fr/Eng/OA   | Congo                 | 22                                | 5-10               | AS/R                      |
| 5F            | 50-59      | M               | Sw/Eng/OA   | EA                    | 21                                | 5-10               | AS/R                      |
| 6F            | 60-69      | C               | Fr/OA   | Congo                 | 17                                | 5-10               | AS/R                      |
| 7M            | 20-        | C               | Eng/Sw/OA   | EA                    | Still in                          | 5-10               | MWS                       |

|     |       |   |               |                          |                    |       |      |
|-----|-------|---|---------------|--------------------------|--------------------|-------|------|
|     | 25    |   |               |                          | education          |       |      |
| 8F  | 30-39 | C | Eng/Sw/OA     | EA                       | 21                 | 10-15 | AS/R |
| 9M  | 30-39 | C | Eng/OA/Sw     | EA                       | 24                 | 2-5   | MWS  |
| 10M | 18-24 | C | Eng/Fr/Sw     | Congo                    | Still in education | 10-15 | AS/R |
| 11F | 40-49 | M | Swa/Eng       | EA                       | 0                  | 5-10  | AS/R |
| 12M | 30-39 | C | Eng/Fr/OA     | Franco-phone west Africa | 29                 | 2-5   | MWS  |
| 13M | 30-39 | C | Fr/Sw/Eng/OA  | Congo                    | 25                 | 5-10  | AS/R |
| 14F | 30-39 | M | Sw/Eng        | EA                       | 11                 | 10-15 | AS/R |
| 15M | 30-39 | C | Eng/Fr/Sw//OA | EA                       | 24                 | 10-15 | AS/R |

|     |       |   |              |       |     |       |      |
|-----|-------|---|--------------|-------|-----|-------|------|
| 16M | 40-49 | C | Fr/OA/Eng    | Congo | 25  | 5-10  | AS/R |
| 17M | 40-49 | C | Fr/Eng/OA    | Congo | 27  | 10-15 | AS/R |
| 18M | 50-59 | C | Fr/Eng/OA    | Congo | c25 | 5-10  | AS/R |
| 19M | 50-59 | C | Fr/OE/Eng/OA | Congo | c25 | 5-10  | AS/R |

EA = Eastern Africa (Somalia/Tanzania/Uganda/Rwanda/Burundi); Congo = Democratic Republic of the Congo/Republic of Congo, OA = Other African language(s); OE = Other European languages, AS/R = Asylum seeker/refugee; MWS = Migrant worker/student visa.

**Table 2. Characteristics of GP participants**

| <b>Id. number</b> | <b>Gender</b> | <b>Age Group</b> | <b>Country of Origin</b> | <b>Work pattern</b> | <b>Foreign language knowledge</b>     |
|-------------------|---------------|------------------|--------------------------|---------------------|---------------------------------------|
| 1                 | F             | 40-49            | African                  | Part-time           | French and African language(s)        |
| 2                 | F             | 30-39            | UK                       | Part-time           | Three European language(s)            |
| 3                 | F             | 50-59            | Europe                   | Full-time           | European language(s)                  |
| 4                 | M             | 40-49            | Europe                   | Full-time           | European and Asian languages          |
| 5                 | F             | 40-49            | UK                       | Part-time           | Other European language (basic level) |
| 6                 | F             | 50-59            | UK                       | Part-time           | None                                  |
| 7                 | F             | 40-49            | UK                       | Full-time           | Other European language (basic level) |
| 8                 | M             | 60-69            | Africa                   | Part-time           | African language(s)                   |
| 9                 | F             | 50-59            | UK                       | Part-time           | Other European language (basic level) |
| 10                | F             | 40-49            | UK                       | Part-time           | None                                  |
| 11                | M             | 50-60            | UK                       | Part-time           | None                                  |
| 12                | F             | 40-50            | south east Asia          | Part-time           | Three south east Asian languages      |
| 13                | M             | 40-49            | UK                       | Full-time           | None                                  |



## 6.2 Africans' perception of chronic disease risk

Early interviews examined Africans' experiences of consulting doctors in the UK's NHS. During these, a lack of awareness of chronic disease risk became apparent, even amongst participants with higher levels of education. Many seemed not to be worried about future illness and this appeared to be due to a focus upon symptomatic conditions and a belief in serious disease as a phenomenon that affects other people:

*“[Africans are not worried] apart from what they are [already] suffering .... there's nothing people are worried of catching, nobody, I have never heard of anybody thinking about cancer. People think that cancer is maybe somebody else's disease... [laughter]... but not theirs... and you know such things... people are positive”*  
(African 1F 25-29 English)

When specifically questioned about major health threats facing African migrants, no participants without an existing chronic disease identified cardiac disease, hypertensive disease or diabetes as important threats. Despite the fact that most had resided in the UK for five years or more, participants tended to talk about infectious and communicable diseases, for example HIV infection, tuberculosis, “flu”, sexually transmitted diseases, colds and what was described as “high fever”. This tendency to consider infectious over non-communicable, chronic disease was underlined by one participant who reported that for lung problems: “I have always thought of an infection, tuberculosis [rather] than cancer”<sup>22</sup> (African 17M 40-49 French).

The predominance of the infectious disease model appeared to influence the language that participants used to describe chronic conditions. It was notable that some French-speaking participants voluntarily described chronic diseases in terms of being “caught”. This verb was used most commonly for cancer, but also for heart disease, diabetes and hypertension. For one participant, transmission was suggested by his attempt to explain diabetes: “how to prevent diabetes from coming or from penetrating my body? I do not know what it is due to, what transports it, or is it the food, or is it the alcohol or cigarette[s]?”<sup>23</sup> (African 16M 40-49 French). For another, it was even reported that Africans might avoid a diabetic

<sup>22</sup> “J'ai toujours pensé à une infection, la tuberculose que le cancer”

<sup>23</sup> “Je vais empêcher le diabète de venir ou de pénétrer à mon corps comment? Je ne sais pas c'est du à quoi... c'est véhiculé par rapport à quoi ou c'est alimentation ou c'est l'alcool ou c'est la cigarette”

person “thinking perhaps it is a contagious disease”<sup>24</sup> (African 18M 50-59 French). Such statements are consistent with evidence from Uganda of a belief that diabetes is contagious and is spread by close proximity or by sharing utensils (Rutebemberwa, Katureebe, Gitta et al., 2013).

Amongst healthy participants the only chronic condition that was said to be a threat was cancer. Cancer was frequently recognised as something to be feared and was viewed as incurable. There was also a notion of lack of control over its causation: “I think everyone is scared of getting cancer - but anyone can” (African 2F 30-40 English). One participant simplified cancer to internal and external forms: “there’s that cancer disease of the skin and cancer inside the body”<sup>25</sup> (African 14F 30-39 Swahili). Others, however, recognised that cancer can affect many different parts of, and organs within, the body: “I know that there are prostate cancers, there are breast cancers, there are stomach cancers, there are cancers in the arms, there are cancers that come in all types”<sup>26</sup> (African 13M 30-39 French).

When asked, most participants volunteered at least one explanation for cancer, although one struggled to find an explanation:

*“Like my friend who died of liver cancer he wasn’t a heavy drinker, he wasn’t someone who drank a lot. You know you are talking about someone who has four or five beers a weekend but he had liver cancer. I really don’t understand, it is something up to this day I don’t understand how it happened” (African 7M 20-25 English).*

However, no-one suggested that Africans were at any greater risk of developing certain cancers than were Europeans. Indeed, a commonly reported observation was that cancer was significantly more common in Europe than Africa: “in our place [in Africa] there is not a lot of cancer, here there is a lot, but where does that come from? Things we eat? In the food?”<sup>27</sup> (African 6F 60-70 French). Indeed, cancer was described as “a European disease”<sup>28</sup> (African 17M 40-49 French).

<sup>24</sup> “Les gens ne pourront peutetre pas l’approcher croyant peutetre c’est une maladie contagieuse”

<sup>25</sup> “Kuna hiyo cancer ya ugonjwa ngozi na cancer ndani ya mwili”

<sup>26</sup> “Je sais qu’il y a des cancers de la prostate, il y a des cancers des seins, il y a des cancers des estomacs, il y a des cancers dans les bras, il y a les cancers qui viennent de toute sortes”

<sup>27</sup> “Mais chez nous il y a pas beaucoup de cancers. Ici c’est beaucoup mais ca vient ou? Les choses à manger? Dans la nourriture?”

<sup>28</sup> “Une maladie européenne”

While some participants considered this observation to be correct, a few recognised the issue of under-diagnosis in Africa: “but now is when I understand that it is only the rich people who could afford to go for scans” (African 7M 20-25 English). Thus, cancer was not only associated with Europe but also with affluence. Only once was this perceived difference accounted for in terms of specific risk factors associated with a “somewhat luxurious life”<sup>29</sup>: cancer was reported to be more common in western “celebrities” due to “cosmetic products” and “frequent artificial suntans”<sup>30</sup> (African 17M 40-49 French).

When confronted with the suggestion that Africans were at increased risk of certain chronic conditions, there was widespread surprise: “I could believe you as a scientist but just looking at [it] like that, I don’t think so”<sup>31</sup> (African 18M 50-59 French). It was reported that the African community was “not sufficiently informed”<sup>32</sup> about chronic diseases and that Africans only “learn by going [to the doctor], by falling ill, yes, you learn by falling ill that there is a [certain] disease that exists”<sup>33</sup> (African 13M 30-39 Swahili). A further reason for little awareness was reported to be that talking to other Africans about serious diseases was considered a “taboo”<sup>34</sup> (African 3F 30-39 French). Possibly as a result of this, participants stated that the internet and emails were important resources for health information.

## 6.3 Africans’ explanatory models of chronic disease

### 6.3.1 Explaining chronicity: imbalance and short-term treatment for symptoms

Some participants struggled to explain chronic diseases and there was sometimes resistance to questioning on the grounds that this information was specialist knowledge for doctors. Chronic disease was described as “permanent disease”<sup>35</sup> (18M 50-59 French) or

<sup>29</sup> “Une vie un peu luxurieuse”

<sup>30</sup> “La majorité des gens que nous entendons, célébrités, quelqu’un qui prend beaucoup soins de lui, les produits cosmétiques, de gamme varié, mode de vie un peu distingué, chaque fois dans le bronzage artificiel. Vous voyez? Moi je crois bien que c’est relatif à ça”

<sup>31</sup> “Je pourrait vous croire comme scientifique mais à bien voir comme ça je crois pas”

<sup>32</sup> “La communauté africaine n’est pas assez informée”

<sup>33</sup> “Tu apprends en allant, en tombant malade, oui, tu apprends en tombant malade que c’est une maladie qui existe et qui peut-être, peut-être ici”

<sup>34</sup> “C’est un tabou de parler, de parler de sa maladie à une Africaine ou un autre Africain”

<sup>35</sup> “Une maladie permanente”

an “incurable disease”<sup>36</sup> (16M 40-49 French). One participant offered an association with recurrence: “a chronic disease is a disease which keeps coming back... it is like the flu and then everyone can have like me a cold, it is chronic”<sup>37</sup> (African 17M 40-49 French). Similarly, for another another participant, a disease was chronic due to absence of recovery, for example a “wound that does not heal”<sup>38</sup> (African 5F 50-59 Swahili and English).

At other times chronic conditions were described in terms of extremes or imbalances of normal physiological states. These diseases were often described as having abnormal states at each end of the spectrum. For blood pressure this appeared to be based on a lay-person’s description of the problem: “hypertension it is when you have, your pressure is very high and hypotension is when your pressure is very, too low”<sup>39</sup> (African 13M 30-39 French). For heart disease, however, one participant based their account on an awareness of medical terminology: “you can have tachycardia or bradycardia... and if that goes up to 140 beats per minute the heart cannot cope, your heart is ill”<sup>40</sup> (African 16M 40-49 French).

Diabetes was reported to be due to both a physiological and a dietary imbalance of sugar. This led to two ways in which this balance could be adjusted or maintained. First, was dietary restriction and exercise:

*“They say perhaps [you get diabetes] if you are eating a lot of sugar. I argue with my young boy here. He loves sugar. When he drinks tea he just puts in a lot of sugar. Me I [do] tell him. Perhaps the thing that is helping him is those [physical] exercises”<sup>41</sup> (African 11F 40-49 Swahili).*

Second, was the use of insulin: “it’s like it’s your sugar level and like constantly you have to inject yourself with insulin like trying to balance” (African 10M 18-24 English).

Nevertheless, deep concern over insulin was identified by the only diabetic participant: “I

<sup>36</sup> “C’est maladie inguérissable”

<sup>37</sup> “Une maladie chronique c’est une maladie qui revient chaque fois, par, selon l’étymologie, même du mot en français, chronique c’est chaque fois, dans le temps, il est comme la grippe et puis quelqu’un peut avoir, comme moi, les rhumes: c’est chronique”

<sup>38</sup> “Kwa mimi chronic disease ni wound isiyopona”

<sup>39</sup> “L’hypertension, er, c’est quand vous avez, votre tension est très élevée et l’hypotension c’est quand votre tension est très, trop bas”

<sup>40</sup> “Tu peux avoir la tachycardie ou la bradycardie... soixant-dix battement, sept zéro, par minute et que si ça augmente à cent quarante battements par minutes, donc, peut-être que ton cœur sa tient pas. Tu es malade au niveau de ton cœur, quoi”

<sup>41</sup> “Wanasema labda ukiwa unakula sukari sana [laughter] nagombana na mtoto wangu wa kiume hapa, anapenda sukari sana, akinywa chai yeye kama hivi basi anatia sukari nyingi. Miye namwambia yeye. Labda kinachomsaidia ni hiyo mazoezi”

do not like medicines against diabetes: the injections every day! No, no I don't like that. I ask God to heal me"<sup>42</sup> (African 6F 60-70 French).

There was also a belief that medication was only indicated for symptomatic – rather than long term, asymptomatic - disease: “when we don't feel well [that is when] we take the medicines, if we feel well I don't think that the [medicines] will be important, even as a preventative”<sup>43</sup> (African 17M 40-49 French). As a result, hypertension was thought to require only a brief course of treatment:

*Interviewer: “and if someone has got hypertension how long do you think they need to take medicine for?”*

*Participant: “I think maybe a week or something, a week, some, some may not need to take medicine, make to rest only ...” (African 15M 30-39 English).*

### **6.3.2 Chronic disease as an acute phenomenon resulting from stress, exertion and older age**

Cardiovascular conditions were commonly associated with stressful events and lifestyles, in particular resulting from hardship associated with seeking asylum. Heart disease was reported to occur in someone “when he or she then gets to hear bad news or something shocking”<sup>44</sup> (African 11F 40-49 Swahili), although one participant suggested a moral dimension by blaming envy of others' material “lifestyle” (African 14F 30-39 English) as a cause of hypertension because “humans are created with a heart of envy”<sup>45</sup> (African 14F 30-39 Swahili). Hypertension was perceived as resulting from the way someone lived their life: “to be honest, we Africans normally do not understand blood pressure, they think of it more in the sense of [resulting from] their way of life”<sup>46</sup> (African 5F 50-59 English and Swahili). Thus, hypertension was perceived as a serious condition that could result in sudden, unexpected death: “I think that it is a very serious problem, very serious. Because we have seen people die without even saying a word, straight away, because they have an attack of hypertension”<sup>47</sup> (African 17M 40-49 French). Two people associated a

<sup>42</sup> “Moi, je n'aime pas les médicaments contre le diabète: les piqûres tout les jours, non, non, je n'aime pas ça. Je demande à Dieu de me guérir”

<sup>43</sup> “Lorsqu'on sent pas bien on prends les médicaments . Si on se sent bien je ne crois pas que le [médicament] sera important pourqu'on puisse en prendre, même à titre préventif, je ne crois pas”

<sup>44</sup> “Ugonjwa wa moyo? Inakuwa kama mfano mtu kama nikisema kama kasikia habari mbaya”

<sup>45</sup> “Kwa sababu tunaamini mwanadamu tumeumbwa na roho ya wivu”

<sup>46</sup> “Kwa kusema kweli blood pressure kwa Waafrika huwa hatuielewi, watu wanaelewa in the sense it is more their way of life”

<sup>47</sup> “Nous avons vu les gens mourir sans pour autant dire un mot, directement, parcequ' ils ont une crise d'hypertension”

hypertensive “attack” with acute symptoms of breathlessness: “Your breath is taken away from you and you do not breathe the air well” (African 11F 40-49 Swahili).

Two participants offered descriptions of disease in terms of sudden end points. One participant gave the following description of a heart attack: “I would think it is a stoppage of how the heart pump the blood through the system you know... dysfunctions” (African 15M 30-39 English). Another participant offered the following explanation of a stroke: “it is like.... a crack in the nerves of the head, I think”<sup>48</sup> (African 17M 40-49 French).

There was confusion for some over the role of physical exertion in hypertension. One participant associated hypertension with excess physical exercise, suggesting the following therapy: “don't get yourself tiredness... so you don't do very physical things” (African 15M 30-39 English). Conversely, another suggested that heart disease was more common in those “who don't do that much physical activity... like who don't do that much sport... or who don't walk that much ...” (African 12M 30-39 English).

Chronic diseases were sometimes perceived as normal in older age. For example, hypertension was reported to be found in “people in their fifties, it is not for young people”<sup>49</sup> such that “the people do not consider it like a disease, especially in Africa the people believe that it is a normal thing when they are old”<sup>50</sup> (African 17M 40-49 French).

### ***6.3.3 Heredity: an explanation for unexplained cases and an inevitable fate***

Heredity was often invoked to account for chronic disease when no other cause could be identified. For example, this was the only suggestion that one participant, whose friend died of liver cancer, could provide: “I really don't even know [what causes cancer], well I think it is hereditary” (African 7M 20-25 English). Heredity was offered as a reason for conditions such as asthma, diabetes and obesity. At times it was linked to a genetic basis and even to an interaction between genes and environment. For example, one participant linked obesity to genetic predisposition and easy access to food in Europe: “their body already had the DNA.... because [obesity] was in the family and then, well, here, with all

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<sup>48</sup> “Moi, je pense que c'est un problème très grave, très grave, parce que nous c'est comme si c'est, sont les nerfs de la tête qui fait une fissure dans les nerfs de la tête, je crois”

<sup>49</sup> “Ca est dans les cinquantaines, c'est pas pour les jeunes gens”

<sup>50</sup> “C'est comme si c'est une longue maladie, une anomalie que les gens ne considèrent pas comme une maladie, surtout en Afrique les gens croyaient que c'est un fait normal lorsqu'on est âgé”

that they can eat here that can encourage the disease to come out [literally to “hatch”] in him”<sup>51</sup> (African 18M 50-59 French).

Family history of chronic disease was discussed as an almost inevitable fate: “for me here now I have already accepted that I am going in this family way, stroke is around in our family right now, and diabetes is in the family, here I feel it is heredity which is coming to me”<sup>52</sup> (African 14F 30-39 Swahili). This idea of chronic disease being a normal event within families was suggested by the language used by two male participants. One hypertensive participant stated that his “familial” hypertension was “not so bad”<sup>53</sup> (African 19M 50-59 French) while an asthmatic man described his condition as a “normal thing” (African 15M 30-39 English). Indeed, for one, acquiring chronic disease was discussed in terms of being a positive thing in the context of family history: “They say that also in their families back home in [Africa] there are some people have suffered from that [diabetes]... yes...yes... also they have that... and then they think that it is good for them because it is the family”<sup>54</sup> (African 18M 50-59 French).

In the absence of a family history, a related explanation of personal predisposition was employed to account for unexplained cases of chronic disease:

*“I think that perhaps it is a bodily predisposition, it’s like, er, people who easily fall sick from diabetes, and others, who do not fall sick from diabetes, and others who do not fall [ill], and I believe there is a bodily predisposition. The human body of an individual can be fragile and ready to receive that disease. Meanwhile the body of another person is not like that....I believe that it is a problem of predisposition”<sup>55</sup>*  
(African 13M 30-39 French)

A perception of inevitability was reported to motivate some participants to be tested: “I used to be worried about diabetes because my dad has diabetes but I went to get checked and I was pretty okay” (African 7M 20-25 English). Conversely, it was reported that this belief led others to avoid screening: “lots of women are saying “breast cancer, ah no I have

<sup>51</sup> “Leur organisme avait déjà de l'ADN, avait déjà des substances qui, parce que ca était en famille et puis, bon, ici avec tout ce qu'ils peuvent manger ici, ca peut favoriser que la maladie puisse éclore en lui”

<sup>52</sup> “Kwa mimi hapa sasa nimeishachukulia kwamba tayari nakwenda kifamily hii stroke iko around kwenye familia yetu sasa hivi na diabetes iko kwenye family kwa hiyo hapa nahisi ni kizazi kinaanza kwenda kwangu mimi”

<sup>53</sup> “C'est un cas d'origine peut-être familiale, familiale, mais qui n'est pas tellement mauvais”

<sup>54</sup> “Ils disent que dans leurs familles aussi au pays il y a des gens qui ont souffert de ca, oui, oui, aussi ils ont ca et puis il pensent que c'est bon pour eux parce que c'est la famille”

<sup>55</sup> “Je crois que c'est peut-être une prédisposition du corps, c'est comme, er, des gens qui tombent facilement malade de la diabète et des autres qui ne tombent pas et je crois qu'il y a une prédisposition du corps. Le corps humain d'une personne peut-être fragile et prêt à recevoir la maladie pendant que le corps d'une autre personne ne l'est pas... .. je crois que c'est un problème de prédisposition”

never been tested [because it has] never happened in my family”<sup>56</sup> (African 18M 50-59 French).

### **6.3.4 Accounting for perceived increased cancer in the west: unseen contamination by toxic agents**

Contamination by chemicals in food was a commonly reported explanation of cancer and used to account for its perceived increased incidence in western countries. Chemical sources included unnatural fertilisers, chick feed for battery hens, and preservatives or “medicine”<sup>57</sup> (African 14F 30-39 Swahili) in tinned foods. Industrialisation in Europe was also implicated because waste was believed to emit toxins into the environment. Some participants offered their own accounts based upon their observations of food production in Europe to support their view that food was contaminated with toxins. First, was the different texture or taste of food:

*“Perhaps [in] the food? The [tin]cans? Perhaps the water?. So I say to myself, all these, [it is] because the food the people eat here has too much fertiliser. It is not really natural. That can cause, that can have consequences – compared with African food where the fertilisers are natural [and] nothing is chemical. So that is a problem. I give you an example. Here you have the impression that chicken [meat] is soft, very soft, [whilst] an African chicken [is so tough] it can pull your tooth out”<sup>58</sup> (African 13M 30-39 French and Swahili).*

Second, was the inferior taste and strength of flavours in British food: “when you are cutting an onion your must cry, the tears must run, but here the tears hardly flow because [the onion] has lost its flavour”<sup>59</sup> (African 18M 50-59 French). A final piece of evidence for contamination was the greater size of livestock available in shops in the UK:

<sup>56</sup> “Beaucoup de femmes disent: “le cancer de seins au non ca j'ai jamais teste, jamais passe dans ma famille”  
<sup>57</sup> “Dawa”

<sup>58</sup> “Peut-être la nourriture? Les boites de conserve? Peut-être l'eau? Donc je me dis toutes ces, parce que la nourriture que les gens mangent ici est trop dans les engrais quoi. Il n'est pas trop naturel. Ca peut causer, ca peut avoir des répercussions - par rapport à la nourriture africaine ou les engrais sont aussi naturelles, rien n'est chimique alors ca fait que c'est difficile. Je donne un exemple. Une poule ici qu'ici tu as l'impression que la poule elle est molle, imekuwa tegetege sana. Kuku ya Africa inaweza kutosha lino kwa sababu imekuwa ngufu sana kwa sababu yu kuku imekimbia fasi zote”

<sup>59</sup> “Ils pensent que d'après les goûts il va que les produits chimiques avec les aliments, en fait, que les aliments perdent leur goût, que l'oignon qu'on peut trouver quand tu es en train de le couper tu dois pleurer. Ca veut [que les] larmes doivent sortir mais ici à peine les larmes sortent parce qu' il a perdu sa saveur”



*“In our country fish are small, but here: today I ate a tilapia [fish]. They are so very fat! So I say ‘but that is [due to the] vitamin[s]!...There are fertilisers that help the fish to get big, to fatten the cattle, the pigs, so we say to ourselves ‘aha, here they eat anything’. Even we are afraid because by changing [to this food] we are going to have cancer”<sup>60</sup> (African 18M 50-59 French).*

Chemical contamination was particularly linked to cancer causation, with such chemicals considered to affect the cells of the body. One participant described the effect of chemical contamination in terms of a small substance that changed the whole body: “it is like taking a bottle of clean water, then take [some] colour and drop it into that water: it changes [and] that’s the way the body is”<sup>61</sup> (African 5F 50-59 Swahili and English). The effects of chemical contamination were considered silent and delayed, with chemical products transported throughout the body in the bloodstream. Indeed, one participant described contamination from chemicals in food in terms resembling metastasis: “my body will just receive it inside there, you do not know if it will settle in the breasts, it will go to settle in the stomach, it will go to the legs”<sup>62</sup> (African 14F 30-39 Swahili). She linked the ensuing cancer with the hidden deposits inside the body: “I will get the effects, perhaps after two years, I will get certain effects. Lo and behold it is that thing which has already come to settle there inside”<sup>63</sup> (African 14F 30-39 Swahili).

Not all participants offered explanations about where these beliefs originated. However, one did suggest that doctors in Africa promoted an association of cancer with food contamination.

*“Since my childhood, well, the general theory that the doctors were giving in Africa at the time it was to avoid [food] stuff that was burned to excess and then, for example, certain [cooking] receptacles, to avoid certain cooking pots... which were giving out something that can cause cancer in the future” (African 17M 40-49 French)<sup>64</sup>.*

<sup>60</sup> “Le poisson chez nous il est petit mais ici aujourd’hui j’ai mangé un tilapia. Ils sont très gros! Donc je dis ‘mais ca c’est vitamine’...Ils sont les engrais qui facilitent que les poissons puissent grandir, grossir les vaches, les cochons. Alors on se dit “ah la la la..” ici vraiment on mange quoique il soit, même, nous on a quand même peur parcequ’on fait que en tournant on va avoir le cancer”

<sup>61</sup> “Your body ni ni ni kama uchukue maji kwenye chupa ambayo ni masafi, halafu chukue colour utie kwenye ile maji hiyo: it changes. That's the way the body is”

<sup>62</sup> “Ndiyo mwili wangu utapokea tu. Sasa mle ndani mle ndiyo utajua kama itakwenda kukaa kwenye maziwa, itakwenda kukaa kwenye tumbu itakwenda kukaa kwenye miguu”

<sup>63</sup> “Nitaletewa madhara labda baada ya miaka miwili. Tena nitaletewa madhara fulani. Kumbeni kile kitu kilisha tayari kukaa mle”

<sup>64</sup> “Depuis mon base âge, bon, la théorie générale que les médecins donnait en Afrique en cet époque la c’était d’éviter plus les choses grille avec un excès, on a beaucoup plus grillé, et puis certains récipients, par exemple d’éviter certains marmites. Ca dégageait quelque chose qui puisse entraîner dans le futur le cancer”

Exposure to other toxic agents was cited as a cause of cancer. These included unseen waves from microwave ovens and regular use of a mobile phone. Finally, excessive sunlight and ultraviolet rays were also discussed as sources of cancer. In this regard one participant differed, suggesting: “what causes skin cancer? I don't know, maybe some lack of sun” (African 12M 30-39 English).

## 6.4 Beliefs about obesity, diet and physical exercise

Some participants volunteered that obesity was linked to chronic conditions, in particular hypertension, diabetes, heart attacks and “problems with bones”. Only one participant associated obesity with more than two chronic condition: “this obesity leads to lots of things and when the heart beats, it tires itself and leads to lots of diseases like hypertension, all that, some little things like that and even the sugar level starts to rise”<sup>65</sup> (African 17M 40-49 French). However, not all participants associated obesity with disease and some suggested that Africans were naturally prone to gaining excessive weight. One participant attributed this particularly to African women and suggested that a tendency to gain weight may be linked to a cultural desire not to appear impoverished:

*“[Obesity] does not constitute a disease but it is a malformation... [because] Africans by nature are fat... I would say... above all the women naturally put on a lot of weight. It is a bit of a cultural [thing], because when you eat a lot in Africa they think you are healthy. But I think it is linked to poverty.....: someone who is very fat, [others] will say ‘he [gets to] eat frequently. Therefore he is not poor. And he who is thin, he is poor. He is suffering’”<sup>66</sup>(African 13M 30-39 French).*

Africans were reported to be unaware of the relationship between obesity and health problems: “obesity is a big problem but the people, they are not well informed about obesity”<sup>67</sup> (African 19M 50-59 French). This was supported by one participant: “what [health problems] can obesity bring? Well, I have no idea”<sup>68</sup> (African 16M 40-49 French). This was despite its being such a problem that “everyone has to change his wardrobe every

<sup>65</sup> “Cette obésité entraine beaucoup de choses et lorsque le cœur bat, se fatigue, et s'entraînent beaucoup de maladies aux alentours de l'hypertension, tout ca, des petites choses comme ca, et même le taux sucre commence à augmenter”

<sup>66</sup> “Je dirais que non, ca [l'obésité] constitue pas une maladie mais c'est une malformation... parce que les africains de nature ils sont gros.. je dirais ... surtout les femmes de naturelle prennent facilement beaucoup de poids... c'est culturelle un peu... parce que quand tu as beaucoup de poids en Afrique on estime que tu es bien... mais ca je crois c'est lie à la pauvreté. Parce que quand tu manges beaucoup tu grossis, quand tu manges moins tu maigris alors quelqu'un qui est très gros on se dit ‘oh il a souvent à manger’, donc il n'est pas pauvre et celui qui est maigre celui la il est pauvre. Il souffre”

<sup>67</sup> “L'obésité c'est un grand problème mais les gens son ignorants. Ils ne sont pas tellement informées de l'obésité”

<sup>68</sup> “L'obésité ca peut apporter quoi? Bon. Mais je n'ai aucune idée”

six months because his size is increasing exponentially, without realising the health consequences”<sup>69</sup> (African 17M 40-50 French). Another participant concluded that obesity was a consequence – rather than a cause – of diabetes: “most of the diabetics that I often see they are a bit fat, well, I do not know what this fatness is due to, perhaps it is the effects of the disease, yes it is that”<sup>70</sup> (African 16M 40-49 French). At other times an association between diabetes and obesity was dismissed because “somebody who suffers from diabetes can be normal [i.e. slim] like you and me. You will not know that this person has diabetes”<sup>71</sup> (African 13M 30-39 French).

Availability of cheap food in the UK was offered as a possible reason for the development of obesity. Obesity was also reported to imply affluence – and even greater health status – amongst older Africans, although this was not necessarily the view of younger participants. However, traditional cooking methods were also held to be responsible. African food was at times considered to be unhealthy, for example using excess oil and lengthy preparation times:

*“When you go into my mum's kitchen there is a lot of palm oil, like just a lot of oil, they are frying stuff.... when you come to eating vegetables we like cook them for a really long time and then add oil in them, so people when you eat well you might put on some weight I think” (African 10M 18-24 English).*

Despite this, there was evidence of a desire to eat more healthily. This was based upon recognition of the need for fresh food, particularly vegetables. Nevertheless, there were practical problems reported to getting access to such products in the UK:

*“[For health you should] eat appropriate food, do you see, food which is healthy like vegetables, leafy vegetables, foods with lots of leaves, all those vegetables which bring strength to the body, to make sure [you] drink lots of water and cereals, do you see, all foods which are fresh. And you know that now it is very hard here for me [to get these]. You know how it is [here]”<sup>72</sup> (African 14F 30-39 Swahili)*

One participant suggested that increased rates of cardiovascular disease amongst Asian people was because “spices, I believe that they bring diseases like heart disease a lot...

<sup>69</sup> “Chacqun est obligé de renouveler sa vestiaire chaque six mois parce qu’il augmente la taille d’une façon vertigineuse, sans tenir compte des conséquences sanitaires”

<sup>70</sup> “La plupart des des des diabetiques que je vois souvent, ils sont un peu gros. Un peu gros comme ca, eh?. Bon cette grosseur la je sais pas c’est due a quoi. C’est peutetre, c’est l’effet de la maladie. Oui, c’est ca, quoi

<sup>71</sup> “Quelqu’un qui souffre du diabète peut être normale comme toi et moi. Tu ne sauras pas que cette personne à le diabète”

<sup>72</sup> “Hivyo kula chakula kinachotakiwa, unaona, chakula iko healthy kama vile vegetable, mbogo za majani, vyakula vya majani majani, mboga zote zile zinavyoleta nguvu mwilini kwa kuhakikisha kunywa maji kwa wingi na vyakula vya nafaka, unaona, vyakula vyote vile ambavyo ni fresh na unajua sasa hivi ni vigumu kama hapa kwa mimi unajua culture”

because a lot of spices are cooked with oil”<sup>73</sup> (African 14F 30-39 Swahili). Salt intake was linked to heart disease by one participant: “heart disease is caused by using a lot of salt at meal times”<sup>74</sup> (African 11F 40-49 Swahili). Exercise was considered to be a problem for many Africans here: “we do not do enough exercise, for example, most [Africans] are stuck in the house, that is to say are not moving, not doing much sport”<sup>75</sup> (African 19M 50-59 French).

## 6.5 The perspectives of GPs on chronic disease in Africans

When asked which diseases represented major threats to African migrants most GPs pointed to serious infections such as HIV and tuberculosis. For some GPs, increased risk of chronic disease was also identified, for example stating “hypertension, obesity just crops up straight away: these are the two main things and, of course, HIV” (GP12 F 40-49 Asia). Nevertheless, this appeared to be a perception of overall increased risk of all chronic diseases with a metabolic basis rather than susceptibility to any single condition such as hypertensive disease. For many this was closely linked to a belief that obesity was a major problem for African patients:

*“I think that stroke disease is common in the African males, a greater preponderance of heart disease, obesity related disorders.... I should have said it: diabetes as well of course has got a far greater incidence in that group too, I am very aware of it” (GP13M 40-49 UK)*

Although some GPs recognised these types of chronic disease as important for Africans, others did not perceive them to be any more common than amongst their wider patient population. For example, one African GP reported diabetes to be “quite common [in our African patients] although not more common than we see in our generic local patient” (GP8M 60-69 African). Indeed, cancer was reported by certain GPs to be less common amongst Africans: “less cancer [amongst Africans], you know the Brits and the Irish get more cancer than these ethnic groups” (GP13M 40-49 UK). Only one GP provided examples of cancers believed to be more common amongst Africans. This GP pointed to her awareness of important cancers in Africa, mainly those arising from viral infections.

<sup>73</sup> “Viungo naamini kwamba vinaleta vinaleta kama magonjwa vile ya moyo sana. Kwa sababu spici nyingi inapikwa kwa kutumia mafuta”

<sup>74</sup> “Maradhi ya moyo,... au wakati wa chakula ukiwa unatia chumvi nyingi, pia inasababisha”

<sup>75</sup> “On a pas assez d'exercices. On ne fait pas assez d'exercices, par exemple, la plupart sont immobilière à la maison. C'est à dire ne bougent pas, ne font pas beaucoup de sport”

Her knowledge of such risks in Africa contrasted with her own personal experience with African patients in Scotland:

*“Is it [increased risk of] primary liver hepatomas? Nasopharyngeal tumours? Um, what other cancers would be more common? Um, Burkitt's lymphomas? I never saw any of these” (GP2F 30-39 UK).*

Other GPs did not consider chronic diseases to be a problem at all for African migrants in the UK. Various explanations were offered for this belief by those GPs. First, it was suggested that the rates of chronic disease were inherently low in Africa, i.e. that “things like hypertension, diabetes, I suppose, they are not so common really in Africa” (GP5F 40-49 UK). Second, GPs pointed to lack of diagnosis in patients’ home countries and a ‘survivor’ effect to explain low rates of chronic disease: “I wonder if, if you don't have money you might not have good care for a chronic disease and therefore you are not alive you know, as simple as that” (GP9F 50-59 UK). Third, perceived low levels of chronic disease were attributed to the young age of migrant patients in the UK: “we have very, very few old [migrant] patients... so chronic disease is not actually a great issue” (GP3F 50-59 Europe). A final factor that may have explained why GPs tended to put little emphasis on chronic disease was the attitudes they attributed to their African patients. One GP reported that African patients themselves did not consider cancer a significant threat: “I don't think you have a lot of them [African migrants] too worried about you know cancer, I don't think so at all, no” (GP12 F 40-49 Asia). Perhaps as a result of this, there was a belief that Africans themselves were reluctant in GP consultations to engage in background health issues:

*“Many of the African students tend to come with a problem and they want you to deal with that individual problem rather than their general health” such that “they don't actually choose to let you in.” (GP11M 50-59 UK).*

Instead, GP accounts typically pointed to considerably greater workload arising from African patients who presented with what doctors perceived as minor symptoms. This issue is examined further in Chapters Seven and Nine. In addition to this, GPs reported two major concerns in the context of chronic disease in African migrants: poor medication adherence and difficulty in implementing lifestyle change. These two issues form the remainder of this chapter.

### **6.5.1 Medication adherence in general practice**

GPs commonly reported poor adherence amongst African and other migrant patients who were receiving long-term medication. This problem was particularly associated with asymptomatic conditions. A number of GPs reported that migrant patients would take medication for chronic disease and then stop these in order to ‘test’ whether they were really required. Such issues were also recognised by African GPs with their African patients:

*“Yes, we have Africans with hypertension, their problem is compliance. Same problem: they feel that taking tablets for life for hypertension is just not acceptable... a number of them take it for some time and then they stop. We constantly have to remind them or ask them to come and have their blood pressure checked because this idea of being on a medication continuously probably for the rest of their life the concept amongst asylum seekers is quite difficult to accept” (GP8M 60-69 Africa).*

Although poor medication adherence was frequently attested to by GPs, only one explored the complexity of tackling this problem with her African patients. Indeed, amongst others there seemed to be an acceptance that little could be done to improve adherence amongst African patients. One reason for this may have been the concern reported by the GP in question over offending patients by suggesting that they may not be complying with the doctor’s order. Thus, suggesting to a patient that they might not be adherent with their medication was reported to risk having an adverse effect upon the doctor-patient relationship in the long run. This GP described this in terms of accusing them of lying:

*“It’s just trying to really work out is that person just saying this [i.e. that they are taking their medication] to please me or are they actually telling the truth? And from the computer records it looks like they are definitely not telling the truth you know... so [there is] conflict from that point of view when you are trying not to accuse them of lying about their medication” (GP5F 40-49 UK).*

A related factor that challenged ongoing engagement in chronic disease with primary care physicians was that failure to cure a chronic disease could be deemed by an African patient to be a marker of a bad doctor. This was attributed to Africans’ limited understanding of chronicity and their expectation of a cure. Instead of indicating a need for long-term medication, treatment failure was attributed to lack of competence of the doctor, such that instead of continuing in generalist care the patient would seek onward referral in the hope of a cure:

*“I think most of African people I have seen they don't understand the concept of chronic disease. They think if it is a disease there must be a cure... most of them then because they know I'm a GP they would say "send us to a specialist" because they think the specialist will be able to resolve the problem” (GP1F 40-49 Africa).*

### **6.5.2 Promoting lifestyle change in general practice**

Rather like addressing medication adherence, lifestyle change was reported to be problematic in GP encounters with African patients. Again, the need for long-term behavioural change contrasted with Africans' expectation of a rapid solution to weight gain. Thus, it was noted that Africans held a preference for medication to treat weight gain rather than adopting long-term dietary and exercise interventions. This scenario, however, illustrated the issues of both reluctance to embrace lifestyle change and long-term adherence to medication.

*“They [Africans] would like quick fixes so if you know historically our practice has been using a lot of Orlistat [for weight loss], you know, which is being handed over to them but I think they don't persevere and they expect the weight loss to happen without the lifestyle intervention” (GP12 F 40-49 Asia)*

This study shows that failure to address lifestyle change for obesity was not solely the product of Africans' beliefs and behaviour. GPs described a reluctance to offer opportunistic lifestyle advice to African patients for obesity. For a number of GPs this was based upon a cultural perception that African women did not and would not undertake physical exercise. In the case of one GP she volunteered that she had never prescribed exercise to African women:

*“I wonder if I think that culturally they don't take exercise... or that exercise isn't a big part of African life... that's not true. ... I am sure it is a big part of African life... but maybe in my head I don't think of it automatically as something they would like to do... that's not good...” (GP7F 40-49 UK).*

Providing dietary advice to Africans was also reported to be problematic. In addition to concerns over time pressures in consultations, there was uncertainty over what Africans eat and this led to difficulties in providing advice. The complexity of such issues was highlighted by the fact that comparable concerns were also voiced by one African GP:

*“Their food [Africans]... the diet they have is not well studied... I do not know for example ... they have [stiff porridge called] posho... nshima... I do not know how much calories in that and it's so difficult therefore to advise them” (GP8M 60-69 Africa)*

## 6.6 Chapter conclusions and discussion

The findings in this chapter suggest low awareness of chronic disease risk amongst African migrants living in the west of Scotland. This was mirrored in the content of some GP interviews and reasons for this belief were various, including the young age of many migrant African patients. The lack of awareness of many African participants was also evident in the incomplete nature of the models offered by some participants. Despite this, even basic beliefs about causation were accepted here as being consistent with Kleinman's (1978) explanatory models approach. This is because they appeared to represent participants' genuine understanding of the nature of chronic diseases of which only a few had had first-hand experience.

Concern over infectious disease dominated participants' perceived health threats and chronic diseases were described by some francophone participants as contagious. Overarching explanatory models were bodily/dietary imbalance, stress/exertion, heredity/predisposition and chemical contamination. These revealed some knowledge about chronic disease risk factors, for example the relationship between lifestyle and developing cancer, between obesity and other chronic diagnoses and a role for the interaction of genes and environment in disease causation. Nevertheless, cancer was perceived to be more common in Europe on account of chemical contamination and cardiovascular disease was described in terms of acute symptoms that required only short term medication. These findings suggest a need to inform Africans and to promote discussion about their increased risk of certain chronic diseases and the need for lifestyle change and medication adherence.

Findings in the context of cardiovascular disease mirror that of Beune's (2006) study of Ghanaians in the Netherlands and Siangonya's (2010) research with Zambian migrants in the USA. In both of these, some participants described cardiovascular disease in terms of acute symptoms and often associated with stress. This belief is not confined to Africans as stress has been reported elsewhere to be an explanatory model of hypertension amongst



Hispanic, African-Americans and white Americans (Bokhour, Cohn & Kressin, 2013). Nevertheless, it may be particularly important for African migrants because stress is so common that the word itself has become an “idiom of resilience” against the social problems encountered in their daily lives (Obrist and Buchi, 2008). Certain findings reported here are also common to studies of European populations, for example perceiving cancer as incurable and implicating hereditary factors in its causation (Scanlon, Harding, Hunt et al., 2006). Unlike research elsewhere showing that family history may not be recognised as a risk factor even by people with a large number of relatives with heart disease (Hunt, Emslie, and Watt, 2001), in the present study many participants were quick to volunteer increased personal risk based upon their own family history. Despite this, development of a condition that affected another family member was perceived by some participants to render the disease less severe. The belief that chronic diseases are familiar and the notion reported in this study of cancer as a random disease suggest a fatalistic view of such conditions amongst African migrants. This is consistent with similar beliefs amongst the white British population (Davison, Frankel, and Smith, 1992).

An interesting component of these narratives was the description by certain francophone participants of chronic diseases as contagious. This perspective is likely to provide insight into participants’ understanding of the value of medication adherence and long-term management in chronic conditions. Although anthropological studies show contagion theories to be important in Africa in respect of infectious diseases (Green, 1999), it has not been possible to identify reports of such beliefs for chronic conditions amongst migrants. This finding is likely to reflect participants’ previous experience of infectious diseases in Africa. Alternatively, it may result from unfamiliarity with verbs such as “to acquire” amongst participants, most of whom were speaking in a second language. A third, important reason could underlie this belief: it is known that infections are, indeed, an important primary cause of many chronic diseases. This belief may therefore have arisen because of previous exposure to education about infectious diseases in Africa, particularly concerning cancer risks associated with HIV infection. Other examples of infectious diseases that occur in Africa include cancers of the liver, cervix and skin caused by viruses, cardiac failure from syphilis and epilepsy from tapeworm infection of the brain. Knowledge that primary infective causes exist for common chronic diseases could pose a challenge to health promotion. In particular, this suggests a need to inform Africans about prevention of acquired chronic diseases through lifestyle change alongside existing interventions to promote knowledge of - and behavioural changes to prevent - infections

such as HIV.

Participants in this study offered articulate and rational explanations for disease causation constructed from personal observation. The beliefs described by participants were consistent with Kleinman's (1978) notion that people's explanatory models of illness arise in their own socio-political context and emerge from individuals' personal historical narrative. In the present study this could be seen in the way participants' beliefs about cancer causation were founded upon first-hand observation of two contrasting worlds: natural production of wholesome food in rural Africa and abnormal mass production in Europe that was driven by reliance on toxic substances. The belief that perceived increased cancer rates in Europe were due to food contamination with toxins appeared to be particularly strong and arose across age, gender and religious categories. This may also explain why some participants described cancer in terms of being "caught". Similar concern over canned food and fertilisers in cardiovascular causation has been reported from Ghana (Abanilla, Huang, Sinners et al., 2011). These beliefs require additional research, not least because such fears may, indeed, be real. There is good evidence for transmission from canned products of chemicals positively associated with cardiovascular disease and diabetes (Carwile, Ye, Zhou et al., 2011). There are also case reports from Africa of fatal botulinum infection arising from canned food (Frean, Arntzen, van den Heever et al., 2004). In addition, the principal researcher has identified internet pages in Swahili linking canned and processed food to cancer. As participants in this study cited the internet and email as important sources of health information, it is possible that the origins of these beliefs may lie in online or media sources. Alternatively, personal observation of decaying cans in Africa's warm climate could be the basis for contamination fears. These findings should inform health promotion in order to emphasise risk factor reduction through multiple dimensions of lifestyle change, rather than just the prevention of contamination. Nevertheless, such interventions should build upon the positive aspects of explanatory models identified in this study, for example a preference for preservative-free and unprocessed food.

These findings have implications for the prevention and treatment of chronic disease. The agreement of these findings with other studies of health beliefs and behaviours of African migrants indicates that evidence acquired in this study builds upon existing knowledge. It also underlines the scale of the challenge to prevent, diagnose and treat chronic diseases in African migrants and opens up areas for research into potential interventions. Evidence

from other minority ethnic communities suggests that one key principle to tackling this epidemic through behavioural interventions is the need to promote cultural sensitivity by using communication strategies that are sensitive to language use (Netto et al., 2010).

### **6.6.1 Promoting effective communication about chronic disease**

The results presented in this chapter highlight the importance of language in communication with Africans about chronic disease, whether it be for health promotion or direct clinical care. The poor knowledge of English shown by some participants suggests that health promotion messages intended for certain African migrants may only be effective if conducted in appropriate African languages. Clearly this is potentially an enormous challenge given the linguistic diversity amongst African and other migrants. This issue is most important with newly arrived migrants from non-anglophone nations, in particular those from rural backgrounds and the elderly. Language barriers, however, are not confined to these groups. This is because the present study points to the existence of practical problems with medical terminology even for Africans who are fluent in English. For example, the findings highlight the importance during clinical consultations with African patients of distinguishing between key terms such as “chronic”, “terminal”, “incurable” and “recurrent”. This highlights a need, not only for education in medical English for African migrants, but also for training of health care professionals about addressing such potential ambiguity. Similar issues pertain to the lay names that Africans give to illnesses or symptoms. For example, it may prove difficult to promote weight loss amongst Africans because of other connotations associated with being thin, in particular since HIV infection is commonly known as “slim disease” (Wiig and Smith, 2007). Such an approach is consistent with Kleinman’s (1978) call to explore the lay names that patients use as part of their explanatory models for illness.

### **6.6.2 Implications for preventing and treating chronic disease**

Specific risk-related beliefs of Africans reported in this study should be taken into consideration in health promotion and research into the effectiveness of clinical interventions. First, is the belief of some participants that hypertension is a condition confined to older people and indeed a normal feature of ageing. This could assist the development of patient-centred interventions to detect asymptomatic hypertension,

particularly for younger African migrants. Second, is the perception that it may be inevitable for Africans to acquire chronic diseases that are already present in family members, although in interviews this was linked to a favourable view of screening and early detection. Third, is the view that certain conditions only required medication for a short period of time, particularly when the condition was largely asymptomatic. Future research should focus on developing interventions to promote long-term adherence to medication for chronic disease, particularly in asymptomatic patients.

These findings can inform education intended to promote awareness and preventive lifestyle change and to improve chronic disease health literacy in Africans in the UK. In so doing, much can be learned from other minority ethnic groups. This includes building upon evidence from research with Pakistani, Chinese and Indian communities underlining the importance of mobilising community resources to publicise interventions, addressing barriers to participation and working with cultural and religious values (Netto et al., 2010). This should also build upon not only participants' existing knowledge of risk factors and disease, but also their self-reliance in the pursuit of a healthy lifestyle and desire to retain cultural knowledge and practice. Such an approach would also build upon similar salutogenic activities reported amongst African migrants elsewhere, in particular the importance of a healthy diet (Vaughn and Holloway, 2009) and taking regular physical exercise (Feldmann, Bensing, and de Ruijter, 2007). This suggests a need to inform newly arrived African migrants of the risks associated with obesity that can result from reduced exercise and easy access to high calorie food in the west. Strategies to improve exercise levels could include the provision of safe places in which to walk in cities and offering single sex exercise groups. Further theoretical and feasibility testing research is required to explore how such health promotion might be delivered.

## 7) Antibiotic beliefs and pluralism in treatment-seeking

As described in Chapter One, exploring discordant expectations of GP consultations formed one objective of the present study. The first part of the present chapter considers one area where Africans frequently described unmet expectations in general practice, namely the reluctance of GPs to prescribe antibiotics for symptoms such as a sore throat, cough, or discharging nose. This is consistent with evidence from the Netherlands that first generation non-western immigrants receive more antibiotics than do native populations (Hogenhuis, Grigoryan, Numans et al., 2010). This finding is considered below with regard to cultural beliefs and behaviours reported by Africans to underlie antibiotic demand. The GP perspective is also presented, including how antibiotic demand was managed in consultations. Additional unmet expectations were reported by Africans due to frustration was over failure to access specialists and imaging investigations. The details of this area were not explored in full depth during interviews because such expectations typically related more to secondary – rather than primary – care. Nevertheless, the latter part of this chapter presents options reported to be available to Africans whose expectations of health care were not met with regard to requests for antibiotics or specialist referrals/investigations

### 7.1 Expectation of antibiotics: previous experience of infectious disease

Prescription of antibiotics proved to be the dominant example of unmet expectations in consultations reported by both Africans and GPs. Africans widely recognised that GPs were “categorical... they do not want to prescribe antibiotics”<sup>76</sup> (African 3F 30-39 French). As a result, it was reported that consultations about antibiotics could be problematic and that disagreement could escalate, such that “when the doctor refuses to give you an antibiotic, it is, wow, you get in to a bit of conflict [with them]”<sup>77</sup> (African 19M 50-59

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<sup>76</sup> Ils sont catégoriques... ils ne veulent pas prescrire des antibiotiques”

<sup>77</sup> “Quand le médecin refuse de vous donner un antibiotique, c’est, phew, vous devenez un peut en conflit avec”

French). As reported elsewhere (Feldmann, Bensing, and de Ruijter, 2007; O'Donnell, Higgins, Chauhan et al., 2007), being dismissed by a doctor was typified not just by refusal to issue antibiotics but by GPs' insistence, instead, that prescribing paracetamol constituted adequate treatment. One reason for this frustration was reported to be because some African participants stated that they had already tried taking paracetamol or other simple remedies for their problem and had experienced no benefit. Beyond feeling dismissed, Africans reported that this rejection could lead them towards giving up their search for treatment from GPs. This was particularly true where antibiotic refusal occurred repeatedly:

*"You tend to go to a GP [and] they give you like a paracetamol. You go away, you come back and they give you paracetamol again! So you don't want that kind of things. You feel like [it is] a waste of time" (African 15M 30-39 English)*

During interviews it became clear that conflict between GPs and Africans over antibiotic prescription occurred in accordance with Kleinman's (1978) theory in two ways. First, there were differing underlying explanatory models for common symptoms. These beliefs, which are described next, led to conflicting expectations over the natural history of the condition and how it should be treated. Second, was a fundamental disagreement over the ease with which antibiotics should be made available in society. This appeared to reflect Africans' experiences of accessing antibiotics in their home countries, from both the professional and folk sectors of health care. This issue is considered in the following section.

During some interviews with African participants it became clear that the dominance of an infectious model of disease was not confined to beliefs about *chronic* disease causation. That is to say that many Africans also held a deep belief in infectious models for common symptoms such as coughs, colds, and sore throats. This was evident in accounts from both Africans and GPs, as illustrated below:

*"Their concept of illness is more infectious diseases: so you take the treatment, you feel better" (GP5F 40-49 UK).*

*"In Congo we believe that a lot of diseases come from infections and whenever [it may be] it is necessary to give antibiotics"<sup>78</sup> (African 18M 50-59 French).*

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<sup>78</sup> "Au Congo on croit que beaucoup de maladies viennent des infections ... et donc à n'importe quelle occasion il faut qu'on donne des antibiotiques"

Alongside this, it was reported that African patients lacked a conceptual distinction between a virus and bacterium. This issue was also evident in the language that some African participants used to describe their treatments:

*“I don't think they understand [how antibiotics work]. And to be honest I've had problem explaining, you know, what a virus [is and] what [is] a bacterial infection: for them it is [a]germ. And germ means antibiotic!” (GP1F 40-49 Africa)*

*“The antibiotic is going to fight the virus that you are suffering from”<sup>79</sup>  
(African 15M 30-39 French)*

First-hand experience of infectious disease in Africa was considered an overarching factor in accounting for these beliefs. One reason for this belief and the expectation of rapid treatment with antibiotics appeared to result from previous experience of life-threatening infectious disease in Africa. For example, one African mother reported grave consequences for a child whose fever was not treated with antibiotics:

*“If he/she does not get [antibiotics], he/she can get even polio, or he/she can get yellow fever, which [is] that drying out of the blood, or you can lose the child”<sup>80</sup>  
(African 14F 30-39 Swahili)*

In addition to first-hand experience of the severity of certain infectious diseases, these beliefs may have emerged for parallel reasons. That includes messages conveyed by health promotion professionals. Public health messages relating to tropical diseases tend to emphasize a need for vaccination or to kill an infective organism, for example with regard to measles or plasmodia. As a result of the expansion of triple therapy in the continent, Africans may even be familiar with the notion that antiviral therapy exists for HIV. These messages are likely to create a broader expectation that untreated infections can kill and require “antibiotics”. Doctors may also have their own reasons for raising expectations of antibiotic treat for febrile children, particularly given limited access to hospital investigations. That is to say, they may fear failing to recognise a life-threatening disease and, therefore, provide blind therapy with antibiotics. Such an expectation could also be driven by patients themselves as they were reported in this study to be anxious about misdiagnosis by African doctors, such that: “they are living with that background: that doctor[s] can miss illnesses because they [Africans] have seen them [i.e. this] happening before their eyes” (Key Informant 40-49 Africa). Thus, it appeared that the desire for

<sup>79</sup> “L'antibiotique va lutter contre le virus que tu souffres...”

<sup>80</sup> “Hiyo wanasema ... asipopata.... anaweza kupata hata polio... au anaweza kupata yellow fever... ambayo... hiyo kukauka na damu mara moja au unaweza kumpoteza mtoto

antibiotics could be driven by fear of missing an underlying serious infection that could only be cured by early treatment with antibiotics. For this reason it was considered necessary to take antibiotics “as soon as they [Congolese] are ill”<sup>81</sup> (African 4F 40-49 French). One participant illustrated how his experiences in east Africa influenced his beliefs in this regard. In this he emphasised his understanding of antibiotics as life-saving drugs that must be administered rapidly, even in Europe. This participant had little experience of UK general practice and held a belief that rapid access to antibiotics in the UK was routine:

*"I would say [the fact that in] Kenya it [antibiotics] is available it is a good thing because there again you don't have a lot of access to a lot of medical practitioners .... I would imagine you would probably [be] saving more lives by having it probably more available because not everyone will get to a doctor than the risk of, okay it might be developing resistance... but I think you are saving more lives by having it available. In the UK it might be a different case because you could probably get to a doctor as easily as an hour or something like that and a prescription could be sorted out in a short shrift [time]" (African 9M 30-39 English)*

Thus, even educated Africans felt that the benefits of antibiotics outweighed negative aspects of use, including the risk of drug resistance. Infact, only two Africans reported that they had heard that taking antibiotics could increase the risk of resistance. As these two participants (African 6F and African 9M) were of different gender, age group and educational level it was unclear what had brought about this awareness.

## **7.2 Expectation of antibiotics: direct access to antibiotics in Africa**

Africans saw little logic in their doctors' perspective that antibiotics should be issued at the discretion of a doctor in accordance with clinical guidelines. Indeed, some Africans perceived their resistance to prescribing antibiotics, instead, as wilful obstruction. There was no evidence in this study of differences in participants' expectation of antibiotic prescription associated with length of stay in the UK. This was despite many having lived in Europe for nearly a decade and included younger and well-educated participants. The interviews suggested that there were fundamental differences in beliefs and experiences about obtaining antibiotics that endured because they resulted from participants' personal experience of this in Africa.

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<sup>81</sup>“Des qu'ils sont malades pour eux il faut prendre les antibiotiques. Ca c'est la pratique qu'on a, les gens qui ont vecu au pays”



Many African participants suggested that access to antibiotics was uncomplicated in Africa, for example that “[in Congo] we give antibiotics easily”<sup>82</sup> (African 4F 40-49 French). In the context of antibiotics, there appeared to be a breakdown between the professional and popular sector of health care such that antibiotics were available simply by paying for them and without having to see a doctor:

*“They buy the medication [antibiotics] on the street. And there are those sweet-talking [pedlars] over there who sell the medicines”<sup>83</sup> (African 18M 50-59 French)*

In addition to the the popular sector of health care described above, uncomplicated access to antibiotics was also reported to arise in the professional arena. That is to say that antibiotics were stated to be available without resistance from pharmacists, nurses and doctors. Unlike the resistance to prescribing antibiotics described by GPs in the present study, African doctors were reported to concede to such expectations from patients. One African GP accounted for this practice in terms of lack of time as well as differing expectations with patients over the need for antibiotics:

*“I think because there is not enough doctors [in Africa]. Instead of arguing with patient or you know spending time explaining, they prefer to give antibiotic and that because when I was working a GP back home I would see easily 30 patients in a morning and 25 in the afternoon and you can imagine if you have [laughter] that is the list of patient! You can't have time to explain "I don't think you need this". If someone comes and say "oh I think I've got a chest infection" and you examine and it's not and [you] say "oh no I don't think so, it's a cold" and then start to explain then I think it was just stressful and most doctors ended up giving up” (GP1F 40-49 Africa).*

Africans described how one consequence of antibiotics being widely available in Africa without a prescription was that this led some to report personal experience of cures. In these cases antibiotics were perceived to have been the origin of the cure, rather than healing occurring as part of the self-limiting natural history of an illness. The experience of such cures from antibiotics appeared to reinforce belief in their efficacy. This concurs with evidence from general practice in the UK that prescribing of antibiotics improves patient satisfaction (Dowell, Pitkehtly, Bain et al., 2001) but serves to enhance belief in the need of antibiotics and intention to consult for similar symptoms in future (Little, Williamson, Warner et al., 1997). Additional benefits in this scenario may have arisen from the placebo effect: “when he takes [the tablet] even if it is a poison, God can cure,

<sup>82</sup>“Je veux parler plus du Congo que je connais. On donne facilement des antibiotiques”

<sup>83</sup> “On achète des médicaments à la rue et il y à des bons parleurs chez nous qui vendent des médicaments”

since we [Africans] are strong believers”<sup>84</sup> (African 18M 50-59 French). What is more, personal experience of cure from antibiotics whilst visiting Africa could promote belief in the value of antibiotics amongst Africans *in Europe*. This was suggested by the example below of a condition not normally treated with antibiotics in the UK:

*“I was in Kenya a month ago and I had food poisoning and I took the Flagyl [antibiotic] for, I mean, two days and that was it. I mean as soon as I started taking that, it was fine, I was fine and I didn’t need to go to hospital or anything” (African 9M 30-39 English)*

A further consequence of easy access to antibiotics in Africa was that it was reported that Africans could acquire empirical knowledge about products, including drug names and their perceived effectiveness. Such knowledge was most notably claimed by one participant – a Swahili herbal healer described further in Chapter Seven - who claimed her authority in the area of antibiotic use to be greater than that of her GP. She contrasted her firsthand experience of taking antibiotics with the limited knowledge and cautious use by GPs in the UK. This lay wisdom led her to be suspicious about the use of “Ampicillin” (a second generation penicillin-based antibiotic related to those commonly prescribed in UK general practice) and implied that GPs chose it purely in order to reduce cost:

*“The doctor here, to speak honestly, they do not know: [they do not] even know antibiotics [at all]! You know, to start with us we are more of a doctor than you [medical] people here! [hand clap and loud laugh] Because [for] me [an] antibiotic: as an African I started to know [about them] since I was a child. I know which antibiotic [to choose], Gentamicin: it's for what! I know [what they are] for, this is for what, I know this is for what, I know this is for what. But here [in the UK] the cheapest useless antibiotic also [i.e. are the ones] you have, like, it's very very, Ampicillin, that is crap! I mean for an African that's a crap antibiotic!”<sup>85</sup>*  
(African 5F 50-59 Swahili and English)

One alternative reason to account for high antibiotic demand amongst Africans was advanced cautiously by one participant. This participant suggested that antibiotics might be requested from the GP in UK (i.e. from the professional sector) in order to send them back to unwell family members in Africa. This illustrated how transnational networks could lead to blurring of the professional sector in Europe with the popular arena of health

<sup>84</sup> “Quand ils voient les tubes que c'est jaunes rouges c'est un certain antibiotique fort... donc les convaincre que c'est un antibiotique fort... et dieu dans sa souveraineté dans sa bonnète et quand il prend même si c'est un poison Dieu peut faire guérir ... puisque... même... parce que nous somme très croyants”

<sup>85</sup> “Daktari wa hapa kusema wa kweli hata hawajui antibiotics... unajua sisi kwanza ni daktari kuliko nyini ya hapa ... [hand clap and loud laugh]... kwa sababu mimi antibiotic kama mwafrika nimeanza kujua toka ni mtoto ... najua natibiotic ya nini gentamicin it's for what... najua for... this is for what... najua for this is for what.... najua this is for what... lakini hapa the cheapest useless antibiotic pia mna ... kama... it's very very... ampicillin.... that is crap! I mean for an African that's a crap antibiotic....au tetracycline”

care in Africa:

*“I hope I am not betraying my compatriots or [indeed] all Africans. Perhaps [they have] a bag of antibiotics in the house to send to Africa so that their relatives can get antibiotics. Instead of them asking [you] for money when they are ill they [just] take the antibiotics that you send [to them in Africa]”<sup>86</sup> (African 18M 50-59 French)*

### 7.3 GPs' responses to antibiotic demand

In early interviews it became clear that addressing demand for antibiotics was a major concern for GPs in consultations with migrant patients. As a result, in later interviews GPs were asked how they would manage a request from an African patient who had severe symptoms of a sore throat but no clinical signs. That is to say, a sore throat that would clearly not require antibiotic treatment according to clinical guidance, for example the Centor score (Centor, Witherspoon, Dalton et al., 1981). In these interviews, GPs widely reported that even if pressed by the patient to do so they would not prescribe antibiotics for African patients with severe throat pain in the absence of clinically important signs of infection. Thus, for GPs, clinical guidelines were reported to take precedence over the severity of the patient's symptoms or any reported previous benefit from antibiotics. In practice, however, GP decisions appeared to arise as much from the routine working patterns that had emerged from their own experience in clinical practice. As part of this, a number of GPs explained that their refusal to issue antibiotics was not confined to African or migrant patients. This is consistent with evidence that much activity in general practice consists of repeated patterns of actions that tend to be stable, even where they involve an interaction of multiple actors (Greenhalgh, Robb, and Scambler, 2006). It should be noted, however, that no GP suggested that African patients might be unaware of a broader policy to restrict antibiotics and that it could be perceived as one only for migrants.

This approach to antibiotics was in no way confined to the European GPs. This was important because it was suggested that African patients might expect an African doctor to be more amenable to prescribing. The result of this was that “most of them [Africans] they are disappointed because I will act exactly like a white doctor here [laughter]” (GP1F 40-49 Africa). This was recognised by both African GPs:

<sup>86</sup> “Peut-être je ne trahi pas mes confrères... mes... mes compatriotes... ou tout les africains... avoir... un peu... avoir un grand bagage de des antibiotiques dans la maison ... pour peut-être expédier en Afrique pour que les parents puissent avoir les antibiotiques... au lieu qu'ils vous demandent de l'argent quand ils sont malades... ils prennent les antibiotiques que vous envoyez”

*“They believe that they have got a sore throat and they believe antibiotics is the thing that will help. I heard that from African patients, from local community patients and so on and I examine and I see nothing wrong but they still complain of pain. I tell them that what they require is not an antibiotic: an antibiotic will not take away the pain. I prescribe something for the pain, er, we may prescribe something like Diflam spray which takes [away pain]. If there is pain there it will help with the pain but an antibiotic will be totally out of place”*  
(GP8M 60-69 Africa)

In interviews with GPs and Africans there was almost no evidence of genuine or successful negotiation of antibiotic prescription by patients. It was not possible to discern to what extent this was true or whether in practice GPs would at times concede to antibiotic requests. This is because GP participants may have been reluctant to admit to such behaviour to a medically qualified researcher. Conceding to antibiotic demands was, however, legitimised by two GPs by referring to the presence of wider health concerns, namely pregnancy and sickle cell trait. Otherwise, only one GP described how they might yield to prescribing antibiotics to a migrant patient:

*“If you have gone through all of that and you've explained everything, and you've told them you don't think it's going to make any difference to the course of the illness and they are still insisting I still would [not], I wouldn't back down on it. I mean I sometimes did if it was a Friday and they were really concerned and it was a child”*  
(GP2F 30-39 UK)

GPs described two other responses to address demands for antibiotics. First, the most common suggestion by GPs was to offer to review the patient's problem again, particularly should their symptoms deteriorate. Unsurprisingly, Africans interpreted this strategy in terms of repeated refusal and ongoing issuing of paracetamol. Conversely, for GPs there was a belief that such consultations represented an opportunity to educate migrant patients: “[I would] just try and increase their understanding of what antibiotics really do” (GP5F 40-49 UK). The effectiveness of this strategy was not widely discussed by GPs. For example, there was little consideration in this strategy of barriers facing migrants trying to obtain another appointment. Only one GP volunteered such problems with this approach, raising significant doubts over the practical implementation of a reviewing strategy in a busy surgery. She did not offer any clinical alternatives to those already tried and implied that length of symptom duration was, ultimately, an important influence on whether or not antibiotics were prescribed:

*“Obviously it would depend on how long the history had persisted. [I use] the same guidelines as you would use for any other patient and again ‘safety net’ them and say ‘look I’m happy to see you tomorrow, I’m happy to see you the following day, whenever’ and we [have been lucky to be able do this because we] had a very flexible system. I appreciate that not all general practices maybe have that. We would often just sit with out fingers crossed and hope that they didn’t come back” (GP6F 50-59 UK)*

A second strategy that was suggested by one GP was a “delayed” antibiotic prescription. This is an evidence-based strategy where the patient is provided with a prescription and informed to take the antibiotic after a certain time period (e.g. three days) if symptoms do not improve (Dowell, Pitkehtly, Bain et al., 2001). Other GPs, however, felt that this approach was inappropriate with migrant patients because “to actually make sure they really understand that concept [of a delayed prescription] is quite hard” (GP5F 40-49 UK). Africans also rejected the strategy outright, mainly as a result of a deep belief in the effectiveness of antibiotics. Thus for Africans, it was suggested that their preference for taking antibiotics would simply lead to immediate – rather than delayed – use:

*“Either you give it or you do not. That is what I think, because a doctor who does that: he gives you an antibiotic so take it! I think, phew, no, I am against that... I do not accept that a doctor should say “hang on to this prescription”. In any case with regard to the Congolese people that I know they are [just] going to take it. They will not wait two days. They will not wait two days... [ ] As the people from Ivory Coast say ‘that is [like] giving [someone] a present!’ [Laughter]”<sup>87</sup> (African 4F 40-49 French).*

These findings suggest that antibiotic demand from African patients was high and usually met by GPs with a refusal. Although GPs used clinical guidelines to rationalise their decisions, other factors may have underpinned their behaviour. Such behaviour, instead, appeared to arise from established patterns of working and through a desire to retain control of consultations. There was also limited evidence that GPs may yield to requests, for example the case described above relating to prescribing on a Friday. The way in which GPs might act counter to guidelines due to pressures in the workplace is considered in Chapter Nine. Before that, this thesis considers the treatment options that Africans reported turning to when their health care expectations were not met by their own GPs.

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<sup>87</sup> “Ou vous donnez ou vous donnez pas! Moi je pense ca, parce que un médecin qui fait ca, il vous donne un antibiotique alors prenez-le! Je pense, er, phew, non je suis contre ca..... Je n’accepte pas qu’un médecin dise ‘gardez cette ordonnance’ en tout cas par rapport aux Africain congolais que je connais ils vont prendre! Ils vont pas attendre deux jours... Ca c’est donner cadeau comme disent les ivoiriens.... laughter”

## 7.4 Africans' responses to dissatisfaction with the NHS

Although antibiotic refusal was the most commonly reported area of discordant expectations in GP consultations, it was clear that Africans' dissatisfaction with the NHS extended well beyond this scenario. Frustration also arose from failure to access specialists and imaging investigations. Alongside this, the NHS was criticised by Africans for being slow and impersonal and these organisational issues are considered in greater depth in Chapter Nine. In light of these frustrations, it became clear that Africans had access to a range of other services for health care. Turning to a diverse range of types of therapy and therapist is consistent with evidence from Africa (Green, 1999) but remains poorly studied in the western context.

### 7.4.1 Seeking a different NHS doctor

Accessing another GP for antibiotics was a strategy recognised only by African participants, including one African GP: "They will change the doctor to see if they can get it [antibiotics] from another colleague" (GP1F 40-49 Africa). There was, however, conflict between the beliefs of other GPs and Africans over the success of approaching the Emergency Department or accessing out of hours GP services as a route to antibiotics. The idea that migrants could successfully seek antibiotics elsewhere was dismissed by one GP on the assumption that the Emergency Department would have the same strict policy about antibiotics:

*"They could attend accident and emergency and [be] told that this was an inappropriate use of accident and emergency services. Often they will be seen [examined in the Emergency Department] rather than [just] turned away, but not given antibiotics" (GP3F 50-59 Europe)*

Nevertheless, for one African who had described "a total lack of understanding"<sup>88</sup> (African 19M 50-59 French) from his GP about his symptoms stated that he routinely resorted to the out of hours service to obtain antibiotics. Here he stated that his request led to "an antibiotic automatically, at least, in my experience"<sup>89</sup> (African 19M 50-59 French).

Apart from seeking antibiotics, Africans were reported to turn to other doctors for two reasons. First, was for asylum seekers to find a GP who could support their immigration

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<sup>88</sup> "Une incompréhension totale"

<sup>89</sup> "Un antibiotique automatiquement, en fin, mon expérience".

claim to remain in the UK. Second, the decision to approach a different doctor was attributed to the underlying feeling that could result from face-to-face encounters with GPs:

*“You feel like betrayed, you [feel] like unwanted and, you know, all those sad feelings. But on top of it you know they get this anger as well, because.... He [an African migrant] hears about good GPs and he hears that GPs are very supportive and nice and stuff like that. But his GP is not nice, so so that's where the anger comes from” (African Key Informant 40-49 English).*

Despite this, changing registration with a GP surgery was reported not to be straightforward. This was because in the UK registration with a GP surgery is determined by the patient's address, thus leading to a tension for some Africans between finding suitable accommodation and accessing a GP whom they liked:

*“Sometimes you are told that ‘oh, there's a very good doctor somewhere [and] you feel like even going to even look for a house close to that place!” (African 1F 25-29 English).*

### **7.4.2 Choosing private health care**

An alternative strategy for Africans who were unable to access desired specialist opinions and investigations was to seek treatment outside Scotland. This finding was consistent with evidence that asylum seekers desired rapid access to specialist care (O'Donnell, Higgins, Chauhan et al., 2008). Africans were reported to resort to such services in three geographical locations: a private “French” hospital in London, francophone countries in continental Europe and private hospitals in east Africa. One benefit of these services was reported to be ease of communication, in particular not requiring an interpreter. Preference for these services was also attributed to a belief that they offered personal service alongside straightforward access to clinical investigations:

*“I want to be treated by a Kenyan doctor, sorry, because I think they will go into the in-depths. They will explore all the channels, they'll do all the tests, they won't just brush it off” (African 2F 30-39 English).*

Particularly positive comments were made about an unidentified “French” hospital in London, although none of the Africans interviewed in this study had actually attended this in person. Again, its service was framed in the context of patients being taken seriously by doctors: “I have not been to this [French] hospital [in London] but there are rumours that

they take very serious care of people”<sup>90</sup> (African 17M 40-49 French). Similar benefits were reported first-hand by one African woman who had attended a hospital in France. This lady had described deep dissatisfaction with the care she received from her GP in Scotland and contrasted this with the fruitful diagnostic tests undertaken in France:

*“[In France] they did tests, tests, tests, [once] the results were given: it’s diabetes, they also found asthma, they found hypertension, everything, everything, everything”*<sup>91</sup> (African 6F 60-69 French)

Benefits of private care were reported to go beyond receiving personal attention and multiple tests. In particular, there was a deep belief that private services would be successful in uncovering diagnoses missed by the UK NHS. For one African this was closely linked to the private nature of such care: “If I were to go private I would know what [my ongoing breast] problem is”<sup>92</sup> (11F 40-49 Swahili).

Despite widespread praise for such services, it was the only African participant with firsthand experience of using a hospital in France who raised concern over the cost of health care outside the NHS. This lady described significant anxiety over her inability to pay a bill of more than one thousand Euros that she had received from the treating hospital in France. In particular, she reported the following worry upon her return to France to see family there: “I wonder if they are going to put me away”<sup>93</sup> (African 6F 60-69 French).

### **7.4.3 Community, family and international networks as resources for health**

It was noted that there was cohesion in migrant communities in the UK and that this is where migrants would first turn to for support. That this traversed boundaries between professional and refugee migrants from Africa was shown by the key informant’s own experience of being approached at a mosque by a refugee with a health problem. He also noted that with regard to employing community networks, healthseeking was just one issue amongst many for migrants in their search for assistance:

<sup>90</sup> “Je n’étais la dans cet hôpital mais il y avait déjà des rumeurs que la on prend soins des gens très sérieusement”

<sup>91</sup> “Ils ont fait des examens... des examens... des examens... les résultats sont donnés... ici c’est le diabète... et ils on trouve l’asthme aussi... ils ont trouvé l’hypertension.... tout tout tout tout tout”

<sup>92</sup> “Ningekwenda private nitaijua tatiso ni kitu gani”

<sup>93</sup> “Je ne sais pas si on va me prendre”



*“They look into the sort of country network, like the national, they look for the nationals and then they try to see if there is anybody who could help them. They find somebody working with accountancy, they find somebody a doctor, somebody working in the hospital a nurse, they will try to ask them about what to do” (Key Informant 40-49 English)*

In addition, it was clear from certain Africans that family networks for advice and support could be extensive and span continents. This finding is consistent with evidence that transnational networks are important for African migrants in the context of illness and therapy (Thomas, 2010). Health information from these networks appeared to be particularly highly valued as a result of trusted relationships. For example, one African reported that her first action when ill would be to telephone east Africa for medical advice from relatives abroad. This health network was clearly extensive:

*“We’ve got a paediatrician in the family, we’ve got a gynaecologist in the family, we’ve got a surgeon in the family, I think we’ve got five different types of doctors so either we just liaise with them” (African 2F 30-39 English).*

Nevertheless, not all participants had access to such professional resources. Instead, they were forced to find more practical ways to meet unmet health needs and accessed health care through the popular sector. That is to say, through self-care or by importing medication via family and friends who were not health professionals.

#### **7.4.4 Self-medication: importing western medication**

African migrants reported a range of proactive treatment behaviours in pursuit of health and to fulfil their expectations of care. For some French-speaking Africans these steps were represented by the notion of “l’automédecine” or “self-medication”. This was reported to be “when you try to prescribe medication for yourself”<sup>94</sup> and was considered to be a practice that resulted from poor satisfaction with the NHS: “this type of [impersonal] treatment drives us to self-medication”<sup>95</sup> (African 3F 30-39 French). Self-medication appeared to embrace a wide range of healthseeking behaviours and products. This included widespread use of home remedies (such as garlic, onions, lemon and ginger) for minor illnesses and, for some, African traditional medicines. The latter is considered in greater depth in Chapter Eight. In addition to these products and the purchasing of over

<sup>94</sup> “Quand vous vous essayez de vous prescrire des médicaments de vous même”

<sup>95</sup> “Ce genre de traitement nous pousse à l’automédication”

the counter pharmacy medications, some African participants showed considerable self-reliance by importing certain western medical products via social networks in the UK and overseas.

Most commonly, medication importation was reported to occur when friends and relatives visited Africa. Importation was even described in terms of products being “ordered” from abroad, suggesting the existence of established transnational networks. This is consistent with evidence of pharmaceutical medications being sent between southern Africa and the UK (Thomas, 2010). This behaviour was reported to be widespread and to involve a range of countries:

*“Oh God! [laughter] We are ordering from China, from Hong Kong, we are ordering from Africa, very many medicines are coming in”<sup>96</sup> (African 5F 50-59 Swahili and English)*

Importing medication separated treatment from consulting a GP, leading to concealed use of products. Most commonly, medication importation was described by Africans in the context of antibiotics. Nevertheless, as a result of reduced airlinks with Africa, direct importation was reported to be more challenging in Scotland than in England:

*“There are some who do it, like [for] Amoxicillin, er, some of our antibiotics, that one for example is made in [Congo]... but here in Glasgow I don't know, but I know that in England lots of people bring it [across] because they have the means, the planes [from Africa] land in England. We here are a bit far away, there are no direct planes to Africa here. But I know that in Africa they make medicines [come across].”<sup>97</sup> (African 18M 50-59 French)*

A further indication to import medication arose in the context of malaria. For one participant, the need to bring back quinine from Africa was prompted by concern over British doctors' competence in diagnosing malaria and their reluctance to treat it swiftly. This was contrasted with the way in which an African could rapidly identify the symptoms of malaria from personal experience and the ability of such individuals to self-medicate to treat it. Doctors' preference for inpatient treatment for malaria appeared to disempower African patients and deprive them their normal and trusted way of managing malarial symptoms. In particular, there was concern over the way doctors were reported to dismiss

<sup>96</sup> “Oh God! [laughter] tunaagiza kutoka China, kutoka Hong Kong, tunaagiza kutoka Afrika, madawa zinaingia nyingi mno”

<sup>97</sup> “Il y a quelques uns qui le font, comme le Amoxicillin, er, un peu de nos antibiotiques la. Cela par exemple c'est fait chez nous, c'est fait chez nous dans [notrepays] ... mais ici à Glasgow je ne sais pas. Mais je sais qu'en Angleterre beaucoup de gens font venir parce que ils ont la facilité: des avions qui arrivent en Angleterre. Nous on est un peu loin. Il ya pas de vols directs de l'Afrique ici mais je sais qu'en Angleterre ils le font [venir], des médicaments”

Africans' perspective on infectious diseases despite the personal experience of the condition and its treatment. Again this led to concealed use of imported medication:

*“A colleague who came from Ghana and had malaria and he was put in observation for a long time and they didn't give him anything and I think he passed away from malaria and I was like ‘no, I'm not going in there [hospital]’. I know - I think - I have it: it could only be malaria or typhoid because I know the symptoms and I was like, so I was like, if I went in there do you think they would listen to me if I said I have malaria? Or would they say ‘no, we want to observe you and see first” or you know try some other things and I said “no, I'm not going in” and I had carried [from east Africa] a full dose for treating malaria and I just self-medicated. So I was off work three days but at the end of my course of treatment I was fine.”*  
(African 9M 30-39 English)

In this study the use of imported medication was described by Africans without concern over its legal status and only one participant described negative consequences from imported medication. This concern arose through taking excess paracetamol-based painkillers imported from Brussels for “bone pain”<sup>98</sup> (African 4F 40-49 French), apparently in association with similar medications prescribed by her own GP. The apparent lack of concern over interactions and the undisclosed use of imported medication clearly points to challenges to promoting safe practice in this area.

## 7.5 Chapter conclusions and discussion

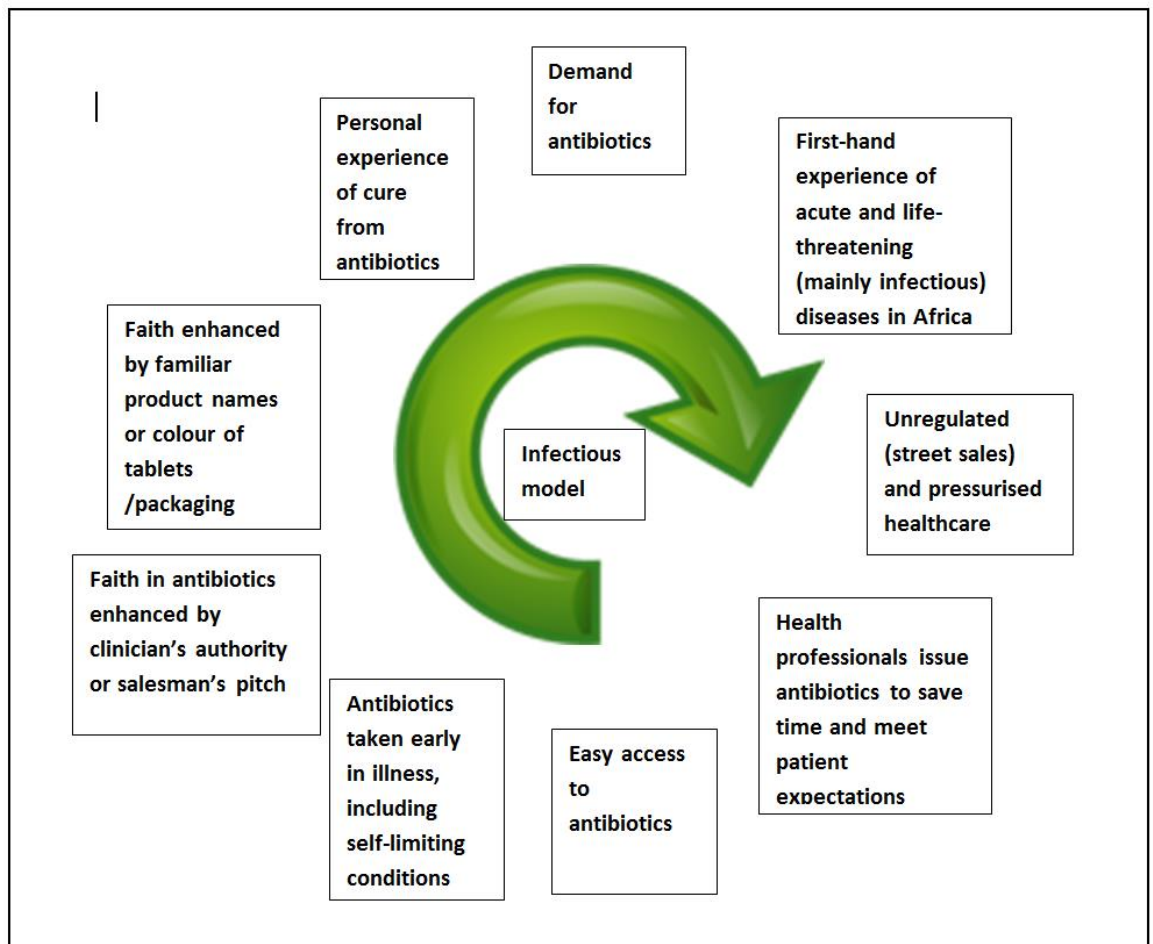
This study contributes to understanding of the health care expectations of African migrants in British general practice. This is by building upon existing evidence of high demand for antibiotics from migrant patients and through exploring the underlying health beliefs of Africans that emerge from experiences of illness and treatment in their home countries. Examining the wider origin of health beliefs in the transnational context is increasingly relevant in a globalised world and the study findings point to a link between treatment behaviours/beliefs in Africa and GP consultations in the UK. This chapter has also considered the health behaviours that Africans undertake in response to unmet expectations of the NHS. These findings highlight the diverse and resourceful way in which Africans pursue their health beliefs and, again, the importance of trusted transnational networks in doing so.

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<sup>98</sup> “J'ai abusé de paracétamol assez fort, ça venait de Bruxelles”

As reported elsewhere (O'Donnell, Higgins, Chauhan et al., 2007), this study reported dissatisfaction amongst migrants over unmet expectations of antibiotics. The wider factors identified in the present study that motivated Africans' faith in antibiotics are illustrated in Figure Two overleaf. Conflicting beliefs between Africans and GPs pointed to a fundamental "expectation gap" over antibiotics. Wider reasons for this gap and possible strategies to improve this situation are now discussed below.

**Figure 2: Factors driving high expectation of antibiotic prescription amongst African migrants**



### **7.5.1 Antibiotics: the “expectation gap”**

This study suggests that African migrants’ health beliefs are shaped by personal experience of life-threatening infectious diseases in their own country, leading to a deep belief in the value of rapid intervention with antibiotics even for symptoms such as a sore throat. A key aspect of the antibiotic expectation gap lies in the fact that the type of diseases that Africans are likely to have encountered prior to migration is very different from those commonly encountered by GPs in the UK. It is, of course, illnesses common in UK populations that shape GPs’ expectations of when antibiotics should be prescribed and form the basis of national prescribing guidelines. For this reason, the way in which GPs in this study resisted prescribing antibiotics appeared to be consistent with current UK guidelines and research evidence that prescribing in cases of sore throat treatment only marginally affects the resolution of symptoms (Little, Williamson, Warner et al., 1997). Despite this, it is important to recognise that Africans also have a sound basis to their concerns. This is because the natural history of sore throats in the UK differs considerably from that in Africa, where conditions such as rheumatic fever remain a major public health problem. This is because in the developing world respiratory infections are more likely to be caused by organisms such as group A haemolytic streptococci that result in rheumatic fever and other serious immunogenic sequelae (Olubodun, 1994). Because of this, primary prevention using antibiotics has even been advocated for Africa (Karthikeyan and Mayosi, 2009). What is more, in parts of Africa patients with symptoms of a sore throat may have reason to worry about acute, life-threatening infections. This is because in western Africa the haemorrhagic disease Lassa fever can initially present with a sore throat (Gill and Beeching, 2004b).

Education about the rationale behind Africans’ beliefs and expectations may help to promote more effective communication in GP consultations. That is to say, for GPs to become aware of African migrants’ deeper concerns about acute symptoms and to address these in consultations. On many levels this is no different from calls for better communication with white British parents worried about the possibility of misdiagnosis of symptoms in their children, in particular meningitis (Kai, 1996). What is distinct, however, is the range of infectious diseases reported by Africans in this study as concerns for patients/parents. These included conditions that do not form a major part of routine GP training in the UK, for example malaria, typhoid, polio and yellow fever. Some GPs, therefore, may feel unconfident about discussing such diseases and providing reassurance

to an anxious African patient. For GPs working with African migrants this calls for wider education about recognising imported infectious diseases using existing teaching resources, such as the website Travax (Health Protection Scotland, 2014). Beyond this there is a need for greater understanding about the expectations of treatment that arise from living in areas where antibiotics are freely available as well as to develop strategies for communicating risk in cross-cultural consultations.

For African migrants, greater education about the risks of side effects and drug resistance from antibiotics and the benign nature of common symptoms in Europe may help to reduce expectations. The present study, however, suggests that achieving change in this expectation will prove challenging. This is because in this study faith in antibiotics was maintained amongst nearly all African participants despite their having spent nearly a decade in Europe. One reason for enduring belief in the value of antibiotics lies in the transnational links with Africa described by participants. Health beliefs are likely to be reinforced through personal travel abroad and via telephone/web-based communication with contacts in Africa, including with relatives who are health professionals. This conclusion is consistent with evidence that Africans' transnational networks extend beyond simple exchange of money and medicines (Krause, 2008). What is more, it is likely that expanding use of the internet in Africa will increase the importance of such networks, for example through the transnational, on-line ordering of antibiotics. This suggests a need for further research to explore the way in which technology and international networks together shape health beliefs and treatment behaviours amongst migrants.

The findings of this study highlight two further challenges to reducing antibiotic prescription. First, in the USA it has been suggested that increasing the proportion of minority ethnic health professionals in the workforce can improve the quality of care for ethnic minority patients (Smedley, Stith, and Nelson, 2003). In the UK such an approach has also been advocated as having benefits not just to individual patients but also to wider society in general, for example through its symbolic importance and potential to transform attitudes in healthcare (Williams & Johnson, 2010). Nevertheless, evidence from the present study suggests that immigrant African doctors are unlikely to be able to bridge the "expectation gap" between GPs and African patients in the context of antibiotic use. This is because they tend towards prescribing behaviour similar to their white British colleagues. Second, this study provides some evidence that both GPs and African migrants are unlikely to accept a delayed prescription strategy. This is important because evidence

exists that this approach for reducing antibiotic use by deterring patients from consulting to seek antibiotics for similar symptoms in the future (Dowell, Pitkehtly, Bain et al., 2001). The present study suggests that discouraging African migrants from consulting for antibiotics may simply lead patients to seek medication elsewhere, for example by obtaining drugs through other parts of the health care system or by importing them. Clearly, this has important implications for safety and illustrates the value of interpreting health-seeking by migrants in terms of Kleinman's (1978) dynamic model of cultural health care systems.

### ***7.5.2 Self-resilience and medical pluralism***

This study illustrates how African migrants take a pluralist approach to health care. The resolve of Africans in the present study to pursue unmet expectations of treatment was manifested in considerable self-reliance and initiative. Such resilience appeared to be inherent in the notion of "self-medication", for example accessing clinical advice or a medication that could not be obtained from an NHS doctor. Alternatives to seeing a GP were not presented by Africans in the form of a hierarchy, except for a belief by some in the superiority of private services. This was typified in belief in the "French hospital" and this service could be considered the very antithesis of accounts of "paracetamol" as a symbol for being dismissed by a GP (Feldmann, Bensing, and de Ruijter, 2007). Although Africans talked about the advantages of private and foreign health care systems, few participants in reality had access to such services. Thus, the notion of the "French hospital" in London appeared to constitute an urban myth amongst francophone Africans: a symbol of ideal care in the absence of first-hand experience. Absence of personal experience may also explain why no concern was raised over the possibility of unnecessary hospital tests or over profiteering by private health care providers.

The reported benefits of seeking treatment from doctors in francophone Europe and Africa may have arisen from more subtle cultural factors rather than differences in health care service. That is to say, satisfaction is likely to be associated with overcoming language barriers, accessing familiar health care services and the presence of family support. Indeed, accounts of better health care abroad may, in essence, represent a deeper longing for home. Similar belief in health benefits from returning to one's own country have been described amongst other migrant groups, for example amongst Ghanaians in the Netherlands (Beune et al., 2006) and African-Caribbeans in England (Brown, Avis, and

Hubbard, 2007). These findings are consistent with the notion that nostalgia for bygone times and a need for cultural affirmation can be expressed through treatment preferences. The present study, therefore, suggests that the underlying determinant of African migrants' health care choice is likely to be based upon two factors: familiarity and trust. Nevertheless, other reasons influencing Africans' choice of treatment resort require more detailed investigation, including the role of barriers to accessing health care, language knowledge, personal empowerment and ability to pay. Future studies might illuminate this issue by considering beliefs and behaviours of affluent African migrants who are likely to possess wider options in their choice of health care systems.

The accounts presented in this chapter focus upon African migrants' pluralist use of what Kleinman (1978) terms the professional sector of health care. Nevertheless, Africans described considerable blurring between this sector and the popular domain of health care, for example, by direct access to antibiotics without recourse to consulting a doctor. The wider interaction between the use of professional, popular and folk sectors of health care are considered in Chapter Ten. Before doing this, however, a further component of self-medication will be considered that arose from evidence of a folk sector of health care operating in the west of Scotland. This was because some African participants described extensive use of folk services that were associated with the use of traditional medicines and healers.



## 8) Traditional medicine use and beliefs

Whilst planning the interview topic guide for Africans, it was anticipated that some participants would report previous experience of traditional medicines – that is before migration to Britain. During early interviews, however, use of traditional medicines by African migrants *within* the UK emerged as an unexpected and, for some, highly valued form of health care. As a result, this practice was raised in interviews with all African participants. Of these, six out of 19 Africans described use of traditional medicines in the UK, either for themselves or their children. These were almost entirely women and spanned both Muslims and Christians, specifically participant numbers 1F, 3F, 5F, 11F, 14F, and 19M. The first three of these belonged to a single sampling chain, although there was no evidence to suggest that these participants were linked through their use of traditional medicines. The other three users were each recruited separately. It was notable that some of these participants (1F and 14F) initially denied taking traditional African medicine but later went on to describe using such products, suggesting that this behaviour might be more widespread in this study than reported.

This was also suggested by evidence that all users and four non-users (African participants 9M, 13M, 18M and GP8M) reported knowing, or being aware of others who used traditional African products in the UK. Africans who described others' use of such products were frequently unclear of exactly what products their acquaintances were taking. For example, one treatment for fibroids being taken by a close friend could not be named and was reported thus: "it is just a dark, funny, rooty medicine" (African 1F 25-29 English). Non-users tended to state that traditional products were not used by Africans in the UK simply because they could not be imported. Similarly, non users reported that traditional medicine was not available in African shops in the UK. Nevertheless, one non-user acknowledged that it was possible where food products were used as medication, such as ginger:

*“I don’t think so [that African medicines are available here]. Where are you going to find that? Perhaps in the shops, but real traditional medicines: no, apart from perhaps the juice of ginger [for coughs]”<sup>99</sup> (African 4F 40-49 French).*

From responses it was plain that the distinction could become blurred between traditional medicines and home remedies that were taken to treat familiar, minor ailments. This was because many African participants described taking a wide range of kitchen remedies, such as lemon, orange, lime, honey, garlic, egg, onions, hot water and gargling saltwater. Use of such remedies cannot be considered to be confined to Africans and these and similar products are not considered here in terms of traditional medicines.

A few products, however, appeared to span the divide between kitchen remedies and traditional medicines. This was most evident in the widespread use of ginger, which was described in both categories. This appeared to depend upon its formulation: thus, ginger was regarded as a medicine when it was used in a prepared (i.e. ground) form or as a “capsule” (18M 50-59 French) or used for a specific condition (e.g. haemorrhoids). Similarly, another participant who reported using ginger in continental Europe described it in terms of a medication when applied topically (i.e. rather than being taken orally):

*“Ginger, exactly, you see that is the African medicine and, for example, in Congo, and at home, for example, we take that a lot, for everyone, ginger is everywhere, even in the markets, you will find it there, yes, it was that which I was taking. You take a piece, you put it inside the anus and that was helping a lot”<sup>100</sup> (19M 50-59 French and Lingala/Swahili)*

The definition of traditional African medicine was similarly blurred by Swahili participants who reported taking a range of herbs and spices for specific symptoms and diseases. These were defined both as medicine *and as food*: “you know that not all traditional medicines are medicines, [they] are food, [they] are spices, [they] are food, they are things like that”<sup>101</sup> (African 5F 50-59 Swahili and English). That food products such as spices possess medicinal properties is a recognised belief amongst many Asian migrants to England (Sandhu & Heinrich, 2005). Most Swahili people have historical links with the coast of east Africa and it is possible that such beliefs are the product of cultural exchange resulting from centuries of trade across the Indian ocean. Nevertheless, spices and herbs

<sup>99</sup> “Je ne pense pas. Ou est ce qu'ils vont trouver ca? Peut-être dans les shops, mais les médicaments traditionnels comme tels: non, à part peut-être le jus gingembre”

<sup>100</sup> “Tangawizi, justement. Donc vous voyez que ca c'est le médicament africain et chez nous, par exemple au Congo, eh, on prends ca beaucoup, pour tout le monde, tangawizi est partout, même dans les marchés, vous la trouverez, oui, c'est ca que je prenais souvent et puis des fois vous prenez tout un morceau vous mettez dans l'anus, eh, et ca aidait beaucoup”

<sup>101</sup> “Unajua dawa zote za miti shamba siyo dawa, ni chakula, ni spices, ni food, ni things like that”

were described by this participant in terms of treating specific symptoms and diseases. What is more, herbs and spices were reported to elicit powerful effects on users:

*“Nutmeg actually is very dangerous: it's a drug. You didn't know [that]?” and “there are people who if they use nutmeg ... it is just a sexual thing... they want sex the whole night!”<sup>102</sup> (African 5F 50-59 Swahili and English)*

Not all traditional African medicine use was oral or topical. For example, inhalation was reported by two Muslim Swahili participants. For one, this was for headache and, separately, as part of Islamic therapy for stress-related symptoms. This involved burning incense on charcoal whilst receiving blessings from a Muslim Sheikh in order to “drive away the demon(s), using those written words [from the Koran]”<sup>103</sup> (11F 40-49 Swahili). This observation suggested that the symbolic or religious nature of a product could contribute to its perception as a traditional medicine.

## 8.1 Influences on use of traditional African medicine

Various factors were reported to be associated with use of traditional medicine by migrant Africans. Only one participant reported using traditional medicine as a result of barriers to accessing their GP but others experimented with it after failure of western medication to elicit a cure. No participant suggested saving money as a reason for use. Use was closely associated with personal experience of cure from traditional medicine: “I don't think there is an educational level or anything, it is just like ‘it works, they use [it]’” (African 1F 30-39 English).

Several barriers to use were mentioned. First, was an unpleasant bitter taste attributed to some traditional African medicines as well as that it could sting when applied topically. Other reasons reported for non-use included high educational level and originating from a city. For one participant whose mother had used herbal remedies in Africa, his non-use was ascribed to migrating at a young age: “I left Congo too young to kind of like think that way” (African 10M 18-24 English). Two participants suggested use was more common in people from unspecified west African countries. Only one participant linked traditional medicine with his/her own ethnic group or country: “It is not Africans actually [using these: it is us the] Swahili people [i.e. a Muslim group of east African society who

<sup>102</sup> “Kuna watu ambao wao wakitumia nutmeg it's just a sexual thing anataka sex the whole night”

<sup>103</sup> “Kumfukuza shetani kutumia hii maandiko haya”

originate from its coast]”<sup>104</sup> (African 5F 50-59 English and Swahili). Indeed, it was notable that the three Swahili Muslim participants were all users of a wide range of products.

The overarching reason reported for using traditional medicine was its perceived efficacy. Rapid cure was a widely asserted belief amongst users such that products appeared to possess a mystical quality: “they say you only use it once [for erectile dysfunction] and that is you sorted” (1F 25-29 English). Benefits of this rapid cure were reported to include avoiding surgical intervention, as well as associated long-term physical incapacitation and general inconvenience (for example, finding childcare during hospital attendance). Only one user reported a faster cure using western rather African medicine, specifically surgery for his haemorrhoids (19M 50-59 French). Otherwise, users consistently contrasted rapid cure from traditional African medicine with slow responses to western drugs: “[haemorrhoids are] treated in two different ways... the Africans have this way which... where the disease heals rapidly”<sup>105</sup> (3F 30-39 French).

## 8.2 Clinical indications for traditional medicines

Participants reported traditional medicine use in the UK for a range of symptoms and conditions. Foremost were “erectile dysfunction, that is the commonest and for women some medication to help them conceive” (GP8M 60-70 Africa). In particular, this GP described a patient in Scotland who was taking a product widely known as “calabash clay” prior to and during pregnancy.

*“Traditional medicines, there’s quite a lot of that. I had one who was eating clay, er it was a west African from Nigeria she was eating this clay before she got pregnant and during the pregnancy and she had this sent from Africa” (GP8M 60-69 Africa)*

Other clinical indications for reported personal use (self or one’s child) in the UK were haemorrhoids (ginger root and leaf), chickenpox (“permanganate”), eczema (herbal products from east Africa, in one case mixed with 50:50 liquid paraffin and in another mixed with aspirin), “flu” (eucalyptus leaves), headache (burning incense), tummy pain and fever (roots of the Neem tree (*Azadirachta indica*) known in Swahili as “mwarobaini”) and unspecified fingernail problems (a herbal product called “pommade camphrée”).

<sup>104</sup> “Si Waafrika actually: Waswahili”

<sup>105</sup> “Est traitée de deux façons différents: les Africains ont cette façon de faire que ou la maladie guérit rapidement”

Participants also named some conditions for which they knew other African migrants to be taking traditional medicine. These included the following: haemorrhoids, erectile dysfunction, diabetes, hypertension, “minor flu”, nasal powder for unspecified discomfort, and fibroids.

When participants talked about the indications for traditional medicines it was clear that single herbal products were often believed to have multiple clinical indications, although these tended to be given as symptoms rather than diagnoses. This was reported by one participant thus: “with herbs it is not specifically for diarrhoea, headache, no, one herb can be for ten different types of diseases”<sup>106</sup> (African 5F 50-59 English and Swahili). This diverse clinical indication for herbal products was also suggested by the very name of plants. Examples included the Neem tree that is known in Swahili as “mwarobaini”: this means the ‘forty – tree’ because it was reported to cure forty diseases. One Congolese participant described a similar phenomenon to account for the name of a medicinal plant in the Kikongo language of western Congo, possibly the plant Aloe vera:

*“There is even a medicine that they call, which is widely for sale, that they call ‘kamasongo’ in Kikongo which means ‘a thousand and one diseases’”<sup>107</sup> (African 18M 50-59 French)*

### 8.3 Accessing traditional African medication

In this study it was clear that the range of products used by Africans was determined by what was available. Some participants suggested easier access to traditional medicines and healers in London. This was because as well as being home to a larger African population, London was perceived as having closer air links with Africa. The only products purchased in the UK were reported to be spices for medicinal uses bought at Asian shops in Glasgow by Swahili participants. There was no evidence of Africans obtaining herbal remedy from western shops selling herbal products on the high street. This suggested a lack of contact with white British people using similar herbal products. Similarly, there was no evidence of products being ordered from online stores.

<sup>106</sup> “It is not ya kwamba let's say one nutmeg that is going to do this, no. One nutmeg kwa how many quantities of water, how many, how long have you boiled it, what is it going to do, kwa sababu with herbs it is not specifically for diarrhoea, headache, no, one herb can be for ten different types of diseases”

<sup>107</sup> “Il y a même un médicament qu'on appelle, qui se vende souvent, qu'on appelle kamasongo en kikongo qui veut dire mille et cent maladies”

Most traditional medicine was reported to be imported directly from Africa. There was only one account of travel to Africa specifically to be treated there with such products. Traditional medicine was reported to be imported from a range of countries in east Africa as well as from the DRC. This involved specific requests through social networks made to friends visiting Africa (or after their return) and was described in terms of “order[ing]”<sup>108</sup> (African 3F 30-39 French). Thus, access to traditional medicine was frequently linked to knowing people who were about to travel to, or had recently returned from, Africa. This pointed to the existence of transnational networks, principally based upon returning travellers to Africa:

*“African medicine you can't get it here. You really can't get it here. You just wait for somebody to go home and then you tell them like "get this for me" or "this is, get this for me" (African 1F 30-39 English).*

*“When a Congolese person goes to Kinshasa everyone is asking him on his return if he brought back [products] like ginger”<sup>109</sup>(African 18M 50-59 French).*

Nevertheless, restriction on importing products was reported to be a barrier to access. As a result of heightened restrictions at airport customs and on carrying fluids aboard aeroplanes it was considered to be harder to import traditional medicines from Africa. Concern over this had prevented one university-educated participant from importing permanganate for medical use from the Congo on behalf of a friend. In this case, her concern over being caught may have been linked to the bright colour of the product:

*“What is the medication that recently [on my visit to Congo] that they were asking me [to bring back], but I did not want to carry [so] not to risk it at Customs? It was permanganate, a red product that we use when children have chickenpox”<sup>110</sup>  
(African 3F 30-39 French)*

There was evidence of traditional medicine being shared by African migrants within the country beyond one degree of contact. For example, when the participant above needed permanganate to treat her own child's chickenpox, she had this posted to her in Glasgow by a relative living in England. This relative had in turn had it brought or sent from Congo. Once brought into the UK, traditional medicine was reported to be spread through the African community by word of mouth. An important reason for this was accounts of

<sup>108</sup> E.g. “Il ya des gens qui commandent”

<sup>109</sup> “Quand un Congolais va à Kinshasa c'est tous le monde à son retour qui lui demande s'il amenait par exemple le ginger”

<sup>110</sup> “Quel est le médicament que dernièrement on m'avait... mais que j'ai pas voulu prendre pour ne pas risquer, er, à la douane. C'était erm, permanganate. C'est un produit rouge qu'on utilise lorsque les enfants ont la varicelle”

successful cure:

*“Maybe you have seen somebody else who has used herbal medicine and you tell them “eh, you know there is this thing happening, have you heard of it?”. You say no, “come I will show you” then somebody will show you. If it helps you, it is just it moves like wildfire, it is just like that, yeah” (African 1F 25-29 English).*

The provenance of traditional African products used by participants was closely related to their country of origin. Nevertheless, it was suggested that people looked to countries other than their own when seeking treatment for specific conditions. For example, one participant went as far as associating individual African countries with specific conditions: “Kenya is where there is the treatment of eczema”, “[for] fibroids I know Uganda leads... laughter”, “epilepsy: Congo” and “[treatment for erectile dysfunction] comes from every country, but I think the Congo is the best” (African 1F 25-29 English).

### **8.3.1 Use of traditional healers and native plants within the UK**

Most participants dismissed the notion of traditional African healers’ practising in the UK. This was considered unlikely due to grounds of professional and immigration status: “a traditional herbal medicine [healer], how are they going to get a visa to come here, really, no” (African 1F 30-39 English). For this participant the questions over the legitimacy of traditional healers in the UK extended to their status within the African community. Indeed, she was scathing over the probable motivation for traditional healers operating in the UK:

*“We normally know that the [healer] people who are there they are just, they are not, they are just lying. It is just that they have got a gap where people, you know, there is demand. So someone has just decided to fill that space and maybe they really don't know what they are doing” (African 1F 30-39 English).*

Contrary to this, another participant looked to his belief that Africans held strongly to their traditions, including when abroad. This, he suggested, would mean that traditional healers must exist in the UK. Nevertheless, he noted that in the UK they would have to practise with much caution:

*“I believe they must be here because Africans are very attached to their origins, even the people whose fathers used to do that [traditional medicine] over there [in Africa] or the grandfather: once here they can also do the same but these are things that happen in a closed circle”<sup>111</sup> (African 18M 50-59 French)*

This scenario was corroborated by the account of two participants who described one (or possibly two) female Congolese healers operating in Scotland. Requests to interview her proved unfruitful, apparently on the grounds that she had changed her telephone number. As part of her treatment, this Congolese healer was reported to provide “a potion”<sup>112</sup> (African 13M 30-39 French) for erectile dysfunction and to “mix leaves” that “she finds here”<sup>113</sup> (African 3F 30-39 French). It was unclear if these therapeutic leaves were purchased or gathered wild in the UK. She was reported to have cured severe haemorrhoids for a patient whose GP had refused treatment for fear of doing so during pregnancy. The healer’s treatment was described in terms of a high cure rate but there was uncertainty over whether or not she charged for her care. It was reported that she was approached by patients through existing personal contacts. In particular, her clinical work took place in the context of strictest secrecy:

*“They [Africans] speak with her because they know that they are going to be cured but each time it is ‘you tell it to no one, if I hear it [said then I will know that] it’s you!’ Also she knows to keep a secret, she will never say ‘right I have treated so [and] so[and] so and [so]’. She will never tell you”<sup>114</sup> (African 3F 30-39 French)*

In addition to this account, one participant described herself as a Swahili herbal practitioner, having been taught in east Africa by her mother and grandmother (African 5F 50-59 Swahili and English). Since coming to the UK she reported practising herbal medicine rarely and only with people whom she knew well: “[I use it for] only people who knows me because I avoid, I have been avoiding it for a long time, I haven’t used a lot except a very, very few people”<sup>115</sup> (African 5F 50-59 Swahili and English). She was reluctant to describe such possible practice in detail. One barrier to her practice was reported to be lack of familiarity with British wild flora. For example, she reported being tempted to use flowers from a wild British tree that closely resembled a similar medicinal

<sup>111</sup> “Je crois qu’ils ne peuvent pas manquer parce que l’Africain est très attaché à ses origines, même les gens dont les papas faisaient ça la bas, ou le grand-père, arrives ici ils peuvent faire ça aussi. Mais sont des choses qui se passent en deh[ors], c’est dans un cercle fermé”

<sup>112</sup> “Une potion”

<sup>113</sup> “Mélanger ces feuilles la, elle les trouve même ici”

<sup>114</sup> “Ils parlent avec elle parce qu’ils savent ils vont être guéris mais à chaque fois c’est ‘tu le dis à personne, si je l’apprends: c’est toi!’ Elle sait aussi garder le secret, elle ne te dira jamais ‘voilà j’ai soigné telle, telle, telle, telle. Elle ne te dira jamais”

<sup>115</sup> “Only people who knows me kwa sababu naavoid. I have been avoiding it for a long time. I haven’t used a lot.isipokuwa very few people”



plant in Africa to treat a friend's diabetes:

*“If someone has diabetes there is in Africa a plant that has white flowers. We take it to bring the sugar down. Now when I came here there was someone [who] was very ill with diabetes. I was not sure whether I should give them [it]. It is here but I am not sure whether it is the same thing. It just looks similar, but I can't say one hundred per cent”<sup>116</sup> (African 5F 50-59 Swahili and English)*

One case of using local leaves was, however, reported by another participant. In her interview this participant specifically stated that she did not use traditional medicine but went on to describe inhaling eucalyptus leaves gathered locally. She later showed the tree to the principal investigator who confirmed it as a species of eucalyptus. She collected the leaves in Glasgow “every season, during the cold period, during the sunny period”<sup>117</sup> and used eucalyptus to treat “fevers, flu, diseases like chest cold, chills, diseases, they say it even helps to cleanse the skin”<sup>118</sup> (African 14F 30-39 Swahili). This participant stated that she had learned about the presence of this eucalyptus by another African. As a result she believed that other Africans came to the same tree to collect leaves.

## 8.4 Explanatory models of how traditional medicines work

Africans offered a range of opinions on how traditional medicines work. For one, this was a simple factor of early intervention. This was because treatment with traditional medicines was usually commenced at the very onset of symptoms: “In Africa we do not have this type [of very large haemorrhoids] because we use these [traditional] products right from the start [clap of hands]”<sup>119</sup> (African 3F 30-39 French).

The accounts of other participants revealed more structured explanatory models of how traditional medicines work, particularly from female Muslim Swahili participants. For some, particular health behaviours were reported to be enacted in order to promote normal physiological processes that were perceived as therapeutic. First, was purging the body

<sup>116</sup> “Kama mtu anasukari kuna Afrika, kuna plant ambayo maua meupe kwanza tunachukua to put the sugar down. Sasa nilivyokuja hapa kuna mtu ambaye anaumwa sana sukari. I wasn't sure whether nimpe. Ipo hapa but I am not sure whether it's the same thing. It just looks similar but I can't say it is a hundred percent”

<sup>117</sup> “Nachuma yale majani kwa kila msimu kwamba wakati wa baridi na wakati wa, wakati wa jua kali na wakati wa baridi”

<sup>118</sup> “Mafever, flu, eheh, magonjwa ya mafua, magonjwa baridi, magonjwa, wanasema inasaidia hata kuwa ku... kuitakatisha ngozi”

<sup>119</sup> “En Afrique on n'a pas ce genre parce que on utilise de ces produits qui des le départ [clap of hands]”

through sweating (11F 40-49 Swahili and African 14F 30-39 Swahili), including temperature regulation. These two participants described preparing and administering traditional medicines in very similar steps in order to induce sweating. The similarities between these two accounts – both of which were practised in Glasgow - was striking and pointed to traditional, ritual-like, steps to promote healing that had been maintained despite nearly a decade in the UK. A model of cleansing the body was suggested to underlie the benefits of this therapy based upon a notion of infection breaching the body, for which provoking sweating was reported to be required for cleanliness and to kill the contagion:

*“I cut them [leaves from the eucalyptus tree]. I come to [my] house here in Glasgow. I cut them [up]. I put them in a cooking pot that takes up to two kilos. I put them in there with water. I boil it on the cooker for about half an hour.... Then when I have finished.... I take a blanket. I cover myself all over that I should not leave a gap. Then I open the lid careful whilst I am inside there, carefully, therefore all that smoke comes [in]. I am wearing lightweight clothes, cotton, or I am dressed like at home [in Africa a sheet of patterned cloth worn by women] we call Kanga”<sup>120</sup>  
... “The great advantage of that steam [is to] bring out sweat, it is indeed [that way] it removes diseases.... It cleans the skin therefore, as we believe that on our bodies there are lots of small holes that we cannot see, they will be opened (up).. if there is fat, that grease, and if there are bacteria which are wanting to attack our skin, [it] will be like it has killed that bacteria, those many small creatures”<sup>121</sup>  
(African 14F 30-39 Swahili)*

A third physiological explanatory model closely related to cleansing was that of colonic evacuation (African 5F 50-59 Swahili and English, African 14F 30-39 Swahili and – only in the context of treating haemorrhoids - African 18M 50-59 French). Use of laxatives was specifically advocated by the Swahili traditional healer in order to rid the body of unhealthy foods eaten (at night) during Ramadan and in order to rid the body of worms considered responsible for a wide range of diseases. This process of “de-tox” (African 5F 50-59 English) was also reported to be beneficial to prepare the body to receive herbal medicine.

<sup>120</sup> “Nakata, nakuja nyumbani hapa Glasgow. Nakata naweka kwenye sufuria na sufuria kama ya kilo mbili naweka humo na maji. Nachemsha kwenye cooker kama nusu saa hivi ... halafu nikimaliza naingia chumbani hapa kwenye corridor nachukua blanketi. Najifunika kote, nisiache nafasi. Halafu nafunua ule mfuniko taratibu nikiwa mimi humo. Taratibu. Kwa hiyo ile smoke yote yanakuja. Mimi nanicover. Nikiwa hapa nimevaa nguo nyepesi tu kama ni cotton ... au nimevaa tu kama kwetu tunaita Kanga”

<sup>121</sup> “Faida yake kubwa ya ule mvuke kutoa jasho ndiyo naamini kwamba ndiyo unatoa magonjwa ndiyo kama nilivyokuambia inasafisha skin kwa hiyo kama, tunaamini kwamba kwenye mwili mwetu ngozi yetu kuna matundu madogo madogo ambayo sisi hatuyaoni. Yale yatakuwa kama yamefumuka. Kama kuna mafuta ile greasei na kama kuna bacteria ambayo yanataka kushambulia ngozi yangu. Ile itakuwa vile nimemwua ile bacteria wadudu wadogowadogo wale”

### 8.4.1 Avoiding chemical contamination from western medicines

A further overarching belief that underlay participants' understanding of the benefits of traditional African medicine was its perceived purity and natural origin. For example, the participant who took lemon to prevent cancer insisted that this must be "natural" lemon (19M 50-59 French). This natural origin was sometimes ascribed to the products' source from plants grown in African soil: "because these are just leaves, garden shrubs, they have no chemicals"<sup>122</sup> (11F 40-49 Swahili). This perspective was not confined to Muslim participants or east Africans. A further valued property was freshness, suggested by the Swahili woman who inhaled eucalyptus leaves collected in Glasgow. She insisted upon collecting the "fresh leaves"<sup>123</sup> that did not "dry out during neither summer nor winter"<sup>124</sup> (14F 30-39 Swahili). This preference is also important given that the participant chose fresh leaves rather than the wide range of menthol-based products available in British shops.

An important and surprising benefit of traditional African medicine reported by users in this study was to avoid chemical contamination from western medication. These participants held strong suspicions not just over the contents of western drugs, but the reasons for their suspected impurity. In addition, concern about chemical contamination appeared to be linked with awareness of wider medical scandals prominent in the British media:

*"These [European] medicines are mixed up with lots of other things, you are going to find paracetamol it has been mixed up with lots of things"<sup>125</sup> (11F 40-49 Swahili)*

*"People are scared, you know people say like injections, they say "that is a chemical" you know, you don't know what chemical you are taking, you don't know in the next five years they will tell you "Ok you are injecting yourself [with] insulin - that insulin wasn't good, it's 'chemical insulin' or something". So people are really scared of that because things are changing every day, people watch the news they say that a few years ago they were putting breast implants like they thought were good now, now they are bad. You know, people usually think of that, that in the next few years something will come up that what you are using wasn't good" (1F 24-29 English)*

<sup>122</sup> "Kwa sababu ni majani tu haya. Miti shamba nini hayana machemical"

<sup>123</sup> "Majani mabichi"

<sup>124</sup> "Ni miti ambayo haikauki Summer wala Winter"

<sup>125</sup> "Hayo madawa mengine yanachanganishwa na mambo mengi... unaenda ukaikuta paracetamol imechanganishwa na vitu vingi"

The purity of herbal produce was specifically invoked by the Swahili traditional healer to account for rapid cures. Surprisingly, she reported that herbal and western medication contained the *very same* active ingredients. To support this view, she discussed evidence that many biomedicines originated from plants, for example aspirin and quinine, explaining that such ingredients had been used for centuries by herbalists and were only now being exploited by pharmaceutical companies for profit. It was her view that herbal medicine worked exactly like western medicine but that hers was more effective because it was “original”, “pure” and “clean” (African 5F 50-59 English) and that this purity was responsible for instant cures:

*Interviewer: “So, why is it that your Swahili medicines work so fast, and ours, the doctors’, slowly?”*

*Participant: “Because your medicines [work using] the very same process of taking [the contents of] plant[s] but now because of the pharmaceutical [companies] – come on, it’s a billion dollar business! – they will take the very same [plant] chemical that me I am using [but] me I will use it pure [and] clean. They [the pharmaceutical industry] will take a little [of the plant product] and put it inside those tablets to dissolve [it] so the process will take longer, such that it will not have reach the dose I use [until] maybe [after taking it for] one month”<sup>126</sup>(African 5F 50-59 Swahili and English)*

The overarching evidence presented for chemical contamination of western products was the presence of side effects from biomedicines. Conversely, evidence of the purity of traditional products arose from their absence of side effects:

*“Chemicals? Didn’t I tell you that I got medicine from the hospital [here and] I have stopped them because my ears were ringing? I don’t know what thing had been put inside it”<sup>127</sup> (African 11F 40-49 Swahili)*

*“You know those western things [sleeping tablets] they make you sleep, but these [traditional almonds] calm you down to be able to sleep gradually without being knocked off”<sup>128</sup> (African 5F 50-59 Swahili)*

<sup>126</sup> Interview: “je kwa sababu gani madawa yenu ya kiswahili yanafanya kazi haraka na yetu madaktari polepole?”

African: “Kwa sababu madawa zenu za ni ni ni ni ni the same same process ya kuchukua plant from A. Lakini sasa kwa sababu ya ya pharmaceutical - it's a billion dollar business, come on! - wao watachukua let's say the same same chemical ambayo mimi ninatumia mimi nitaitumia pure clean. Yeye atachukua kidogo atatia katika ile tablet kuiyeyuka so it will take a longer process mpaka haijafika ile dose ambayo mimi nilikuwa nimetumia .... maybe one month”

<sup>127</sup> “Chemical? Kama hivyo si nakuambia mimi nimetoa dawa hospitali nimeziacha kwa sababu nasikia mashikio yananiwuma? Sijui kimetiwa kitu gani mle”

<sup>128</sup> “Unajua niniyo ya kizungu inaku, inakulaza lakini hii [lozi] inaku calm down, to be able to sleep gradually without being knocked off”

Further reassurance was drawn from the origin of many Swahili remedies as food products. As food products it was stated that “they cannot affect [harm] me”<sup>129</sup> (5F 50-59 Swahili). As reported in Chapter Six, evidence of the purity of African produce was reported to lie in its superior taste that resulted from natural and pure origins. In this way, the impurity of the British ginger was stated to result from contamination by chemicals in fertilisers that led to a bland taste:

*“Because we believe that the ginger from here, we [tried] buying it here where it is grown with chemical fertilisers [as well as] that which comes from Congo – [the latter] is very strong and when we eat them together [we can] truly [tell that] “ah this [one] comes from the village, it is good”<sup>130</sup>(African 18M 50-59 French)*

Nevertheless, concern over contamination did not stop traditional African medicines being mixed with western ones. In these cases the western products used were commonly encountered items, in particular aspirin (African 9M 30-39 English) and “50:50 liquid paraffin” (African 1F 25-29 English). In both cases this was reported for treating children with skin conditions:

*“[Hydrocortisone] didn’t seem to be working and my friend’s mother-in-law came over with some medicine from home, some herbs, leaves and mixed that with aspirin and used it on the boy [with eczema] and the boy turned out quite fine” (African 9M 30-39 English)*

In both of these cases it was notable that chosen western products were widely used ones, namely aspirin and liquid paraffin. This suggested that first-hand experience of western products and trust in their safety was key to their use. Conversely, one participant suggested that a belief in the power of western medicine to treat any harmful effects from traditional medicines could lead to experimentation with herbal remedies. This scenario was described by one participant whose friend was taking an unidentified product for fibroids:

*“The first time I saw my friend taking it, it was like “do you know you might take this and then die!” ... laughter... she is like “an ambulance will be thirteen minutes away, if I was back home in Africa I could be scared of taking, but here... laughter... I am not that scared, I just carry my bottle and I know the poison I have taken”. You know people even have that faith that here it is really hard to die, you know, like for*

<sup>129</sup> “Dawa zote za miti shamba siyo dawa, ni chakula, ni spices, ni food, ni things like that so haiwezi kuniiaffect”

<sup>130</sup> “Parce qu'on pense que le gingembre d'ici on est allé l'acheter la ou on la fait pousser avec les engrais chimiques et que celui qui viens du Congo il est très piquant et quand on les mange ensemble, vraiment, "ah ca vient du village, ca c'est bon”

*example you just carry the poison and they will tell you, then get an antidote for that poison” (African 1F 25-59 English)*

### **8.4.2 Psychological factors as an explanatory model**

Although some participants were adamant that traditional African medicine did not work as a placebo, this was offered as an explanation by two participants. First, was by one African GP (GP1F 40-49 Africa). Second, the Swahili traditional healer suggested that the placebo effect was a *central part* of her tradition of herbal medicine, such that: “black people have been using that [placebo effect] for centuries” (African 5F 50-59 Swahili). She explained how her own therapeutic accomplishments arose from the presence in her consultations of what she called (in English) “psychology”. She did not define this phenomenon, but it appeared to be based upon emotional support for the patient:

*“Ninety nine point nine percent of herbs is “mentality”, yeah, medicine is there but ninety nine point nine percent is that there is more kind of “comedy” if you put it that way! Laughter” (African 5F 50-59 English)*

The role for psychological factors was reported to be particularly valuable in the migrant context where social isolation and mental health problems dominated. Her expectations of treating patients also appeared to be linked with duration of consultation. Although she did not say how long her consultations were, she bemoaned the brevity of routine encounters in UK general practice as an inefficient means for supporting patients and that these were not long enough for Africans to address their psychosomatic issues:

*“It is more expensive for NHS: [rather] than the NHS giving us 15 minutes with our GP instead of the 5 minutes [let us have] 15 minutes with my GP this week then I will stay for almost seven months without going [back to the GP!]. But five minutes with my GP I am so unsatisfied I go back and I start feeling every pain everywhere....[and] after one week I call I go [back to the GP]. That is [how to save] money - so which is the best 15 minutes more or the five minutes?” (African 5F 50-59 English)*

Finally, the account of the Swahili traditional healer suggested that other aspects of her practice were likely to enhance patients’ belief. First, was her status belonging to a long family line of healers. Indeed, she described her knowledge of posology as “inborn” (African 5F 50-59 English). Second, was her ability to provide a medicinal product that was tailored to the individual and his/her problem, according to what she called the

patient's "bodily nature"<sup>131</sup>. Central to this was appropriate dilution of the herb and her description of the importance of dilution resembled that of homeopathy. This suggests that it may offer similar psychological benefits:

*"It is not that, let's say, one nutmeg is going to do [just] this [effect]. No. One nutmeg per [i.e. diluted to] how many quantities of water, how many, how long have you boiled it, [this determines] what is it going to do"<sup>132</sup>(African 5F 50-59 English and Swahili)*

## 8.5 Herbal medicine use for chronic disease and implications for adherence

In this study there were references to health behaviours associated with traditional medicine for the prevention and treatment of chronic disease. First, two food products were reported to benefit healthy people in terms of the prevention of cancer. These were lemon and (possibly just in Africa) Brussels sprouts. For example, one participant reported taking lemon preventively on the advice of a circular email forwarded by an African friend advocating the use of natural lemon in cancer prevention:

*"An email which landed here, at home, [from] other [African] friends connected to email, who were speaking about lemon - that lemon is the top medicine, for example, to combat cancer and most of the cancers. I think prostate [cancer]"<sup>133</sup> (African 19M 50-59 French)*

In addition, there were accounts of traditional African medicine being taken for the long-term treatment of chronic disease. In particular, two participants were aware of other Africans who were using imported herbal products for diabetes. For one, this was suggested as a way of avoiding insulin. For another, it was notable that herbal medicine was being used and imported by an African who had been in the UK for more than two decades:

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<sup>131</sup> "Kimwilimwili"

<sup>132</sup> "It is not ya kwamba let's say one nutmeg that is going to do this, no. One nutmeg kwa how many quantities of water, how many, how long have you boiled it, what is it going to do"

<sup>133</sup> "Un email la qui est tombé chez moi, les amis aussi qui se sont connected to email qui parlait du citron, eh, que le citron est le grand médicament par exemple pour combattre le le cancer et plupart des cancers. Je croit de prostate ou de quoi comme ca, si je ne me trompe pas. Les citrons naturels"

*“I don’t know how to describe [it]: all in a big bottle like that [illustrates with hands] that he brought from [his own] country. It is a Nigerian who lived here more than twenty years but he told me these are the medicines that he takes for diabetes but I have no idea what they were”<sup>134</sup> (African 19M 50-59 French)*

Certain advantages of traditional medicine were reported in the context of medication adherence. In particular, the instant cure associated with traditional medicine was considered a means of avoiding long-term adherence to western medication. Concern over long-term adherence to the use of western medication was contrasted with traditional medicine which was reported to be taken “religiously, like always” (African 1F 30-39 English). This participant described how Africans might use prescribed repeat medication such as emollients as a means of applying traditional – rather than western - medication:

*“It is not that they don't trust it [western medicine] they say that it is good, yes, it works, [but] it is something that you have to take always, you know, you have to be on [it]” and later “People use herbal medicine and it works for them and they stop taking repeat prescriptions of stuff from the hospital because they only take the 50:50 because they mix it with the [African] powder and it helps with their kids” (African 1F 30-39 English)*

Nevertheless, there was also concern in this study that traditional treatments for chronic diseases may lack efficacy. This was reported by two participants. First, the Swahili traditional healer reported that in her experience prevention of diabetes was not possible using traditional medicine. As if to establish the veracity of this fact, she noted that her mother – who was also a herbalist - had failed in this challenge. Second, another user reported that a friend’s hypertension was unresponsive to traditional African medicine and that she returned to western medication:

*“There is another lady I had she said that she was taking it for her hypertension but it wasn’t really helping because she had to go back to her normal medication” (African 1F 25-29 English)*

## **8.6 Discussing traditional African medicine in GP consultations**

Despite all having treated African patients, none of the non-African GP participants had encountered patients using traditional African medicines. Their only reported evidence of this was identifying old scarification marks during clinical examination of patients’ skin.

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<sup>134</sup> “Je ne sais pas comment décrire, toute dans une grande bouteille comme ca, qu’il a amené de du pays. C’est un Nigérien qui a vécu ici plus de vingt cinq ans mais il m’a dit que ce sont des médicaments qu’il prend pour le diabète mais je ne sais pas en tout cas pour vous dire mais de quelle nature”



Instead, traditional medicine was much more closely associated by GPs with their patients of Chinese origin. Importation of medication was reported to be routine amongst Chinese students such that they “normally bring with them a medicine chest of local remedies which they would access as and when required” (GP11M 50-59 UK). This choice was reported to be not just due to previous experience of traditional medicine but in order to save money while studying in the UK. Others were reported to have purchased Chinese medication locally. Where GPs had encountered Chinese traditional medicine there was widespread concern over its use, in particular for children:

*“There will just be these bags of things, meds, I don’t know, I don’t even want to call them medicines, items. Where did you get that? Oh I got it from so and so down the road and what about the prescription I gave you? Oh no they said that’s much better. Don’t put that on your child!” (GP10F 40-49 UK)*

One explanation offered by GPs for the low awareness of traditional African medicine use was a reluctance to take an alternative medicine history from patients. This was not only reported for European GPs but even for one African GP. Her reluctance to enquire about this was attributed to her own lack of knowledge about traditional medicine and, therefore, an inability to offer advice. In addition, she reported that African patients were usually reluctant to talk about traditional medicine in consultations and that, if they do, the doctor’s reflex response was to advise them to stop taking it. Thus, she offered the following reason why Africans would be reluctant to report use in a GP consultation:

*“From my experience again back home, because they know doctors don’t believe in them [traditional medicines] and yet they [the patients] do, so it is like “I don’t want to tell them about it because they are going to say stop it” (GP1F 40-49 Africa)*

Two other participants reported being reluctant to tell their GP about using traditional medicine. One appeared uncomfortable admitting to the GP her use of medicinal vegetables in pregnancy. For the second - whose child’s eczema had been cured by a traditional powder imported from Kenya - she felt comfortable telling the practice nurse but unable to inform her GP. This was out of deference to the doctor’s status and concern about challenging his perception as responsible for bringing about healing:

*“We have okra, an African vegetable. I know that to take a sprig when you are nearly at term [in pregnancy], you should eat that for good effects.... If I say that today to my doctor “no, no, no, I am going to take that, I prefer to take okra. What effect is that going to have?”<sup>135</sup> (African 3F 30-39 French)*

*“[I did not tell my GP] because it is like “I give you something and you are not using it, you jump to another one” you know so you would rather just keep quiet and he believes that it is his medicine that did it... laughter!” (African 1F 25-59 English)*

## 8.7 Chapter conclusions and discussion

The present study concurs with evidence from London that use of alternative medicines (food supplements, such as vitamins) is common amongst black women of African background, including those of higher socio-economic status (Cappuccio, Duneclift, Atkinson et al., 2001). These findings also support evidence elsewhere that African users perceive therapeutic value in traditional medicines and use them in order to affirm cultural identity (Thomas, 2010) - for example by continuing ritual-like treatment practices learned in Africa. Findings also confirm evidence that Africans adopt a “mix and match” approach to traditional and western medicines (Barimah and van Teijlingen, 2008). Finally, the indications cited in this study for traditional medicines supports the notion that for African migrants individual symptoms can come to represent an illness (Pavlish, Noor, and Brandt, 2010), rather than focusing on an underlying long-term diagnosis.

Unlike evidence from Italy that use by African migrants of herbal products was solely dependent upon importation (Ellena, Quave, and Pieroni, 2012), the present study found that Africans in the UK purchase products in minority ethnic shops and may forage wild leaves, particularly Muslim Swahili women. The latter finding supports evidence elsewhere (van Andel, Mitchell, Volpato et al., 2012) that African-origin migrants seek herbal remedies that resemble those available in their homeland. The present study also revealed significant ambiguity in respect of the term “traditional medicine” for African migrants in the UK, suggesting that use may be even higher than reported. This is because people taking “household” remedies and “foraged” products may not perceive these as traditional medicines. Unlike reports of direct shipment of traditional medicines from Africa to individual Africans in London (Thomas, 2010), the present study found that

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<sup>135</sup> “On a ocre, un légume africaine, je sais qu’une fois manger une brindille quand tu arrives presque à terme, il faut manger ça a de bien faits mais c’est un légume ça n’a rien à voir avec... si je le dit aujourd’hui à mon médecin: “non non non, je vais pas prendre ça, je préfère prendre, manger de l’ocre. Quel effet ça?”

carrying medicines on aeroplanes was considered the dominant method of importation.

Africans described a wide range of remedies with specific clinical indications.

Nevertheless, in this study it was not possible to test consistency in such beliefs between participants. Despite this, findings here support evidence that African migrants value traditional medicines as part of an ongoing, deep attachment to cultural beliefs and behaviours (Thomas, 2010). This may be seen in two ways. First, the account of certain practices closely mirrors that from parts of Africa. For example, the process of inhalation of eucalyptus leaves reported in this study is almost identical to that described in east Africa. This may be seen in the instructions below for treating colds from a Kenyan book on traditional African medicines:

*“Add a handful of the [eucalyptus] leaves, fresh or dried.... to one litre of boiling water in a bowl. Inhale the steaming vapour for 10-15 minutes 3 or 4 times a day, under a covering towel to ensure maximum penetration”(Dharani and Yenesew, 2010) page 138*

Second, some of the explanatory models reported in this study closely resemble those described in Africa, including balance of temperature, spiritual attack (Beckerleg, 1989) and indigenous belief in contagious disease (Green, 1999). The persistence of these models and related treatment practices suggest that health behaviours continue after nearly a decade living outside Africa, underlining the extent to which migrants' health beliefs may be resistant to change. In addition to its religious basis, a reason for maintenance of such behaviour may be that healing rituals possess their own benefits for well-being. This suggestion is consistent with evidence from Africa (Rasmussen, 2008) and African migrants (Papadopoulos, Lees, Lay et al., 2004; Svenberg, Mattsson, and Skott, 2009) that ritual and prayer are important in treatment processes.

This study supports other evidence that African migrants' use of traditional medicines results primarily from a deep belief in their effectiveness and cultural value (Thomas, Aggleton, and Anderson, 2010b). Participants' responses reflected reasons reported elsewhere for choosing traditional African medicine, principally due to perceptions of lack of side effects (Thomas, 2010) and absence of chemicals (Amutabi, 2008). This suggests that when prescribing medication GPs should provide African patients with specific instructions on how to respond to possible side effects. Explanation of the botanical origin of many western products for certain chronic diseases (for example, digoxin and aspirin) may also encourage medication adherence amongst African patients. Finally, some

participants reported the use of herbal treatment for chronic disease, suggesting that research is required into potential benefits of such products. This is important because there is evidence for the efficacy of traditional herbal medications in chronic disease, for example from the Caribbean where a range of products has been shown to possess biodynamic antihypertensive effects (Halberstein, 1999).

Despite what appeared to be beliefs and practices with longstanding historical origins, changing beliefs and treatment use was suggested by two participants who reported that traditional medicines could be mixed with western products. That these were commonly-used products such as aspirin and white soft paraffin, underlines the importance of trust and familiarity in the adoption of products or practices from a foreign medical system. It was also notable that these products did not appear to counteract Africans' beliefs in the purity and authenticity of their herbal products.

### ***8.7.1 Accounting for belief in an 'instant cure' from traditional medicines***

Findings from this study suggest various explanations to account for the perceived benefit of traditional African medicines, including their "instant cure". First, traditional African medicines may be genuinely efficacious. Second, faith in traditional medicines was reported wherever participants experienced rapid symptom relief, often for minor illnesses. This may have been reinforced by ritualistic treatment practices learned in Africa that affirmed cultural identity. What is more, some participants' belief in the effectiveness of traditional medicine was linked to physiological effects beyond simple relief of symptoms. That is to say, underlying explanatory models for illness reported in this study incorporated a therapeutic need to elicit physiological processes such as colonic evacuation, sweating and temperature balance. It is very likely that certain traditional products *are* indeed capable of producing rapid laxative effects, diaphoresis and temperature change. Thus, in addition to symptom relief, by eliciting rapid physiological responses such as these traditional medicines may give the impression of providing an instant cure or effect. Belief in cure may be particularly enhanced where the underlying model is one of internal infection that is "cured" by the purging of body fluids, such as sweat.

Second, in this study the Swahili traditional healer accounted for the effectiveness of traditional medicine through an explanatory model of psychological support. This is consistent with reports elsewhere that a high proportion of patients of African traditional healers may suffer from psychosomatic or existential disorders (Abdou, 2007). This may be particularly important for African migrants in whom stress is common and economic hardship has been found to triple the incidence of such psychological problems as sleep loss, depression, and unpleasant memories (Simich, Hamilton, and Baya, 2006). Thus, in contrast to the brief biomedical consultations provided in British general practice, traditional healers may achieve clinical successes for psychosomatic and social problems through longer, empathic consultations that embrace deeper cultural factors. In this way traditional healers may profit from what is known in general practice as “doctor as drug” (Balint, 2003), where the consultation itself offers therapeutic value for patients even in the absence of intervention (Bower, Gask, May et al., 2001) by providing the vital human link that can give patients the strength they need (Horn, 1999). Additional aspects of a person-centred approach undertaken by traditional healers was also illustrated in the present study by the suggestion by the Swahili healer of the preparation of a unique prescription for each individual patient. Such preparation of specific products for individual patients has also been documented in rural Africa (Redmayne, 1969) and may increase the perceived value of therapy. A similar phenomenon known as the “remedy matching process” is reported to be associated with benefits for patients who are using homeopathy (Thompson and Weiss, 2006). What is unclear from this study and the existing literature is details of the fees charged by African healers practising in Europe who provide such personalised treatment. That is important because it has been reported amongst the Asian community in the UK that straightforward access to trusted healers is associated with costly fees (Henley, 1979)

Certain other factors reported in this study may serve to enhance placebo effects. For example, the bitter taste of traditional medicines reported by some participants is a recognised characteristic of many African (van Andel, Mitchell, Volpato et al., 2012) and Asian (Pieroni & Torri, 2007) medicines. That observation is important because ingredients with a bitter taste or a distinctive smell are recognised as enhancing both physiological and placebo effects of products (Eccles, 2006). These concepts concord with reports from Africa of other psychological and cultural factors that may serve to increase cure rates from traditional healers. Examples from Africa healers that may enhance therapeutic outcomes include the following interventions: presenting an aura of

omnipotence, a charismatic personality, the use of symbolic paraphernalia, the use of fear and the desire of the healer to do their “best” in the event of a crisis (Asuni, 1979). It is also likely that longer consultation time is a factor for there is evidence that traditional healers in rural east Africa see fewer patients than a British GP, indeed as few as ten patients per week (Sindiga, 1995a; Sindiga, 1995b). As a result, African healers may possess greater personal or emotional strength to provide care for individual patients.

Finally, the Swahili herbalist’s explanation of rapid cure resulting from greater purity of active agents in traditional herbal products is a further possible reason why the efficacy of traditional African medicine may be perceived as superior to that of western medicines. Establishing the veracity of this claim would require comparative chemical analysis of traditional plant products and western tablets. Nevertheless, this may not be acceptable to African traditional healers. This is because African practitioners may perceive that in the laboratory a medicinal plant is removed from “its therapeutic context and stripped of much of its meaning” (Beckerleg, 1989). Similar issues have been reported in the context of assessing the efficacy of homeopathy, where the role for the active ingredient is reported to be “intimately woven” with the patient’s relationship with their healer (Van Hootegeem, 2006).

**Table 3. Factors likely to promote faith in African traditional medicines****Communication skills of healer/person providing medication**

Longer 'consultation' and empathy

Expectations of cure raised by person providing medication

?payment for medication

**Physical quality of product**

Bitter taste

Stronger flavour of foods taken for health (i.e. than British-grown produce)

**Beliefs about products**

Natural origin

Pure nature, proved by lack of side effects

African origin

'Magical' origin - for example products derived from animals with symbolic power eg rhinoceros or carnivore

**Effects and belief in 'rapid cure'**

Relief of symptoms

Physiological effects consistent with explanatory models of illness (eg diaphoresis to cleanse body of infection)

Ritualistic and/or religious behaviour as part of treatment

**Timing of use**

Used early on in illness, probably including rapidly self-limiting conditions

?In west where access may be limited, used as a "last resort" late in illness close to point of resolution

**Efficacy**

Reports of cures from traditional medicines circulating in African community

Effectiveness reported to be enhanced by increased purity of active botanical agent

**8.7.2 Addressing the concealed nature of use**

This study suggests that use of traditional African medicine in the UK is largely concealed or, at least, private. In addition, access to traditional African medicines in the west of Scotland does not appear to be commercialised, instead being built upon social networks or food products from minority ethnic shops. The services of traditional healers in the UK were reported to be secretive and based upon close relationships, in particular in the case of

intimate problems such as erectile dysfunction. The precise reason for this secrecy was not uncovered in this study. It may have related to concern over unregulated practice or, as reported elsewhere (van Anandel, Mitchell, Volpato et al., 2012) to a desire to protect commercially valuable knowledge. The present study concurs with others that African migrants are also reluctant to disclose traditional medicine use to doctors and that clinicians may fail to take an alternative medicine history (Thomas, Aggleton, and Anderson, 2010a).

A further factor that may lead to undisclosed use is the blurring of the definition of traditional medicine stated in the present study. For example, products such as ginger and spices were reported to be used as treatment but not always considered as “medication” This suggests that specific interview skills may be required in GP consultations to elicit information about patients’ use of lay remedies. Equally, the emphasis that African participants placed upon the natural quality of traditional African medicine suggests that GPs should enquire about “natural” or “home” remedies in addition to specifically seeking details of use of “herbal” products.

Traditional medicine use in this study was sometimes closely associated with two broad conditions: erectile dysfunction and gynaecological problems. This is important because particular risks have been identified with traditional medicine use for such problems. First, specific warnings have been issued about certain products for erectile dysfunction used in the UK, for example the lay Chinese product “African black ant” (Medicines and Healthcare products Regulatory Agency, 2011). Such substances have been reported to be contaminated with “Viagra” type medication (Medicines and Healthcare products Regulatory Agency, 2011) which possesses serious pharmacological interactions with commonly prescribed drugs for angina. Second, in this study there were two reports of use of traditional African medicine during pregnancy. One participant stated that her friend had turned to a traditional healer because of failure to obtain treatment during pregnancy from her GP. What is more, one GP reported a patient’s use of “calabash clay” without reference to its potential danger of poisoning from lead and arsenic (Farley, 2012). That is despite evidence of campaigns to target GPs in parts of the UK about the dangers of such geophagy (“soil eating”) amongst patients from Africa and Asia (Campbell, 2002; Public Health England, 2013). Use of traditional medicines, especially herbal ones, is common in pregnancy in Africa (Malan and Neuba, 2011) and it is therefore possible that this practice may be widespread. A further potential risk identified in the study is the use of



inhalation therapy, which is recognised to be associated with serious scalding accidents (Baartmans, Kerkhof, Vloemans et al., 2012).

This study suggests a need to promote awareness of, and openness about, traditional medicines amongst both African migrants and British GPs. This includes a need to educate medical and other health professionals about Africans' beliefs, and reasons for choosing traditional African medicines in the UK. In particular, this should emphasize that traditional medicine use is not confined to poorly-educated African migrants or those originally from rural areas. Also, awareness should be promoted of the diverse range of products taken by African migrants and, specifically, that these are not confined to herbal remedies but include spices, steam, smoke and prayer. Good practice in these areas requires active engagement with the African community and further education for clinicians and medical students in order to promote open discussion during consultations about lay treatment use. Beyond simply promoting disclosure of use of herbal medicine, the present study supports the suggestion from the Netherlands that improved liaison between formal services, traditional healers, religious leaders and self-help groups might be beneficial to migrant African patients (Knipscheer and Kleber, 2008).

More detailed research is required into the botanical and chemical nature of products being taken by Africans, as well as their knowledge of the nature of such medicines. This should consider the diverse practices exhibited by migrants from a wide range of African countries, religions and ethnic groups. One way of undertaking this in the UK would be to examine products that have been confiscated at airports from flights originating in Africa. A challenge to such research would lie in determining the identification of the species of small pieces of plant products, especially where these have undergone extensive preparation which may alter their content and properties (van Andel, Mitchell, Volpato et al., 2012). Additional research should also be undertaken to examine natural products taken by African women in the UK to promote health during pregnancy. Ascertainment of such risks could inform the establishment of community-based interventions to encourage use of products that are known to be safe.

### ***8.7.3 Use of traditional medicines in the treatment of chronic disease and minor illnesses***

The present study suggests that interventions to prevent and treat chronic disease might be built upon Africans' deep belief in natural therapies. This may be achievable because evidence exists of efficacy in certain conditions. For instance, anti-hypertensive effects of botanical products from tropical regions have been demonstrated (Halberstein, 1999). In the UK, beetroot juice has been shown to be a nitrate-rich product that elicits dose-dependent anti-hypertensive effects (Webb, Patel, Loukogeorgakis et al., 2008). Given this, consideration should be given to population-based interventions. For example, when beetroot is incorporated into the bread production process its hypotensive effect persists (Hobbs, Kaffa, George et al., 2012), thus providing the potential for a population approach to the prevention of hypertension. Such a model would be wholly consistent with the food-based traditional medicine approach advocated in this study by the Swahili healer and one that might be acceptable to other African migrants in the UK.

This study also suggests that Africans' faith in traditional remedies should be considered as a strategy for promoting self-care of minor illnesses. It was unclear whether Africans were aware that herbal remedies are available in British high-street shops. Further research should examine whether promoting the purchase from the high-street of apparently safe herbal remedies for minor illness might reduce demand for GP appointments, in particular those to request antibiotics. Such an approach may have wider benefits to Africans. For instance, using the established folk sector in this way may provide Africans with practitioners who are willing to engage in non-biomedical explanatory models for illness and who offer the personal service that they clearly seek.

## 9) Migrant consultations in general practice: a street-level bureaucracy?

Nearly one half of the African participants reported dissatisfaction with UK health care, mainly resulting from their experiences of using general practice and emergency departments. Central to such dissatisfaction was failure to access key resources, including the following: prescription of certain drugs (particularly antibiotics), clinical tests (such as scans) and specialist referrals. Alongside these were wider concerns about the perceived failure of NHS and its staff to respond to individual migrant patients and their problems appropriately. This was expressed in two ways. First, the NHS was reported to be “good, but slow: there are a lot of delays”<sup>136</sup> (African 19M 50-59 French). Second, there was a common belief in dismissive, impersonal treatment from NHS staff and that this started from their first contact with the clinic:

*“When I want to go there I want the receptionist to smile to me, I want the receptionist to know me, I want it to be personal kind of thing and it's not” (African 5F 50-59 English)*

To account for these problems Africans pointed to a belief in insufficient resources within the NHS, in particular a “lack of staff”<sup>137</sup> (African 17M 40-49 French) and “pressure on time” (African 9M 30-39 English). Alternatively, dissatisfaction with NHS care was identified by some Africans as a consequence of the public – rather than private - nature of the UK health care system. That is to say, that it was reported that “in a private institution you might find that you have a keener ear to listen to you and to your concerns” (African 9M 30-39 English).

The basis of these concerns suggested a role for resource limitation and working conditions upon the perceived quality of health care delivered to migrants. As described in Chapter Two, the chosen approach for data analysis in this area was that of Lipsky (2010), namely to review interviews to seek evidence that migrant health care may operate in accordance with his notion of a street-level bureaucracy. Use of Lipsky's theory to consider data in

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<sup>136</sup> “Le système est bon, mais de lenteur, eh? Il y a beaucoup de lenteur”

<sup>137</sup> “Alors c'est un problème d'insuffisance de staffs, soit c'est les staffs n'est pas comme complets, on doit ajouter encore d'autres personnes, investir dans les domaines de médecins et puis des infirmières”

this retrospective fashion is consistent with similar qualitative research in primary care (Drinkwater, Salmon, Langer et al., 2013). This theory was considered appropriate for a range of reasons. First, study findings presented in Chapter Seven suggested that the antibiotic-prescribing behaviour of GPs emerged from established working patterns of doctors as much as from formal guidelines. Second, a wider perspective was sought for interpreting competing expectations and interpersonal conflict in consultations, in particular one that considered the real world working environment of employees within a public service organisation such as the NHS. Specifically, this was because evidence from interviews found significant friction in migrant encounters with GPs that resembled Lipsky's (2010) notion of "conflict over interactions with citizens [i.e. clients]".

The value of Lipsky's approach to such issues lies in its "bottom-up" focus upon employees' need to husband limited resources within public service organisations like the NHS. This is by recognising that a largely autonomous and professionalised workforce such as GPs must develop practical "work arounds" in order to make their tasks achievable. That is to say, that GPs are likely to resemble other front-line staff in public organisations in the form of "inventive strategists" (Moore, 1987) who must employ pragmatic solutions to complete complex and ambiguous tasks that may include bending the rules (Maynard-Moody and Musheno, 2003). Evidence for this is presented below using themes from street-level bureaucracy theory that relate to resource limitation and interactions with clients. Initially, these are considered in the context of the two places where face-to-face encounters take place with patients in general practice: the surgery reception and the GP consultation.

## 9.1 Conflict and control at the GP reception

A sense of patient processing was suggested by African participants' reported dissatisfaction with the need for patient registration to access a GP. Registering with a family doctor was described by Africans as an unfamiliar concept and there was concern over being asked excessive questions at reception. This appeared to be a particular anxiety for patients who were asylum seekers, presumably attributable to concern that personal information might be shared with immigration officers. GP registration was contrasted with less complicated, payment-based health care systems in Africa. A related phenomenon was widespread dissatisfaction reported with the concept of an appointment-

based system, particularly amongst Africans who had sought attention for acute health problems. Africans perceived appointments in terms of being inflexible, rigorously enforced and, for some, too complicated to negotiate. For certain participants, this included a sense of becoming demoralised through repeated rejection of calls for help:

*“It is [available] just by [way of] appointments. Once I was seriously ill. I phoned the hospital [GP surgery]. They said ‘it is not the hospital here’. I said, ‘but it is the number that they gave me to ask [for help] if you are ill’. [They responded:] ‘No Madam, it is not here. It is not the number you have called’. Ah [tut]... [So ] I go there [in person], I say ‘Madam, truly I am ill, I feel unwell’ [and they respond:] ‘no, no, you must make an appointment’”<sup>138</sup> (African 6F 60-69 French)*

Appointments were thus perceived by Africans less as a way of organising services to improve patient access and more as a barrier to care. Appointment systems, however, appeared to have a broader impact on Africans’ beliefs about general practice. Failure to get appointments led to a common belief that general practice should be by-passed for serious or complicated problems, typically by attending the emergency department. As a result, some migrants were reported to hold general practice in low esteem.

The struggle for control between migrant patients and GP receptionist was illustrated by two accounts from African women. In both cases these patients successfully by-passed reception using strategies to impress upon staff that their symptoms were urgent. First, one GP described how an African lady on two occasions collapsed at reception after being refused an appointment for a sore throat. On both occasions she was successful in gaining instant attention from the doctor. This strategy seemed to succeed in part because it occurred in the public gaze of the waiting-room. This placed the receptionist and GP in a difficult situation, with few options other than to provide the desired immediate consultation:

*“[An African patient with a sore throat] did not appreciate that she could wait twenty four hours [for an appointment to see the GP]: she then proceeded to collapse in the waiting room.... She thought she was an emergency and she collapsed: there's not much more we could have done. We have to, we have to give her attention, we have to make sure that she was safe and funny enough all the other patients were happy to see her being seen before them. So it was, you know: she achieved her goal” (GPF3 50-59 Europe)*

<sup>138</sup> “Ce n'est que les rendez vous. Une fois j'étais sérieusement malade. J'ai appelle mon hôpital ils ont dit ce n'est pas l'hôpital ici .. j'ai dit "mais... c'est le numéro que m'avait donne pour demander si vous êtes malade" ... "no madame... ici c'est pas... c'est pas ce numéro la que vous avez téléphone"... ah [tut] .. j'avais appelle maintenant comme c'est pas loin... je vais la bas... je dis "madame vraiment je suis malade... je me sens mal..." ... "no ..no ... il faut prendre rendezvous"

Collapsing was perceived by the GP as manipulative behaviour that needed to be addressed. This belief was based upon the assumption that her migrant patients were young, relatively healthy and likely to present their problem as a crisis in order to access health care. The GP responded to this behaviour by exploring with the patient why these collapses occurred at the reception and, in so doing endeavoured to place “a full stop” to the behaviour. Nevertheless, the GP was uncertain if her advice would be heeded, stating that “I would not be surprised if it does happen again” (GPF3 50-59 Europe).

A different scenario was reported firsthand by one African participant. This mother described how her request to see her GP was rebutted by the receptionist, who stated that “chickenpox, I don't think there will be something that [the GP] will do [for you]”<sup>139</sup> (African 3F 30-39 English and French). Such a response is consistent with evidence relating to Asian patients, specifically that some GP receptionists feel that they intentionally abuse emergency appointments in order to access a doctor (Hawthorne, Rahman & Pill, 2002). In order to access her GP, she resorted to proving the severity of her son's chickenpox by quickly undressing him in the surgery reception in order to convince the receptionist. Again, an important feature in this account was that the event occurred in front of “everybody, doctor, receptionist, other patients who were there”<sup>140</sup> (African 3F 30-39 French). This participant described how her protest was successful in obtaining an immediate consultation with the doctor and, in this case, eliciting an apology:

*“I sat myself down on the ground in the reception, I spoke, I lifted up his cloth[es] – ‘oh sorry, sorry’ [said the receptionist]”*<sup>141</sup> (African 3F 30-39 French).

The latter account illustrated not only the contrasting beliefs about the severity of chickenpox but also suggested that receptionists' own interpretation of common illnesses influence patients' access to GP appointments. As such, this vignette is likely to represent the receptionist' using her own autonomy to adjudicate the suitability of the patient for receiving care. This is consistent with evidence from South Africa that front-line administrative staff in health centres exert significant control over who may access treatment (Moyo, 2010). In the cases described above it is unknown what training or guidance individual receptionists had received about managing migrants' requesting

<sup>139</sup> “La c'est la réceptionniste: “le chickenpox I don't think there will be something that she will do””.

<sup>140</sup> “Tout le monde, médecin, réceptionnistes, d'autres patients qui étaient là”

<sup>141</sup> “Je me suis assise par terre à la réception. Je dis, je soulève son vêtement: ‘oh sorry, sorry!’”

emergency appointments. Similarly, study data did not conclude if these receptionists' behaviour was limited to African patients or whether they treated such requests similarly, regardless of patient ethnicity.

## 9.2 Pressure and complexity within the GP consultation

Positive experiences of general practice were mainly described by younger male African participants who had consulted only for minor health complaints. Satisfaction in these cases appeared to arise from the uncomplicated nature of the problems young men presented which were likely to be straightforward for GPs to address, for example an examination for routine patient registration or a request for a specific test such as for diabetes. Africans with more complex problems were typically dissatisfied with their care and GP consultations were widely reported to be brief and pressurised. Descriptions of such encounters pointed to pressure and processing in a language consistent with that of street-level bureaucracy theory. These opinions were expressed in brief comments based upon personal experience from both Africans and GPs:

*"The doctors here] really like to work you and get you out of the door" (African 1F 35-59 English)*

*"I mean it's what are you here for, in/out: go away" (African 2F 30-39 English)*

*"[Seeing my GP was] more like a factory"<sup>142</sup> (African 3F 30-39 French)*

*"[It is] a total pile-up... of other patients, other demands" (GP2F 30-40 UK)*

*"[It is] just keep it churning through, so we get through people" (GP7F 40-49 UK)*

In accordance with street-level bureaucracy theory, there was also evidence that at times doctors faced conflicting pressures over the distribution of resources between their patients:

*"Obviously every one is an individual as well, but yeah, definitely sometimes when you sort of think hang on a minute I've only got so much time" (GP5F 40-49 UK).*

One aspect of this pressure reported by some GPs working with migrants was patients' poor time-keeping. Poor punctuality was considered to be particularly stressful and to lead

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<sup>142</sup> "C'était plus, er, comme une usine"

to dilemmas for GPs over whether or not to provide care to unpunctual but needy patients. Poor time-keeping was considered to be a particular problem for African patients, summed up under the notion of keeping “African time” (GP7F 40-49 UK). Nevertheless, GPs typically described only having one African patient with particularly poor time-keeping and it appeared that such individuals had come to represent a stereotype. Some GPs were aware that Africans’ lives were busy with other important commitments and, for this reason, accepted that little could be done to tackle late attendance. Specifically no GP participant suggested that they had directly confronted African patients about poor time-keeping and, instead, the phenomenon was often laughed off:

*“[The African lady] came the next day at the right time but an hour later, so she came twenty five hours late for her appointment! [laughter]” (GP13M 40-49 UK)*

Pressure in consultations with migrants was not, however, confined to lack of time. Migrants were also reported to present with “complex health situations” (GP5F 40-49 UK) that “are not at all fitting into neat boxes” (GP2F 30-40 UK). What is more, they were considered to be “more complicated to talk to” (GP5F 40-49 UK) such that “you can’t get the full picture” (GP6F 50-59 UK). A number of factors was reported to be associated with this increased complexity. First, a commonly reported phenomenon was the breadth of issues that could arise in migrant consultations. One GP considered this to be a problem particular to UK general practice and an issue not faced by doctors in Africa: “I see someone - an African person - they would come and want me to deal with everything from medical to social issues” but in Africa “they would expect the doctor to resolve their medical issue but not social [ones]” (GP1F 40-49 Africa). Multiple presenting complaints were reported to be particularly common amongst asylum seekers, especially those who had lived through traumatic life experiences:

*“They are coming with multiple social problems, adjustment disorders that are post traumatic disorder from a previous coming out of war zones or torture and on top of that the general practice problems that they present with are different or they interpret them differently” (GP2F 30-40 UK)*

Such problems were stated to be exacerbated by migrants’ lack of familiarity not just with how the health service works but also with more basic tasks required to survive in the UK. General practitioners appeared to be one of the few options for assistance available to some migrants, sometimes leading to requests for help with basic tasks. One GP summed this up as follows: “They don’t know where else to go and it is lack of understanding of the system and where you would go for help with, say, filling in the form” (GP2F 30-40 UK).



For asylum seekers, there was an additional bureaucratic complication caused by the complex demands of the immigration process. Again, such issues were brought to the GP: “they see the GP as someone who can make a big difference to the ultimate goal of obtaining leave to remain [a form of refugee status in the UK]” (GP3F 50-59 Europe). This was reported to lead to considerable additional workload for GPs as a result of requests for medical reports and letters to support claims.

A further complexity in consultations with migrant patients lay in differing expectations of the role of the GP within the health care system. One dimension of this ambiguity lay in evidence that Africans held doctors in particularly high esteem. Indeed two participants provided religious analogies to articulate their faith in doctors: “Daktari [i.e. doctor] is your brother, Daktari is your father, Daktari is your Jesus Christ and Mohammed all combined in one” (African 5F 50-59 English and Swahili). Nevertheless, experiences of encounters with GPs challenged this perception for some Africans. One reason given for this was because the perceived competence of a clinician was closely associated with the belief that the doctor should intervene by providing treatment of some form. Typically, the perception of receiving an effective treatment was associated with secondary – rather than primary - care: “people are used in Africa to getting something done, normally at hospital” (African 15M 30-39 English). As a result, doctors faced conflict with certain migrant patients’ over their assumption that the GP would be unable to help and needed to be bypassed. This was reported to be “because they know I’m a GP they would say “send us to a specialist” because they think the specialist will be able to resolve the problem” (GP1F 40-49 Africa). This issue was reported to be less of a problem amongst patients who had little experience of using secondary care in their original country, for example people from Somalia or Afghanistan.

Second, an important factor in complexity in consultations with migrants was reported to be the language barrier. Central to this concern was dependence upon interpreters who increased the amount of time required to deal with patients’ problems: “If there are language problems, if there is interpreters, oh you need double that [from 10 to 20 minutes consultation time]” (GP6F 50-59 UK). Increased complexity was not, however, confined to greater time demands. This was because interactions between GPs and interpreters could become problematic, leading to increased stress for the clinician. One GP identified frustration with poor quality interpreters as “the biggest stress in the consultation” (GP4M 40-49 Europe). Behind this lay anxiety over inaccurate translation, for example in

situations where interpreters were reported to provide only a brief summary in English of what a patient had taken a number of minutes to say in their own language. In such cases GPs reported fear over losing control of consultations. This was stated to occur where the interpreter and patient ended up in lengthy discussion such that the GP perceived that he/she had become excluded from the encounter. As a result of such problems, deep concern was expressed by some GPs over the effectiveness of using interpreters in consultations about important clinical investigations and life-threatening diagnoses.

Despite issues of translation, there was also a belief amongst GPs that communication barriers with migrants were not purely linguistic. Cultural differences were reported to be as great a problem: “in fact it is not the lack of language, it is maybe the lack of cultural perspective and putting it in the patient's own framework that is the issue” (GP13M 40-49 UK). This highlighted that the challenge for clinicians lay in negotiating patient expectations that were inconsistent with usual practice or clinical guidelines. Such interaction closely resembled struggles faced by workers in street-level bureaucracies who must seek to implement “organisational policy” (Lipsky 2010) over the distribution of limited resources:

*“Probably you would decide quite quickly that that patient doesn't need antibiotics yourself but 90 per cent of the consultation is persuading the patient that they don't need it” (GP2F 30-40 UK)*

### **9.2.1 Negotiation and maintaining control in consultations with GPs**

In such situations GPs commonly reported conflict to be inherent in “persuading the patient”. This was because some patients could apply significant pressure on clinicians in pursuit of their demands. This was reported by GPs to be manifested in various ways. First, accentuating the severity of symptoms was stated to be one method of emphasizing need for clinical action to be taken: “They don't change their story but they will just come, you know, with, you know, symptoms getting worse to try, to try to get what they want” (GP1F 40-49 Africa). In addition, powerful body language was reported to be used to communicate dissatisfaction: “It would be [sigh], a louder voice, it would be facial expression, body language, it would be avoiding eye contact and tutting” (GP3F 50-59 Europe). Such negative body language could culminate in the patient's refusal to cooperate with the doctor: “they would say "no, they are not leaving" without it!” (GP3F

50-59 Europe). These scenarios illustrated that, like street-level bureaucrats, GPs must seek their clients' cooperation in order to complete their daily tasks in a smooth fashion. At times achieving cooperation between doctor and patient appeared to arise from what Lipsky (2010) terms a "structure of [competing] alternatives". Whilst GPs tended to offer alternatives in the form of prescribing paracetamol or offering review if symptoms worsened, there was evidence that some patients could invoke more drastic alternatives. This was illustrated where conflict escalated and led to one patient employing an array of threats to seek to influence their GP's decision:

*"[The migrant patient tried] not listening, repetition, asking the same again, threatening, threatening to complain, threatening to sue, threatening that their blood would be on my hands... threatening I think, I think this particular patient offered me that, that, that there would be curses put onto me" (GP4M 40-49 Europe)*

In this case the GP reported that he ultimately resisted the patient's demands. The reason why such a stance was necessary was reported by GPs to be concern over becoming manipulated by patients. Thus, giving in to a patient's request was perceived as setting a dangerous precedent that would lead to greater demands. For example, issuing antibiotics inappropriately could lead to the following scenario:

*"[This] could become a pattern for every subsequent consultation: that they are actually in control and they can change something and that becomes can become quite manipulative behaviour and they just come in with a list of what they want" (GP2F 30-39 UK).*

Further evidence of this phenomenon arose from the one African who reported consistently very positive experiences with her GP and surgery. Her satisfaction arose from the way in which the GP did not seek to resist the patients' requests, in particular for specialist referral. The participant did not know whether other patients were treated similarly, but did state that her doctor's approach was not broadly sustainable and that he was only able to provide such personal, care by strictly excluding patients living outside the surgery's designated geographical area. Without this, she stated, the surgery would become "swamped"<sup>143</sup> (African 4F 40-49 French). She described her unfettered access to specialist referrals in the following way:

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<sup>143</sup> "Mon GP serait surpassé"

*“Perhaps I am going to surprise you now! When it comes to the GP I have not had a bad experience like those that other Africans speak of. I have been surprised myself. It is truly a surgery that receives people very well.... Truly, I cannot tell you why [my surgery is so helpful]. All the appointments that I wanted with specialists I have [had], I have seen all the possible specialists I could see, I saw the rheumatologist, I saw the, phew, I, I saw everyone I wanted to see”<sup>144</sup>(African 4F 40-49 French)*

One way in which some GPs appeared to promote cooperation from their patients was through the use of a patient-centred consultation style. Despite this, it was reported that attempts by doctors to be patient-centred could be counterproductive and misunderstood. This was considered to be an interaction of patient-centred GPs and Africans who felt uncomfortable expressing themselves to doctors, who were held in very high esteem. This was because Africans were reported not to be accustomed to stating their ideas and beliefs to doctors and, therefore, kept quiet. In this situation, a patient-centred approach led the participant to question the value of the consultation:

*“There is this question most GPs ask them [Africans] which they don't feel comfortable [about. It is] is like "what can I do for you?". ... [ ]...they feel like 'I should just stay home and ask myself that question!'. So they can't, they don't really feel that some GPs do help and some don't really give them the help that they need” (African 1F 25-29 English).*

GPs in the UK are trained to undertake such patient-centred consultations but there was evidence in the present study that this was not always the case in encounters with migrants. This is because some GPs expressed deep concern over losing control in consultations with migrants and, as a result, a more “doctor-centred” consulting style was advocated:

*“I think they need to perceive you as an authoritative figure, helpful, friendly, empathic but none the less somebody who knows their job, sticks by their guns, has got good morals and gives them the best advice in their interest. But not somebody who is a push over...” (GP3F 50-59 Europe)*

Thus it was essential to maintain boundaries within the terms of a more traditional doctor-patient relationship:

<sup>144</sup> “Peut-être vous étonnez ici! Je n'ai pas eu une mauvaise expérience dont parlent certains Africains au niveau de leur GP. J'ai été surpris moi même. C'est vraiment un surgery qui reçoit très bien les gens... Je suis vraiment incapable de vous dire pourquoi! Tout les rendez-vous que j'ai envie chez des spécialistes j'ai, tout les rendez vous que j'ai envie chez des spécialistes j'ai! J'ai vu tous spécialistes possibles que je pouvais voir: j'ai vu le rhumatologue, j'ai vu de de de, phew, j'ai vu tout le monde que j'avais envie de voir”

*“If they [African patients] say ‘oh, how do you find the health system here as a doctor?’ - because I have had patient asking me that - I would say “Oh it is great, you know it is free and you know they, you know, they look after you” and then I will say “by the way, how can I help you today?” or “you were saying that you've got a headache?” and try to, you know, show them I am not going down that route! ‘Let's come back to business!’ [laughter]” (GP1F 40-49 Africa)*

One African participant provided an illustration of how this could occur. Her GP succeeded in controlling the consultation and restricting his workload by laying down ground rules about the terms of the interaction. This was by restricting the number of problems the patient could present:

*“A man doctor, he saw me, he asked me ‘what is the problem? You can only give two problems, no, not three, not four. What is the problem that brings you here [today]?’<sup>145</sup> (African 6F 60-69 French).*

### **9.2.2 GPs as “inventive strategists”**

Limited evidence was identified of GPs manipulating their work setting in order to make their tasks more achievable. In addition to the attempts reported above to maintain control in consultations, GPs reported introducing some measures to contain workload and to facilitate the smooth running of their clinics. For one, this involved starting clinics earlier and staggering those appointments with migrant patients who required interpreters. Nevertheless, it was reported that there was, in practice, little scope for implementation of major organisational changes to restrict patient demand. This was illustrated by this salaried GP's frustrated attempts to introduce a formal restriction on patient numbers in her clinics. That the proposal was blocked by practice management corroborates findings elsewhere of conflict between policy and practice in general practice (Drinkwater, Salmon, Langer et al., 2013):

*“The management here are very reluctant to turn anybody away so they are, despite being asked ‘can we put a kind of top limit on the number of people [migrant and non-migrant] that we'll see in an afternoon’ I've never been able to get them to agree that” (GP7F 40-49 UK).*

A further strategy was to draw upon resources from other services. This was consistent with Lipsky's (2010) notion of referral to other agencies as a means of conserving resources: “you really have to see your role as a GP as a gatekeeper to a lot of other

<sup>145</sup> “Un docteur qui est monsieur il m'a vu. Il m'a demandé: “quel est le problème? Il faut seulement donner deux problèmes. Pas trois, pas quatre, non. Quel est le problème qui t'amène ici”

services rather than thinking you can do everything yourself” (GP2F 30-39 UK). Examples cited by other GPs included referring to secondary care, health visitors and to social services. Lipsky reports that in a street-level bureaucracy such referrals can be “symbolic” i.e. offering services from another agency that may not, in fact, be available. This appeared to be the case for the African participant described in section 9.2.1, whose GP had provided her with apparently unhindered referrals to secondary care. In one such referral the patient experienced considerable conflict with a gynaecologist who declined a request for surgical sterilisation. This account suggested that not only was workload being passed onwards but also the potential conflict over unmet expectation of treatment.

The final area in which organisational changes might be implemented by GPs was in managing demands that were external to the NHS. This occurred in the area of requests for letters for housing and, for asylum seekers, medical reports to support immigration claims. For some GPs, however, these demands became excessive. As such, a number of strategies were reported to succeed in stemming the demand. This included the introduction of a fee and ensuring that all requests came directly from lawyers, rather than by being presented in consultations by patients:

*“We were inundated by patients who were making appointments because they wanted reports and letters documenting why they fled their country so we, um, we decided as a practice that um something had to be done because we could not cope with just dishing out letters this way” (GP3F 50-59 Europe)*

Interviews also identified three areas in which the behaviour of GPs appeared to differ from that in formal practice and, as such, could be considered to be working as “inventive strategists”. First, the most widespread area where GPs reported discretion to undertake pragmatic decisions was in the use of interpreters, in particular informal ones such as friends and relatives. This approach appeared to run counter to current local policy on interpreter use, which states the following:

*“Only professional interpreters should be used in a health appointment or intervention. Only in an urgent/emergency should a friend or family member be used until a professional interpreter arrives, but not children under 16 years. A young person may be asked for information to establish facts only” (NHS Greater Glasgow and Clyde, 2012)*

Despite this, GPs widely reported acceptance of informal interpreters based upon the belief that “I presume that [if] they have come with someone they are normally pretty happy with them” (GP11 50-59 UK). In addition, GPs felt this approach was acceptable where the

topic was not too personal. One reason for this decision may have been concern over, or lack of awareness of, telephone interpretation services. Indeed, only one participant stated that they had used such an approach. One GP acknowledged that a lack of translator services was not ideal and could lead to no alternative but to let a child interpret:

*“I mean having worked out in [west of Scotland town] there are quite a number of eastern Europeans where it would be the child you know who is acting as interpreter and at times that is just totally inappropriate. Especially if it’s going to be a gynaecology problem, you know, if it’s a gynaecological, you can’t ask, you know, about sexual, its inappropriate for a child to be or any immediate family to be, you know, it’s a confidentiality issues and you know you don’t get advanced warning and there is a limit to what you can do with sign language” (GP6F 50-59 UK)*

Second, time pressures led to one GP reporting that for migrant patients she might compromise routine clinical procedure. This related to routine pre-test patient counselling for a PSA (prostate) blood test. This calls into question the ethics of such an action and illustrates that GPs possessed discretion in the extent to which they share information and clinical decision making with migrant patients. In this example pre-test counselling was omitted as a result of the pressures of addressing the different health beliefs of migrants:

*“I think one of the big barriers actually is time because, er, when you spend so long going through the problem they have come with and disentangling health beliefs on that and then to actually address screening on top of it in a ten minute consultation sometimes I have to admit I have just done it with out actually explaining it ... [] - taken an extra set of bloods for something and I think ‘well, if that’s positive then I will explain it to them [when the result comes back]” (GPF2 30-39 UK).*

Third, one participant described being refused access to care by a GP. In this case the patient and her interpreter were ejected from the consultation room and sent to search for additional paperwork. It was not possible, of course, to establish the veracity of the claim. Nevertheless, the scenario suggested that a decision on patient’s right to access may be taken by a GP at the outset of a consultation rather than by administrative staff. Whatever the truth about this event may be, it illustrates that regulations could be enforced in a draconian fashion:

*“[The doctor] came back, he saw me: “what is the problem?”. I told him it is the first time I [had] come here [and] that I am not well etc, etc, etc. “Are you an asylum seeker?” he said. I said: “No, I am not an asylum seeker, well, I was but now I have my [residence] papers”. [He said]: “No, go [away], if you are an asylum seeker [you cannot come] here”. I said “Doctor, no, I am not an asylum seekers” so [the doctor] said to me “where is the paper from the Refugee Council” .... The interpreter was there [too] .... She said to the doctor: “no, doctor,*

*this is not an asylum seeker, she is British, she has her papers, [British] nationality". [The GP said]: "no, no, no, no!"<sup>146</sup> (African 6F 60-69 French)*

Where this situation arose, some Africans attributed impersonal service from NHS staff to discrimination on the basis of race or immigration status:

*"Being black we have already been judged. So we are not intelligent! We are thieves: somebody can't even invite us for dinner or something like that. We don't have any knowledge about anything! We don't er. We can't even think for ourselves. So [as] if somebody has already judged you... my GP thinks of me like that" (African 5F 50-59 English).*

*"He [the GP] made me feel sick, truly, and him, he is a doctor! [An] asylum seeker is not an animal, [they] are human like us [all]"<sup>147</sup> (African 6F 60-69 French)*

Again, exactly what occurred in these encounters cannot be verified. This is important because some allegations of racism may have resulted from discordant expectations between Africans and GPs. Such a situation arose for the participant described above who gave the following reason why another GP only inspected a swelling on her arm : "perhaps they [the GPs] have fear of [touching] our [African] bodies"<sup>148</sup> (African 6F 60-69 French). Whether or not discrimination was genuine, Africans were clearly left with a deep sense of hurt. This phenomenon suggests that the pressures of the primary care workplace may place GPs into a position that in order to complete their daily tasks – and in accordance with street-level bureaucracy theory – they may be forced to use their discretion in a way that denies others their humanity.

It is, however, possible that GPs used their autonomy in other ways to render their work more achievable. This is because whilst GPs were open about the existence of work pressures, in particular insufficient time and a desire not to run late, they appeared reluctant to acknowledge pragmatic decision-making in the workplace. Instead, they reported a desire to treat patients equally that was consistent with Lipsky's (2010) notion of workers

<sup>146</sup> "Il est rentré. Il m'a vu: "quel est le problème?" Je lui ai dit c'est pour la première fois que je viens ici, je ne suis pas bien tout tout tout. "Vous êtes asylum seeker?". " No, je ne suis pas demandeur d'asile», non, j'étais mais maintenant j'ai les papiers". "Non, allez, si vous êtes asylum seeker pas ici". J'ai dit "Docteur non, je ne suis pas asylum seeker" alors elle m'a dit "ou est le papier de Refugee Council?".... L'interprète était là. Elle est venue presque en retard, elle m'a trouvé et le docteur je lui ai dit "voilà, le docteur, elle m'a dit ceci ceci". Elle a dit au docteur "non docteur, ce n'est pas une asylum seeker, elle est British, elle a ses papiers, la nationalité". "Non non non non.."

<sup>147</sup> "Il m'a fait mal au cœur, vraiment, et lui c'est un médecin. Asylum seeker n'est pas un animal, c'est un homme comme nous!"

<sup>148</sup> Interviewer: "Il ne vous examine pas?" Participant: "Non, peut-être ils ont peur de notre corps. Je ne sais pas"



needing to feel that they were “doing good” in some way. This was necessary because GPs described other members of their patient population who were – just like migrants – vulnerable. As a result of such competing demands, GPs sought to do their best for all patients and to treat them equally. The way in which this was undertaken was consistent with Lipsky’s (2010) notion that street-level bureaucrats must invent strategies for mass processing of clients that more or less permit them to deal with clients “fairly, appropriately and thoughtfully”. This belief was typified by one GP with the following analogy:

*“I don't particularly feel that I deal with ethnic minorities in a different way from anyone else, you know, you just try and approach their problem in an individual basis as you would with anyone's and live by the old doctor's principle of treating them as you would treat your granny and you can't go far wrong” (GP13M 40-49 UK)*

### 9.3 Migrant advocacy and GP burnout

GPs generally described their experience of working with migrant patients in positive terms. For some GPs there was a strong sense of a desire to be an advocate for patients, particularly asylum seekers who were vulnerable: “here's a patient who is in distress and looking for help from the doctor and is there so you want to help them” (GP7F 40-49 UK). There was also particular understanding from certain GPs who had been immigrants themselves of the problems faced by migrants and a desire to provide support for those struggling to establish themselves in the UK:

*“I would say a very positive experience in my opinion [of working with asylum seekers]. The reason being first and foremost I feel that I am somebody who has come into this country. Having come from [Asia] and therefore I know of the struggles that one has to go through in order to establish themselves here” (GP12 F 40-49 Asia).*

Counter to the accounts described in section 9.2, some GPs described using their discretion to support destitute patients and, effectively, *increase* their own workload. This is because when faced with the desperate situation of some patients certain GPs described providing assistance well beyond their normal clinical role. Helping patients was described mainly at times of failure of an asylum claim, financial destitution or homelessness. On occasions this meant providing basic humanitarian support. For example, there were reports of doctors purchasing food for hungry migrant patients: “Yes, absolutely, I bought rolls and sausage myself... how do you walk away from a starving [eastern European] family. I

think it is really, really difficult” (GP10F 40-49 UK). Only one GP described giving money to migrant patients in need. Such actions did not appear to arise from direct patient requests but spontaneously from GPs’ own discomfort at witnessing humanitarian need. In particular, such interventions seemed to be based upon the transparency of a patient’s “desperate situation” (GP2F 30-39 UK). At times this went beyond food even to providing accommodation in the doctor’s home. This action was presented as the only solution to a situation where routine health and social services were apparently unable to fulfil their duty to meet basic humanitarian needs:

*“My [GP] colleagues ended up taking a [migrant] family home for a whole weekend because the mother was sectioned and the four children didn't have any where to go and they couldn't sort it out. Everything had shut. Out of hours social work weren't helping” (GP2F 30-40 UK)*

GPs reported personal consequences of working with vulnerable migrant patients and providing such additional support, particularly for asylum seekers. One GP described himself as being burntout and that, as a result, he had given up regular work with migrant patients. It was notable that this participant also described great satisfaction with his original role of caring for asylum seekers. Because of stresses encountered he was left contrasting this enjoyment and his ability to perform at a high level with the burnout that occurred. This GP gave the following description of his burnout:

*“Professionally it was one of the most satisfying times most interesting times and I found the, the, the challenges interesting and I felt I was actually doing a very good job. So the burnout was, was, which did happen and which was definitely significant and limited me in my ability to actually work well - as in getting easily ratty, easily stressed out about things, getting easily upset and angry. [It] even made, made, made it impossible [for me] to continue in this [role]” (GP4M 40-49 Europe).*

Burnout was reported by this GP to result from excessive advocacy for vulnerable patients, particularly asylum seekers. This was linked with a sensation of responsibility that went beyond the normal role of a GP:

*“[I] saw myself [as a] more strongest advocate than, than I necessarily needed to be...[I] often felt terribly responsible for things which I was absolutely not responsible for” such that “I probably internalised a lot of the stresses people experienced themselves” (GP4M 40-49 Europe).*

Although only one GP provided a firsthand account of burnout, this notion appeared to be associated with GPs who were passionate about the welfare of asylum seekers. For example, it was also suggested by another GP that caring for asylum seekers amounted to

“carry[ing] them” and their “burden” (GP5F 40-49 UK). This was also recognised by one African patient who reported that “people who are working in the NHS has got so much to do that they can't even have a second for themselves” (African 5F 50-59 English).

Another GP participant offered a model to account for how increasing workload resulting from advocacy beyond the normal GP role and how this could lead to burnout:

*“If you are more patient centred you have to think of some pretty good coping mechanisms because the job will become more and more and more stressful. It is almost like a kind of exponential effect. You start showing people that you care, you start giving the mi[le], little bit of extra time, you start going slightly beyond the remit of your job ...[ ]... then they are asking for letters, for this, that and the other. ...But if you start doing all of that you become very [overwhelmed]. I think the stress of that and the sense of being overwhelmed can have [consequences] ... and a lot of doctors that I know have had to bale out of working with this kind of groups because of stress.” (GP2F 30-40 UK)*

As a result, this GP described changing her consulting behaviour: “So you have to become slightly more doctor-centred and not pick up on every cue [from the patient]” (GP2F 30-40 UK). Similarly, another GP advocated changing one’s working pattern in order to avoid burnout in doctors who are caring for asylum seekers: “only work very part time, laughter, like me. I only do two sessions which I think is a bit of a lifesaver” (GP5F 40-49 UK). Additional issues that were reported to increase stressors were isolation from colleagues and lack of training in the role of a GP to migrant patients, particularly refugees.

## 9.4 Professional dilemmas

GPs described a range of professional dilemmas that arose from encounters with migrant patients. At times unusual patient requests risked placing GPs in professionally compromising situations. Typical examples included request for medication, some of which (for example, “Ritalin” for Attention Deficit Disorder) would not normally be commenced in general practice. Sometimes these medication requests were made for other family members, including those overseas:

*“They also say they have an uncle, auntie somewhere who has these symptoms and they expect to give a diagnosis and you know sometimes they even want me to give medication so that they can take it and post it out to them” (GP12F 40-49 Asia).*

At other times reports of professional dilemmas emphasised the vulnerable circumstances of certain migrants and how differently they perceived the role of the doctor. A commonly reported concern was the professional dilemmas that arose from asylum seekers’ pressing

need to secure their immigration status. Most often this related to requests for letters and medical reports to support claims for immigration and welfare, for instance social housing. More complicated immigration dilemmas faced by GPs related to the uncertainty of patient identity. For example, one GP reported a request to confirm by clinical examination the age of adolescent African patients. Such an opinion was considered important in order to determine whether the individual was to be treated under immigration law as a child or an adult. Second, a GP described feeling uncomfortable providing DNA testing to confirm that an African mother and child were related. Finally, one African GP reported that knowing that certain patients were claiming asylum under false nationalities could put him in a difficult situation of whether or not he should report them. Nevertheless, in this situation he did not act to inform government authorities but, instead, urged patients to be honest with medical staff:

*“I have patients who I know are [from my own African country] and they come here and tell me that they are Somalian which I know is not true. So I am forced to ask them directly “you speak and you look as if you come from [my own country] - are you sure you are Somalian?” then they laugh and admit that [they are not]... that is a very challenging situation. What I have done is to immediately tell them to be truthful particularly on matters concerning their health, that if they do not tell the truth about their health they may be given the wrong treatment” (GP8M 60-70 Africa)*

At times more extreme requests concerning immigration were described by GPs. First, one GP described being asked to partake in illegal activity by a patient: “I was asked whether I could help someone to leave the country illegally or to get someone else illegally into the country, that happened a few times” (GP4M 40-49 Europe). Second, another GP described a request for a medical report that appeared almost farcical:

*“[An African] university professor who on a monthly basis had to have a bit of paper signed to say that he was alive and this had to be faxed back to his university and on receipt of the fax they would then pay him [here]” (GP11M 50-59 UK)*

For some GPs there was recognition that developing a personal relationship with migrant patients could make it easier for them to present difficult demands to the doctor. GPs expressed concern over steps by patients that appeared to blur the boundary between doctor and patient: “people would sometimes inappropriately see me as their best friend with, er, then inappropriate requests coming, coming through” (GP4M 40-49 Europe). One aspect of the doctor-patient relationship with migrants that appeared to symbolize this desired proximity was the giving of gifts to doctors. Some GPs described this taking place in the context of presenting food as a gift, both brought into the surgery and, for one GP,

during a housecall. Other gifts described included physical objects, typically imported from the patient's home country. At times certain GP described situations where a gift was interpreted as an apparent inducement for favoured treatment:

*"I was presented with this very expensive [crocodile] wallet as his thanks which I did my best not to accept! When it became apparent that he wanted to find out slightly more information about his son's care I simply explained to him that that wasn't possible and if he at this point wished to take back his gift he was welcome to do so" (GP11M 50-59 UK).*

That such gifts could be offered as an inducement was suggested by the way one female GP was presented with a kaftan robe in a very public manner. This occurred in the surgery reception in front of other patients, leading the GP to infer that it was offered in a public manner in order to make it difficult to refuse: "with a great flourish [he] presented this to me [laughter] and I was slightly mortified but tried to accept it with good grace" (GP9F 50-59 UK). That this was a "middle eastern gentleman" illustrates that presenting gifts is by no means a behaviour confined to African patients. Nevertheless, in this case the GP implied that the flamboyant manner in which it was presented differed from how she had received presents from her Scottish patients. Discomfort on the part of other GPs at receiving gifts from migrants arose not just from concern over being manipulated. This was because they recognised a professional dilemma in that they believed that asylum seekers simply could not afford expensive gifts and should spend their money in more practical ways. Despite this, there was concern by GPs that refusing gifts could offend migrants.

A final area where there was evidence of professional dilemmas arose where GPs were approached for treatment by patients outside routine NHS services. This appeared to emerge from close relationships with patients as well as different concepts of the role of the doctor. For example, one GP described how his phone number had been leaked amongst the migrant community and that out-of-hours requests arose from "two persistent offenders":

*"I was phoned up at four or five o'clock in the morning in the the house [i.e. at my own home] cos someone had somehow managed to get hold of my telephone number and they were worried about their child, er, and I was on the other side of the city. I was not in any form or shape [for] providing out of hours service and I had to make up my mind very fast what actually is going on and, secondly, how to direct them properly and, thirdly, how to ensure that, er, my wife and my family doesn't get constantly harassed with phone calls in the middle of the night and that was a bit of a challenge" (GP4M 40-49 Europe).*

In addition to the dilemma of how to manage the clinical case over the telephone, this GP faced professional issues in terms of reforming the patients' behaviour. In particular, he felt that this risked breaking the patient's confidentiality:

*"I spoke with someone I knew was respected [in their community] and said "look, this one is phoning me at home. I don't know how he got hold of my home phone number, [but]I don't like that" and that was [it]. How appropriate that was in terms of confidentiality, patient confidentiality, I don't know for sure but it certainly solved my problem (GP4M 40-49 Europe).*

## 9.5 Chapter conclusions and discussion

In this study GPs and African migrants described pressure in consultations from limited time, the presence of conflict between doctor and patient and certain attempts to render work tasks more achievable. In doing so some GPs used personal discretion to operate in ways that were contrary to formal policy, a finding consistent with the notion of bureaucrats as "innovative strategists" (Moore, 1987). A further conclusion is that clinical encounters with migrants, especially asylum seekers, were characterised by increased complexity. Complexity was multi-layered, including language barriers, discordant health beliefs and the presentation of problems that were psychosocial or legal in nature. This is consistent with evidence from other vulnerable patient groups that a range of interacting material, cultural and organisational factors ultimately determine the way in which people access and use health care (Dixon-Woods, Cavers, Agarwal et al., 2006). As in a street-level bureaucracy, this complexity meant that GPs must make decisions with only limited information.

Although there is no specific test to determine whether or not an organisation operates as a street-level bureaucracy, this study offers evidence that accounts of GP consultations with migrants resonate with Lipsky's model<sup>149</sup>. What was not clear from these interviews was the extent to which pressures consistent with Lipsky's theory were part of the day-to-day working conditions of these GPs or whether such problems arose only at certain times. It was sometimes difficult to disentangle stories about particularly problematic or amusing patients from what is routine. Whilst GPs might not be comfortable with the label of street-level bureaucrat, such a conclusion is consistent with Lipsky's (2010) notion that "some street-level occupations are highly respected and well-paid". It is possible that

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<sup>149</sup> Additional consideration to this is given as a personal reflection at the end of Chapter Ten.

status and salary may account for the fact that despite a very heavy workload and challenging, complex consultations, most GPs in this study reported enjoying their job and a desire to do good for their patients. This is also consistent with Walker & Gibson's (2004) study of nurses in South Africa that reported amongst participants both resentment *and* job satisfaction. The present study did not, however, consider beliefs about the effect of remuneration on motivation and satisfaction and this should be considered in future research. This is important because Walker & Gibson found evidence from nurses in South Africa that burnout is likely to be a greater problem in free health services and where employees are poorly paid.

As professionals, doctors may be unwilling to acknowledge pragmatic compromises at work. This suggests that a combination of qualitative approaches is required to explore street-level practices in operation in health care, particularly when this relates to professional cadres. Like Moyo's (2010) South African study, the present research was strengthened by examining the "client" side of general practice: that is to say, patients' experience of consultations. This perspective is particularly useful for exploring routine encounters in general practice where consultations are private and access to documentation highly privileged. Other approaches may be necessary to uncover the true nature of "inventive strategies" used by health professionals. Again like Moyo's (2010) study, further insight could be gained in this area from focus groups and participant/non-participant observation. The value of observation in studies of the working patterns of health system employees is illustrated by other research from South Africa where low ranking auxiliary staff have been witnessed redirecting patients who were turned away by one doctor into a queue where they could consult another, more sympathetic doctor (Schneider, le Marcis, Grard et al., 2010). A further strategy would be to interview retired health professionals who may feel free to discuss the realities of the workplace.

The beliefs and experiences of two other groups could provide valuable additional qualitative data about interactions between migrants and general practice. First, are those who translate for patients in GP consultations, both professional interpreters and informal translators such as friends and relatives. Second, research into migrant use of general practice would be strengthened by examining the beliefs and experiences of GP receptionists in order to consider the primary interface between migrants and health care providers. This approach is consistent with the notion that public services should be examined in a "bottom-up" fashion by considering how low-level, but reasonably

autonomous, workers use personal discretion to deliver organisation policy at the front-line (Lipsky, 2010). As in Moyo's (2010) study of administrative and clinical staff in South Africa, participants in the present study provided accounts where GP receptionists appeared to exert a considerable degree of personal judgment in determining the suitability of migrant patients to receive medical attention. The existence of significant personal autonomy for GP receptionists supports the notion of them as powerful gatekeepers (Hammond, Gravenhorst, Funnell et al., 2013) and "gatekeeper to the gatekeeper [i.e. GP]". Historically, the way in which this has been enforced has been perceived by some patients in terms of the proverbial "dragon behind the desk" (Arber and Sawyer, 1985). There is, however, increasing evidence relating to the reasons behind the working patterns and interactions of GP receptionists. First, receptionists are forced to negotiate expectations within the context of a rigid appointments system and the working hours of patients (Hawthorne et al, 2002). In that study, conflicting expectations were found to be a particular problem with Bangladeshi patients because many worked late at night in restaurants and found it difficult to attend morning appointments. Second, receptionists face the challenging tasks of prioritising patients in the context of little time, information and training (Hammond et al., 2013). Such dilemmas are entirely consistent with Lipsky's (2010) concept of the typical "low-level" street-level bureaucrat. One consequence of these working conditions is the emergence of verbal patterns when communicating with patients at reception, even in non-routine situations (Hewitt, McCloughan, and McKinstry, 2009). It is therefore unsurprising that, at times, receptionists may be perceived as undiplomatic. Further examination of these areas using qualitative research is required with GP receptionists who work in surgeries that serve African patients. Moyo's (2010) study suggests that such research would be particularly valuable in the context of the most vulnerable and often stigmatised patient groups - for example, asylum seekers whose immigration applications have been rejected. What is clear, however, is that the solution to improving communication at reception is unlikely to lie purely in the provision of additional training. That is because it risks failing to address system problems and, instead, depicts problems purely as individual failings (Hammond et al, 2013).

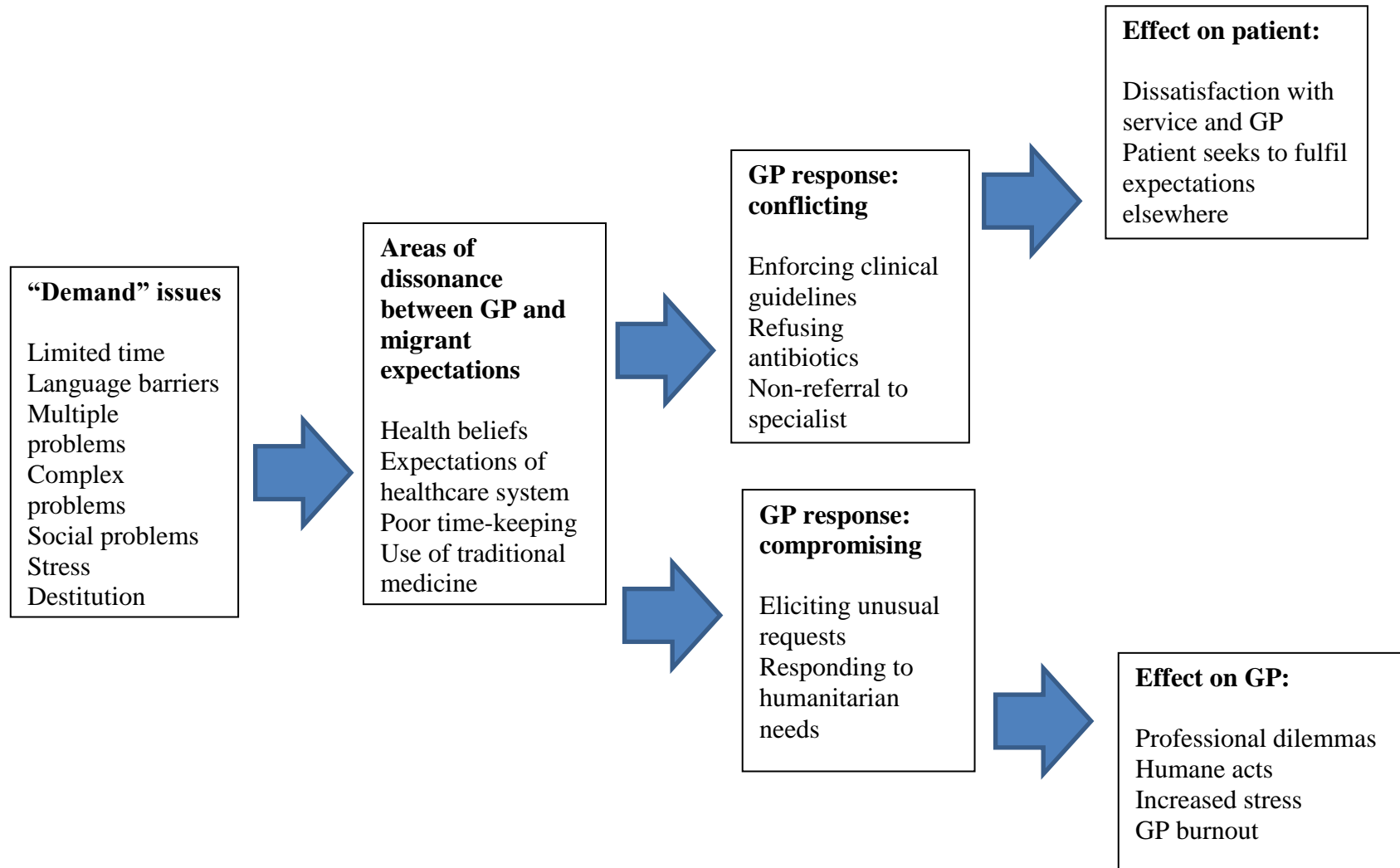
### ***9.5.1 Patient advocacy and burnout in GPs***

In the present study some African participants were left feeling wounded after their encounters with GPs. This is consistent with evidence from South Africa that front-line



health care staff may behave negatively towards migrant patients (Moyo, 2010). Such findings also agree with Lipsky's (2010) notion that street-level bureaucrats may be forced to act in a way that denies vulnerable clients their basic humanity. Depersonalising behaviour would be consistent with street-level bureaucrats who adopt "negative behaviours and attitudes" (Bovens and Zouridis, 2002) towards clients and it may also represent a manifestation of burnout (Maslach and Jackson, 1981). The present study suggests that the syndrome of burnout is a particular risk for altruistic GPs working with vulnerable migrants, especially asylum seekers and refugees. The relationship between these phenomena suggested by the findings is illustrated in Figure Five below. This highlights the importance of taking workload and coping strategies into account when studying doctors who care for migrant and other vulnerable patients. This also indicates the potential scale and complexity of undertaking advocacy for migrant patients in general practice. That is to say, where GPs explored migrants' beliefs and expectations these tended to revolve around complex, time-consuming problems that could be difficult to fulfil and professionally challenging. At times, doctors may feel moved to act beyond the normal scope of a GP in order to provide humanitarian support for a patient. At other times demands may even be illegal or, seemingly, farcical. Although undertaking such acts of advocacy appeared to render GPs more at risk from burnout, it is likely that some individuals are more resilient and resistant to this. Future research should explore what street-level behaviours are necessary to address the excessive workload and complexity in this context and the degree to which GPs who experience burnout possess such skills.

Figure 5. The effects of conflict and compromise in GP consultations with migrants



Consideration of the interaction between complexity, vulnerability and GP burnout illustrated in Figure Five should inform undergraduate medical education and GP training. Central to this is consideration of the effects on teamwork that may result from the interaction between consultation style and workload evident in the present study. This is because the findings suggest that the different consultation styles of doctors may lead to unequal workload distribution and leave certain team members more vulnerable to burnout. This is because doctors with patient-centred consultation styles are more likely to elicit migrant patients' complex expectations and psychosocial problems. Doctor-centred colleagues, conversely, may be unaware of the complexity faced by patient-centred colleagues and inadvertently drive additional workload to them due to a desire for a more sympathetic approach. The effect of such a shift should be understood not only in terms of the numbers of consultations but also the qualitative nature of challenging professional dilemmas that are likely to ensue. Clearly this has implications for workload management, morale and burnout amongst GPs caring for vulnerable migrant patient groups.

### ***9.5.2 Improving migrant health care in a street-level bureaucracy***

The present study suggests that thinking about migrant health care in terms of a street-level bureaucracy could facilitate the development of broader solutions to improving services in the NHS. First, this perspective acknowledges the different perspectives between, and challenges facing, migrant patients, clinicians and management. Such recognition is, at least, a transparent foundation for reforming services. Second, the presence of a street-level bureaucracy would suggest that a general expansion of current service delivery is unlikely to improve clinical care and patient satisfaction. This can be seen in the area of antibiotic prescription described in Chapter Seven: GPs perceived antibiotics as “non-negotiable” outside normal practice or clinical guidelines. To expand service provision in this context would simply lead to a greater number of dissatisfied Africans and frustrated GPs. Indeed, it may only serve to render clinical staff less compassionate and more ineffective in their work.

This conclusion is consistent with recognition that ethnic inequality may ultimately arise from pressures within the health care system. This is because the quality of care provided is known to be highly influenced by organisational factors, in particular time pressures, cognitive complexity, and pressures for cost containment that shape the working conditions

of health care staff (Smedley, Stith, and Nelson, 2003). Further evidence pointing to the importance of working patterns and conditions is data to show that ethnic health disparity arises not from differences in access but from inequalities in the quality of health care provided (Szczepura, 2005; Thomas, Fine, and Ibrahim, 2004). Thus, time pressures and complexity of consultations with migrants reported in the present study are likely to lead to clinical uncertainty such that even conscientious GPs may inadvertently provide unequal care to migrant patients. In this situation, ethnic inequality in health may result from assumptions about the patient rather than from an informed clinical picture:

*“Any degree of uncertainty a physician may have relative to the condition of a patient can contribute to disparities in treatment. Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g., race). The doctor can therefore be viewed as operating with prior beliefs about the likelihood of patients’ conditions, “priors” that will be different according to age, gender, socioeconomic status, and race or ethnicity” (Smedley, Stith, and Nelson, 2003).*

This predicament suggests that to improve the health of migrant patients measures are required on a level that extends beyond refinement of policy, indeed outside the boundary of health care. For improvement to be realised in the presence of a street-level bureaucracy Lipsky’s (2010) asserts that significant reform to public sector services cannot be realised in the absence of “a broad movement for social and economic justice”. This suggests that simply altering service delivery will not ultimately tackle inequality as its origins lie in more complex and deeply rooted societal factors. Central to this is the low socio-economic status of many African migrants and wider assumptions about their place in British society. Thus, there is a need to consider and tackle the wider issues facing migrant African communities, namely socio-economic vulnerability, unemployment and lack of empowerment. This is important not only to Africans but also to wider society. This is because there are broad benefits to improving the welfare of migrants. In addition to individual health improvements and promoting social justice, benefits to society include improved public health protection and reduced overall health care costs (Smedley, Stith, and Nelson, 2003). As a result all have a reason – as well as a responsibility – to improve the health and social status of African migrants.

## Discussion

## 10) Discussion

Like most qualitative research, this study contributes useful knowledge about the perspectives of a range of participants on the issues under examination. Amongst African migrant participants this includes evidence of low awareness of chronic disease risk (particularly from hypertensive disease), the pre-eminence of infection as an explanatory model for chronic diseases and minor illnesses, belief in increased cancer incidence in Europe attributed to chemical contamination and frequent use of a range of traditional medicines for, inter alia, chronic diseases. Finally, this thesis has considered the workplace issues encountered during migrant health care encounters in the NHS using the theory of street-level bureaucracy (Lipsky, 2010). The latter area is a novel approach to studying migrant care in general practice, not least because most other such studies have not considered the patient's perspective or to explore the GP consultation.

This final chapter considers wider interpretations and implications of the findings within Kleinman's (1978) theoretical model of cultural health care systems. In addition, major implications for policy and a personal reflection upon the experience of conducting this study are presented. First, however, consideration is given to the strengths and weaknesses of the present study and the practical issues encountered therein.

### 10.1 Study strengths: building upon trust

The present study represents an uncommon approach to qualitative research, namely one undertaken by a clinician-researcher-translator. Although there is a tradition for bilingual clinician-researchers in large minority ethnic communities in the the UK, African language speaking white researchers are infrequent in the field of academic primary care. It is, thus, consistent with the assertion that, where possible, cross-cultural research should remain close to the translation process (Muller, 2007). It also heeds a call for researchers to seek "authentic voices" amongst study participants (MacDougall and Fudge, 2001) - that is, to capture the ideas of ordinary people rather than their community representatives, family members or interpreters. A practical problem to gaining access to the "authentic voices" of

migrant groups is that such participants are typically harder to identify and to recruit. What is more, such individuals may have deep concerns over confidentiality with people from their own ethnic or linguistic groups (Bhatia and Wallace, 2007)<sup>150</sup>. That the present study successfully explored such perspectives was suggested by inclusion of participants who were harder to reach, for example a traditional healer and two Muslim Swahili participants with little formal education. Avoiding using an interpreter permitted participants to speak directly to the researcher and without fear of being judged by a peer or someone from their own ethnic or national group. The absence of an interpreter thus appeared to promote trust and openness with participants<sup>151</sup>. This also seemed to be beneficial by permitting some exploration of health beliefs that differed from standard western ones, for example certain supernatural forces.

A further strength of the present study was that it took accepted theoretical models and applied these to a novel setting. First, it highlights the scope for employing Kleinman's explanatory models approach in contexts beyond individual patients' symptoms, i.e. to explore people's wider health behaviour, even in the absence of illness. This is because this study and others (Feldmann, Bensing, and de Ruijter, 2007; Vaughn and Holloway, 2009) illustrate the way that African migrants' salutogenic beliefs impact upon behaviour even in people without symptoms. In the present study, this was evident in Africans' preference for food that is unprocessed and their use of herbal remedies in disease prevention. This suggests that the explanatory models approach is important not only in respect of the way clinicians interact with patients but also has implications for understanding health-related behaviours that may be amenable to public health interventions. Second, was the application of street-bureaucracy theory in the context of migrant health care in the UK and in relation to health care consultations, rather than wider system organisation. Finally, it has sought to combine these two independent theories (Kleinman's explanatory models and street-level bureaucracy) into a single model for African participants in the present study. This is considered in Section 10.7.

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<sup>150</sup> This was expressed by participants in the present study. For example, one participant reported that "[If] the interpreter who arrives is an African they are not [going to] say why they really came to see the doctor. They will prefer to speak [directly] to the doctor. Now, if they want to speak to the doctor but if they [need to] have an interpreter that this interpreter should be a White [person], someone they do not know, who knows no one in the African community, to be sure that their secret is safe" (African 3F 30-39 French)

<sup>151</sup> This was also suggested by the following comment from a different participant: "I can say all the people were truthful [about stating] their country of origin because they didn't have to prove themselves to you and at the end all were very comfortable to tell you anything because they felt they could trust you and I have had no complaint about your questions, they were comfortable you didn't take anybody out of their comfort zones and they were easy to answer". Reproduced anonymously and with consent.

## 10.2 Power in interviews and the researcher as an “outsider”

The identity and representation of the principal researcher calls into question the relative benefits of being an “insider” or an “outsider” with regard to the study population. That dilemma is rooted in the paradoxical position of the qualitative researcher, namely the need to comprehend the meaning behind what is being studied without letting one’s own assumptions influence the interpretation of data. It is suggested, therefore, that researchers who are an “insider” (i.e. members of the group under study) possess privileged insight from their cultural knowledge and language skills. Conversely, fieldworkers from the same cultural background as the participants may fail to recognise important emergent issues, considering them too commonplace to deserve description (Watson, 1977). In the present study, for example, a solely “insider” researcher might not have recognised the way Africans’ explanatory models of chronic disease causation differed from western or biomedical ones.

Central to this issue is the place of power within human relationships during the research process: the interviewer is normally interpreted as being the individual possessing power and the participant without. In the present study, Africans’ responses may have been influenced by their perceptions of the social status of the principal investigator on multiple levels. That is to say, there exists significant social inequality between the interviewer - a white English male doctor - and the status of many participants as black women who had come to Europe as asylum seekers or refugees. A further factor that can impact on the perception of participants is recognized to be the academic status of the researcher and their association with an institution of higher education (Liamputtong, 2010). Thus, faced with a doctor-researcher, participants may have felt compelled to provide ideas that they expected the interviewer was seeking, for example by emphasising a biomedical explanation for illness. That status may specifically have made Africans’ less likely to offer traditional or supernatural explanatory models of disease. Alongside this it is possible that Muslim participants perceived the principal investigator to be Christian and that might have discouraged them from discussing Islamic beliefs relating to health. A



further dimension to power in this study is beliefs and attitudes that may have arisen from the historical legacy of European colonialism in Africa<sup>152</sup>.

The present study illustrated how researcher and participant may, at times, both possess the status of “outsider” and share power in the context of language. In the first case, this resulted from the participants and researcher not being Scottish. Participants were informed about the personal background of the principal researcher during informal discussions prior to interviews. As a result of Africans knowing that he was from England, may have made them more willing to criticize the service they received from the NHS in Scotland as well as to highlight language barriers, specifically difficulty comprehending the accents of GPs in Glasgow. Second, a state of shared – or, at least, broadly equal - power arose on occasions where the principal investigator and participant were both speaking a *second* (or third) language, i.e. Swahili or French. That is to say, wherever the interviewer and participant were both limited by communicating in a non-native tongue this led to a collective desire to promote communication. Although such a scenario risks translation errors, it suggests that additional benefits may accrue from the openness that exists where researcher and participant undertake interviews in languages other than their mother tongue.

In the present study it could be argued that on one level the participants possessed overarching power over the research process. That is because they are recognized to hold not only privileged “inside knowledge” (Rabe, 2003) but also to retain significant control over access to community members and their beliefs. Accepting this proved critical in the present study, in particular in order successfully to undertake chain sample (“snowball”) recruitment. As a result, the principal researcher found it necessary to meet what he perceived to be social expectations of participants, for example by using respectful language and behaviour during interactions with older Africans.

That said, power in qualitative studies may also be considered to rest with researchers as it is they who determine how findings are disseminated and what is published (Rabe, 2003). In that context, one way in which participants might have been empowered in this study

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<sup>152</sup> This was considered in one interview with an African GP who dismissed it in the GP context as follows: Interviewer: “Is there any legacy still [of colonialism]? Are expectations of people born in Africa, grown up in Africa, that have come out of their history of colonialism that are carried here?”

GPI: “Er, not quite sure if it would be in clinical medicine context. But yes, in general I would say yes. But not particularly in relation patient doctor really”

was through the use of a narrative methodology. Such an approach minimizes the scope for researchers to edit and misrepresent participant accounts for their own ends. A further strength of the narrative method is that it captures not only the chronological sequence of events but also the context behind people's experiences and beliefs. That is particularly relevant for African women as it is recognized that their lives are the consequence of the cumulative impact of physical, social and spiritual hardships beyond their control, a phenomenon described as leading "contingent lives" (Bledsoe, 2002). As a result, there are benefits to exploring and understanding wider factors and the human stories that underline the choices apparently taken by people.

The status of the qualitative researcher as an "insider" or "outsider" cannot be considered to be a static one (Rabe, 2003). That too is evident from the present study. For instance, the principal researcher was able to go to a varied degree to being a linguistic "insider" with different participants. Despite that effort, these interviews represent only brief ventures into the complex and challenging day to day lives of the migrant African community in Glasgow. In order to be a genuine "insider" in this context would, surely, imply greater exposure and understanding of the trials facing an African migrant? Of these, illness is but one. Although theory exists to offer intermediate stages between the states of "insider" and "outsider" (Liamputtong, 2010), the principal researcher in the present study must ultimately be perceived as being an "outsider". Nevertheless, the stance of an "outsider" still offers insight and has value as a means of seeking knowledge and truth (Merton, 1972). Beyond this, it can serve to give a voice to the unheard.

### 10.3 Study limitations

In this study bias in participant selection may have resulted from two factors. First, initial interviews arose from positive responses from certain churches and community organisations whose members came from specific African countries or language groups. Second, use of a chain-sampling approach may have limited diversity in age, religion, gender and educational level. This is because some African participants appeared to belong to small social networks<sup>153</sup>. Although the term "Africans" is used here, it is

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<sup>153</sup> This phenomenon was suggested by a number of participants: for example, one who later commented "I gave you all [the contacts] I had, all the people I asked said yes they are just the ones that we could ... reach because we had lost touch [with other African friends]".

important to note that nearly all participants came from across Africa's central belt. As such, the study cannot be considered to be representative of all African migrants. This is because within African migrant populations there is great diversity in diet, culture and psychosocial factors that can have an effect upon health, including chronic disease risk (Okwuosa and Williams, 2012). Additional diversity such as religious faith, language use, length of stay in the host country and personal migration history can also influence perceptions of health and well-being.

The inclusion of only a relatively few Muslims interviewees in the present study was partly due to the fact that some participants came from countries where Islam is not widespread. As a result, there is a paucity of perspectives from this section of African society with distinct beliefs and practices (Rasmussen, 2008). This is relevant to the implications of the study findings because there is evidence that Muslim migrants' knowledge of chronic disease may be underestimated and because Islam may have an important role in supporting health promotion (Grace, Reha, Syed et al., 2008).

An important limitation to the present study was that qualitative analysis of the data was constrained by the diverse demographic characteristics of participants and the wide range of topics considered in interviews. This meant that there was significant variation in the content of interviews due to Africans' diverse experiences of the illnesses, treatments and services under study. What is more, some had no knowledge or first hand experience at all of some of these issues. For that reason it proved difficult to interpret some findings beyond a basic description of what was reported and impossible to capture the consistency of beliefs between participants. A further limitation was that the relatively high educational level of participants in this study may have elicited explanations closer to western models rather than private folk beliefs described in Africa, such as taboo violation and "magical causation" of disease (Green, 1999). The interpretation of findings was also limited by the absence of a comparison group from the indigenous population. It is, therefore, not possible to draw definitive conclusions about the effect of having an African origin and being a migrant upon the results. The study would also have been strengthened by extending the sample frame to examine additional demographic characteristics, in particular socio-economic status, detailed educational level and age at migration. Although this was considered during the planning phase, it was decided that recruiting a participant group large enough to incorporate these variables (in addition to age, sex and religion) was beyond the scale and resources of the current project. Similarly, it would

have been desirable to include UK-born Africans to explore longer-term effects of migration on chronic disease beliefs.

Finally, the patient selection did not allow for clear comparisons between recently arrived and long-term residents to show the impact of acculturation. This is because it proved difficult to recruit recently arrived migrants probably because they had not yet formed established networks or, perhaps, due to concern over confidentiality. Nevertheless, an insight into these issues was gained from long-term residents who provided some comments on their own experience when they first arrived in the UK.

## **10.4 Practical challenges to recruiting and interviewing African migrants: the “snowball explosion”**

The findings of the present study are important because they consider areas where the current literature is sparse. One reason for this is the problematic nature of such research. Whilst it is recognised that most researchers will inevitably encounter challenges undertaking qualitative studies (MacDougall and Fudge, 2001), additional practical problems lie in the investigation of migrant and ethnic minority groups. As reported elsewhere (Bhui, Abdi, Abdi et al., 2003; Lien, Nafstad, and Rosvold, 2008), involving participants from migrant communities in the present study did not prove easy. That this was particularly true for people from refugee communities is also consistent with the experience of other researchers (Pernice, 1994). Some of the challenges encountered in the present study can be seen in the reasons that were offered by Africans, nearly all of whom were reported to be male, for not participating:

- One female community group leader (a European) was reluctant to approach members because of “research fatigue”.
- Some community leaders did not respond to email
- One community organisation leader stated that her ‘snowball’ contacts would probably think that she was being paid for their recruitment to the study
- One community group leader discussed the proposed study with members and reported that they felt that the study should not just be aimed at Africans and that the opinions of all members should be included

- One highly educated African reported that he was not an expert and that others would be in a better position to comment. This may have been associated with having to sign a consent form in order to participate
- One participant initially declined because she believed that taking part in research automatically meant having ‘blood tests’. She was later keen to participate when she realised it involved only an interview.
- One highly educated man was reported to have declined because he did not feel ‘comfortable’
- One declined because he had ‘no experience’ of using NHS health care
- Two snowball contacts could not be reached because they had moved to London and east Africa
- Two snowball contacts reported that they would be willing participants became uncontactable after a serious illness. When this became clear, no further attempt was taken to invite the individuals to participate. This avoided an ethical dilemma over whether to undertake an interview about chronic disease with individuals whose families had recently been struck by a serious health matter.

These practical difficulties are consistent with recognition that additional steps are required to recruit minority ethnic people for research and that a culturally sensitive approach is essential. A key aspect of this is the need to identify ways of establishing reciprocal benefits for the researchers and participant communities (Sheikh, Halani, Bhopal, et al., 2009). That is important in order to tackle fatigue amongst both participants and community representatives as well as to promote sustainability in research. The challenges in the present study corroborate Sheikh et al. (2009) findings with leaders from south Asian communities that minority ethnic people may decline to participate due to lack of understanding of what research entails and is seeking to achieve.

During recruitment it became clear that trust was central to success. This was evident from the observation that, once a participant had experienced the interview, most were willing to inform their friends about it<sup>154</sup>. At times this happened straightaway, for example, at the

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<sup>154</sup> Observation in this study suggested that snowball recruits were sometimes more influenced by information from the primary contact than from reading the study information sheet. For example, one

end of an interview through telephone calls to multiple friends. During this study, this phenomenon became informally known as a “snowball explosion”. Although this was clearly beneficial to recruitment, it proved a challenge in other ways. First, this situation created problems in apportioning time, as it put pressure on the principal investigator to undertake, transcribe and translate interviews quickly enough to incorporate newly emerging issues. Second, “snowball explosions” made it difficult to organise targeted sampling in accordance with the purposive sampling frame of demographic characteristics of participants (Table Four in the Appendix). Despite these hurdles, given that recruitment was expected to be difficult, priority was given to accepting snowball participants even if they did not follow the purposive sampling strategy.

Trust appeared to be particularly critical to recruitment due to participants’ concerns over confidentiality. This is consistent with evidence that minority ethnic participants lack faith in the research process (Bhatia and Wallace, 2007). The present study also found that, as in the work of Higgins and O'Donnell (2007), asylum seekers and refugees expressed fear that participation could have an adverse effect upon their asylum claim<sup>155</sup>. During the present study, trust was established with African participants in a number of ways. In addition to time spent meeting community group leaders, the principal investigator found it necessary to expend considerable time in discussion with individual participants prior to commencing recording. Such informal chats are recognised to be important in conducting qualitative research with African migrants (Siangonya, 2010). These conversations sometimes took up to one hour and typically explored the researcher’s background and personal reasons for being interested in interviewing the participant. This appeared to be particularly important with older participants. Concern over confidentiality may also have been assuaged in the present study by the principal investigator’s status as a medical doctor. The role for trust was also noted in regard to the collection of demographic data about participants. This proved much easier at the end (rather than beginning) of an interview when personal trust had been established and participants realised that the

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female participant (with excellent English) dressed particularly smartly for the interview and was most disappointed to discover that the recording was purely audio and not video!

<sup>155</sup> That trust was central to recruitment was emphasised in the message below sent from one participant. In this she points to an important concern highlighted by a few Africans who declined to participate in this study. This was that refugees had been required by their immigration lawyer to sign a document stating that they would not undertake interviews: “Most of the people I asked were friends so I just reassured them that everything is going to be fine and their names are not going to be disclosed but when they saw the recording machine it was a bit scary because of trust issues sometimes you don't know how its [sic] going to be used for or against you. Yes, most of us have ‘Leave to Remain’ in this country but it has regulations they [there] are some things if you are found doing your leave to remain can be evoked so this is not a free pass to do what you want you should always be on the right side of the law”

interview contents were not a cause for concern.

Whilst key to recruitment, the establishment of trust with African participants posed a professional challenge to the principal researcher as it risked inviting requests for medical advice. Given the barriers to accessing healthcare experienced by African migrants in the UK that are referred to in Chapter three, it was expected that some participants would seek advice on illness or treatment. In the end this was not the case and a number of factors may explain this. First, the presence of recording equipment or the formal nature of the paperwork involved in taking signed consent may have deterred such discussion. Second, given the length of the interview and that demographic data were collected at its conclusion this may have prevented requests due to fatigue or distraction. Finally, the spoken and body language of the principal researcher may have communicated an inner concern over this matter, for example by emphasizing that his role on the day was to listen rather than to be the “doctor”. The methodology of this study did not examine reasons for why there were no treatment requests. In future research it would be valuable to gain insight into the interviewees’ perspective on this matter by consulting participants.

As reported elsewhere (Wilkinson and Moore, 1997), a further motivating factor for recruitment was probably the use of a financial incentive<sup>156</sup>. Despite this, the range of participant occupations - from manual workers to professionals - suggests that any effect was small. A further suggestion that payment was not imperative in participation was the observation that many participants showed concern that the financial incentive might be the interviewer’s own money and would only accept it once informed that it was part of a study grant<sup>157</sup>.

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<sup>156</sup> This was seen in the following comment from a participant: “Paying the 15 pounds was a big incentive for just talking to someone for 2 hours. That made people accept the offer very fast to some it was more than they make in [a day]. Others were doing it on their days off just to make that extra money”

<sup>157</sup> This concern was also managed in this study by placing money in an envelope prior to the interview and writing the person’s name on it. This approach proved particularly valuable where interviews were undertaken in public spaces (such as cafes) where researcher and participant alike would feel uncomfortable being observed transferring cash.

## 10.5 Arranging and conducting interviews: the interview “hijack”

Arranging interviews sometimes proved complicated, seemingly resulting from cultural misunderstandings during communication<sup>158 159</sup>. Central to successful recording in public spaces was identifying a suitable interview location. This had to be acceptable to both participant and interviewer but also suitable for audio-recording. For interviews in public spaces, such as a café, it proved essential to identify a suitable venue in advance. One ideal location was found to be the basement seating area of a café that could easily be located by participants close to a major bus stop. When interviewing in such spaces it proved useful to place a cup or bottle on the table to conceal the microphone in order not to elicit unwanted attention from other customers.

It often proved difficult to explore all the interview topics in the guide with African participants. This was most commonly because some participants were quick to say that they did not know about certain issues. Examples included those with little experience of the UK health service or participants who had never encountered traditional medicines. Most people, however, conveyed a preference for what they most felt comfortable talking about and this was respected. For example, certain Africans talked at great length about their dissatisfaction with the NHS or their preference for traditional treatments. On three occasions there were episodes of what came in this study to be termed interview “hijacks” where the participant dominated the interview by talking about topics particularly important to themselves. Instances included religious discourse and dwelling on personal problems such as financial hardships. Where the focus of such “hijackings” was relevant to the study the contribution was welcomed and included in the data analysis.

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<sup>158</sup> One cultural difference arose over the expectation of a suitable time of day for meeting. When the principal investigator arrived for one morning appointment arranged for ‘10.30’ it was quickly apparent that this male African participant meant 10.30 pm. It was also noted that instructions from African participants were sometimes difficult to follow, for example misspelling of street names and choice of ambiguous landmarks, for instance citing supermarkets with many branches in the city.

<sup>159</sup> A further organisational mishap resulted from dialectal differences in naming the days of the week. In standard coastal Swahili the days of the week are numbered around Friday, the Muslim Holy day and Saturday is accordingly called ‘day one’ (‘jumamosi’). In the Swahili of one participant from eastern Congo, however, the term ‘day one’ of the week was used, instead, to mean Monday. This was based upon on the Christian holy day, Sunday. Intriguingly, the same participant used other Swahili terms in an Islamic way. Thus, when he offered to meet in the ‘evening’ he used the word for the final Muslim prayer of the day, ‘ma[n]garibi’. In standard Swahili this term either refers, instead, to the Muslim evening prayer or to the geographical west.



## 10.6 Challenges of transcription and translation

A major problem in this study for the principal researcher was the workload involved in transcription and translation. This is because transcribing an interview in French or Swahili was estimated by him to take three times as long as one in English. On top of this, translating interviews from French or Swahili to English needed at least five hours for each hour of interview time. This was important because particularly rich data emerged during interviews in French and Swahili. As a result, the principal researcher had wished to undertake a greater proportion of interviews in these languages. Nevertheless, this proved impracticable due to limitation of time.

Like all qualitative research, this study encountered difficulties where participants provided incomplete sentences and changed subjects rapidly. In addition, participants often spoke more quietly when discussing personal issues and this, at times, was hard to capture clearly in the audio-recording. A further barrier to transcription was intermittent interruption by children, visitors and mobile phone calls. During transcription certain francophone Africans' accents were difficult to comprehend, with frequent use of non-standard grammar, particularly for verb endings. This loose approach to language was also reflected in the way francophone Africans switched freely between using the informal 'tu' and formal 'vous' with the interviewer. These observations are a reminder that French in Africa should not be considered to be a single, unified tongue. Whilst an official language in many African countries, national dialects and pidgins of French have emerged (Ball, 1997). A similar phenomenon was observed in the present study with Swahili, in particular in respect of speakers from the DRC where it remains an important vehicular language that has undergone significant "pidginisation" (Fabian, 1986)<sup>160</sup>. These experiences have implications for future researchers using these languages, specifically that a single interpreter may not suffice for each language.

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<sup>160</sup> The various Swahili dialects from the Eastern half of the Congo have been known collectively as 'Kingwana' (Whiteley, 1969). Examples of differences between standard Swahili arose during interviews with Congolese participants, including the following changes: inserting of 'n' ('magharibi' to 'mangaribi'), shifting of standard 'd' to 'j' ('ndiyo' to 'njiyo'), standard 'j' to 'l' ('jino' to 'lino'), 'g' for 'j' ('jinsi' to 'ginsi'), 'v' to 'f' ('nguvu' to 'ngufu'), 'u' to 'bu' ('uchafu' to 'buchafu').

Practical problems in transcription included discriminating between homonyms<sup>161</sup> and similarly sounding words<sup>162</sup>, in particular interpreting the alveolar trill (rolling ‘r’) used by Bantu language speakers in both French and Swahili. This is because many speakers of Bantu languages do not distinguish between ‘l’ and ‘r’, often using the rolling ‘r’ for both<sup>163</sup>. These challenges were particularly acute where participants mixed two or more languages, sometime even within one sentence<sup>164</sup>. This issue highlights the need for researchers to request clarification over ambiguous terms during the interview or to consider wider participant verification. It also points to the importance of undertaking transcription as soon as possible and, ideally, by someone with linguistic knowledge or background close to those of the participant.

Finally, a further dilemma in transcription and translation was participants’ use of body language. This was evident in the way many Africans communicated, particularly older participants. In the present study, it arose most frequently when Africans’ described unsatisfactory experiences of health care and their experiences of social isolation. The observation was consistent with findings elsewhere that interviewees may use facial expressions and body movements to convey their distress or anxiety (O’Flynn, 2006). The use of cultural body language by African participants in the present study illustrated the importance of note-keeping and rapid transcription in order to document these responses accurately at the earliest possible occasion.

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<sup>161</sup> For example, in Swahili the word “kizazi” can mean ‘uterus’ and ‘heredity’, “viungo” can mean “joints” and “spices”, and “rohoni” can be interpreted either as ‘in the throat’ or ‘in the spirit/soul’. These were often resolved by the participant touching a bodypart while speaking.

<sup>162</sup> Examples of this problem encountered in English included the following: “went”, “want” and “won’t”, ‘lack’ and ‘like’, ‘walk’ and ‘work’, “[epileptic] fit” and “feet”, and “doctor” and “daughter”. Examples in French included: “je sais” and “c’est”, “certain” and “satan”, ‘sang’ and ‘sein’, ‘coeur’ and ‘corps’, “fragile” and “Flagyl” (the trade name for metronidazole, an antibiotic and antiprotozoal widely used in Africa). Where participants mixed languages, there was sometimes confusion between closely sounding words in different tongues, for example ‘kama’ (i.e. ‘like’ in English) and ‘coulement’ (‘discharge’ in English). Dropping of the letter ‘h’ sometimes produced problems in English. In English this led the expression “back home” to be pronounced as “bacon”.

<sup>163</sup> For example, “pray” and “play”

<sup>164</sup> For example: “hizi [Swahili] problèmes [French] is [English] nguvu [Swahili], I speak now English! [English]”.

## **10.7 Study findings and the 'internal structure' of cultural health care systems: reconstructing Kleinman's model for migrant Africans**

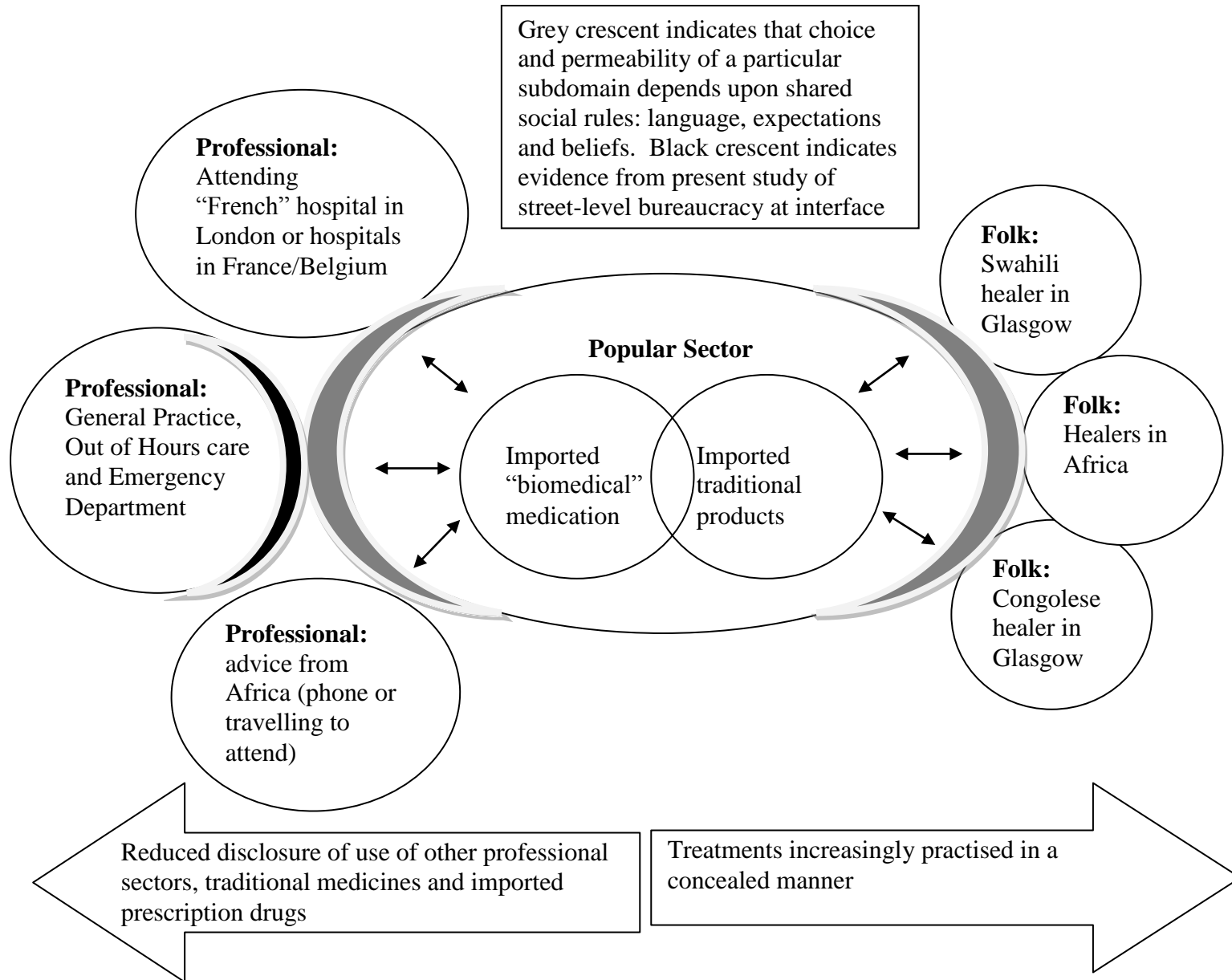
The present study has considered aspects of migrant health in diverse areas that relate to explanatory models, treatment behaviours and personal experiences of consultations in primary care. One way to bring together the broader findings of the the present study is within the context of Kleinman's (1978) model of cultural health care systems. This is because his approach embraces pluralistic health-seeking behaviour that is recognised to be undertaken by Africans (Green, 1999). The basic model for the internal structure of Kleinman's cultural health care systems is illustrated in Figure Three in Chapter Two. The present section considers ways in which this might be modified to incorporate the complexities of migrant Africans' cultural health systems in the west of Scotland. In this way, the findings can offer some insight into the nature and size of the social space occupied by health care systems used by this group of African migrants.

Given that the population of sub-Saharan African migrants to the west of Scotland was relatively small prior to the turn of the millennium, the timing and location of the present study offered an insight into a nascent and diverse migrant community. This heeds Kleinman's (1978) call for cross-cultural studies to examine medical systems in their local setting. Given that chronic conditions are associated with urbanisation and adopting a European lifestyle, the present study is also consistent with Kleinman's (1978) appeal for researchers to examine the impact of modernisation on cultural health care systems. To a lesser extent, this thesis has also considered what Kleinman terms wider, "non-medical" functions of health care systems. For example, African participants' perception of racist treatment within the NHS reported in this study could be interpreted as being consistent with Kleinman's (1978) assertion that health care systems fulfil deeper and concealed social functions, in this instance as a means of exerting social control over groups who may be perceived as not entitled to benefits such as health care.

Kleinman's cultural health care system illustrates that the health beliefs and practices of African migrants in the west of Scotland can be understood as a spectrum between modern and traditional viewpoints. This observation is consistent with qualitative research from Africa that has found tension between traditional and modern views on health and society

(Beckerleg, 1989). This is likely to be an increasingly important dialectic due to increasing urbanisation, migration and access to digital technology. The overlapping nature of the model illustrated in Figure Six represents the observation that, at times, African participants in the present study were comfortable engaging in both traditional and biomedical approaches - for example, their taking western and traditional treatments illustrated overlap between the professional and folk domains of Kleinman's model. A "mix and match" approach such as this is consistent with findings from sub-Saharan Africa (Green, 1999). At other times, however, the traditional and modern were not presented by participants as conflicting themes - for example, the concealed manner in which Africans used kitchen and traditional medicines and the way that GPs did not consider exploring such behaviours in consultations with African patients.

**Figure 6. Kleinman's (1978) model of health care systems modified for African migrants in the west of Scotland**



The present study reveals the existence of multiple, unrelated, entries for African migrants into the professional sector. This is because many African participants described adopting a dynamic approaching to the professional sector, being willing to try various services. This is represented in Figure Six in the form of arrows to suggest that repeated attempts at accessing different sectors may be undertaken in the pursuit of treatment. This leads to the conclusion that the professional sector cannot be understood as one unified arena with communication between those involved. Instead, participants reported using a range of geographically and structurally unrelated professional services, including the “French” hospital in London, hospitals in francophone Europe and health professionals in east Africa.

Other findings in the present study related largely to the popular and folk domains and suggest that for many African participants these arenas form the mainstay of their health seeking behaviour. The significance of the popular sector is evident in the way Africans’ beliefs about chronic disease were deeply held and appeared to influence their likelihood of adopting behaviour change and engaging in screening activities. Behind this finding is evidence for the importance of trusted relationships upon the health beliefs and behaviours of Africans. This is consistent with evidence for the importance of trust in migrant interactions within both the professional (O'Donnell, Higgins, Chauhan et al., 2008) and folk sector (Thomas, 2010). Whilst some Africans held deep concern lest their health issues become known in their wider community, it was clear that information and decisions were shared openly within trusted relationships. Such trust appeared to be stronger within the popular and folk domains than in the professional one. Indeed, some of the most trusted relationships appeared to be with family members, including those in Africa. This study, therefore, emphasises that important relationships are maintained even in the transnational context and this has been incorporated into Figure Six. Given the existence of trusted transnational sources and the use of the digital media for health information reported in this study, it could be inferred that the popular domain of cultural health systems for African migrants in the UK should, in fact, be interpreted as a globalised arena. Indeed, the growing use of information and communications technology will only increase the size of this social space in the future. Such a conclusion suggests that health messages in western countries cannot be treated as separate from ones that circulate in Africa and transnationally, particularly through the use of mobile telephones, email and digital social media. These issues clearly have relevance to health promotion amongst African migrants and suggest a need for further research into the impact of digital health information on

beliefs and behaviour.

The finding that African migrants reported friction in their interactions with the employees from the professional sector is consistent with the nature of Kleinman's (1978) cultural health care system models. Kleinman describes the existence within health care systems of fundamental "institutionalised conflicts" between lay and professional views of clinical realities. One reason for this is that illness behaviours and health care interactions are governed by sets of socially sanctioned rules that differ distinctly between the professional and popular zones. In the present study, this was apparent in the way certain health beliefs and behaviours remained undisclosed at both ends of the model: that is to say, Africans felt that discussing traditional medicines was not sanctioned by GPs and, likewise, that consulting African folk healers was reported only to be undertaken in a secret. These findings indicate that there exist social rules governing what is acceptable for Africans to voice when they veer too far from the centre of the popular arena, whether this be into the professional or the folk sectors. Indeed, the conflicting expectations of health care identified during the present study suggest that it is these different social rules that ultimately determine where African migrants turn for medical care. From participants' accounts, it seemed that the trust that determined choice of professional and folk sector services appeared to be based upon three factors: that the patient and therapist shared 1) a common language, 2) the same religion and 3) agreement over the underlying explanatory model of the illness. In Figure Six, Kleinman's model has been modified to incorporate these factors in the form of grey crescents at the interface between the sectors.

For some African participants, the response to unmet expectations of the GP that were not satisfied was to undertake semi-professional treatment themselves, mainly in the form of importing prescription medications. This indicates that, that when the professional sector resists engagement with the popular arena, there is likely to be a "blurring" between the two sectors at another part of the model. In this case, such blurring appeared to arise at the interface between the popular sector and the pharmacy component of the professional arena, although in the present study it was unclear which professionals were ultimately responsible for making prescription medications available in Africa. Thus, the easy availability of formal medicines and the willingness of some Africans to "mix and match" these with other remedies illustrated considerable, unseen interaction between the professional (or biomedical) arena and the popular one. In this way, GPs in the UK who do not prescribe may ultimately drive patients into facing the same medication-related risks

(for example, side-effects) but within the popular arena instead of the professional one. Other benefits, however, may arise from pushing patients out of the professional arena into the popular and folk ones. This is because it is suggested that illness may benefit from what Kleinman (1978) calls “cultural healing”. That is to say, by promoting social and traditional solutions to illness that consider the patient and their family as a whole, people are likely to experience healing on a level that is often not met by the professional sector’s more individualistic, organ-specific and drug-based approach.

The practice of traditional treatment rituals and the use of healers described herein illustrate that, amongst Africans who had been in the UK for less than ten years, a folk sector is quickly re-constructed by newly formed migrant African communities. The present study suggests that this folk sector is maintained along ethnic and linguistic lines and that there may be little communication between different traditional healers. Findings from the present study also suggest that religion is fundamental to the way some African migrants choose treatment from the folk sector; this is consistent with evidence from France that African religious leaders (“priests”) fulfil both spiritual and medical functions (Parish, 2011). Further research is required to consider the way in which the African folk sector develops in new migrant African communities, in particular the differences between, and interaction amongst individual folk sectors such as Swahili and Congolese traditional healer services.

As predicted by Kleinman (1978), the results of the present study show that the interaction between the popular and professional sectors can be particularly problematic. A key conclusion of the present study is that, at least at times, the interface between the professional and popular arenas operates as a street-level bureaucracy and that this observation should be incorporated into Kleinman’s model of cultural health services. This has been added to Figure Six in the form of a black crescent at the entrance point to NHS services. It is possible that other street-level factors operate at the interface with other professional and folk domains; this is not illustrated in Figure Six as such phenomena were not explored in detail in the present study.



### **10.7.1 Policy implications**

There are clearly needs to promote amongst migrants knowledge of primary care and the means to access it. A further, important, health promotion issue is Africans' risk of chronic disease, in particular hypertension. Hand-in-hand with these, it is important for certain Africans to receive language skills training in order to express themselves better and negotiate need. The present study indicates that such messages should be conveyed in a form that is built upon a relationship of trust. Despite evidence from this study and elsewhere (O'Donnell, Higgins, Chauhan et al., 2008) that such trust may be lacking in GP consultations with migrants, the GP surgery remains one place where such messages might be imparted. Other locations could include colleges, community organisations and churches/mosques.

Another way to improve service provision for migrants lies in creating a willingness amongst clinicians to engage in social, cultural, and environmental aspects of illness that extend beyond the western biomedical model of disease (Thomas, Fine, and Ibrahim, 2004). This could include, for example, educating medical students and doctors about the importance of taking a traditional medicine history. Another approach might be to promote patient-centred and empathic consultations with migrant patients. This is because empathy is known to be an essential factor in promoting patients' sense of empowerment following a clinical consultation (Mercer, Jani, Maxwell et al., 2012). Empathy may be particularly important when dealing with African refugees because many of them are likely to have experienced traumatic life experiences in their journey to the UK. Indeed, the present study suggests Africans expect compassion from medical doctors. There is, therefore, a need for medical students and GP trainees to be aware of the value of empathy with vulnerable patients, particularly those for whom little may be practicable in terms of ameliorating their situation. The present study underlines that, at the same time, it is essential for this to be coupled with consideration of strategies to protect GPs from burnout.

This is important because, by adopting a street-level perspective, the present study indicates that implementing change is unlikely to be straightforward. A further barrier to considering policy implications is that, as highlighted in Chapter Three, there remain challenges to extrapolating findings from small and qualitative studies of migrants to wider

settings and populations. As part of the Conclusion sections to each of the four Results chapters, certain broad implications for policy and research have already been suggested. These indicate four areas where policy change might be achievable, as outlined briefly below:

1. The development of part-time posts for GPs in order to address burnout in GPs who work with migrants. Such individuals are likely to have greater energy to tackle the complex problems that are presented by many African migrants. Alongside this, there should be the establishment of supportive networks between clinical colleagues working in similar roles.
2. Training of undergraduate medical students and GP registrars should include information about doctor burnout, in particular the fact that generalists who choose to work with vulnerable patient populations may be at increased risk
3. Education amongst undergraduate medical students and specialist doctors concerning ethnic differences in chronic disease risk and treatment, especially hypertension, in Africans.
4. Antenatal medical records should include an enquiry about the taking of traditional and herbal medications. For African patients this should include specifically enquiring about the use of calabash clay.

### **10.7.2 Future research**

Certain areas for future research have been identified in the conclusion sections at the end of each Results chapter. Amongst these, the following prominent areas are ones that build upon the present study and which could ultimately inform strategies to improve the health of migrants and the quality of health care they receive:

- 1 Future research should focus on developing interventions to promote long-term adherence to medication for chronic physical disease amongst Africans, particularly in asymptomatic patients.
- 2 Further research is required to explore the beliefs and behaviours of African migrants in the UK who use traditional medicines for chronic disease.

- 3 African herbal products that are routinely confiscated at UK airports should be sent for examination to identify and document their botanic or other origin. As part of this, the Customs Officers would be required to document travellers' beliefs about the product - for example, its medical indication, its country of origin and basic demographic characteristics of the end recipient.
- 4 Further research should consider the extent and nature of traditional medicine use by second and third generation African migrants.
- 5 Future qualitative research should explore the beliefs and experiences of GP receptionists to examine how their work patterns and verbal routines affect the way that vulnerable migrant patients access health care. This should be triangulated with interviews of professional interpreters who translate for this patient group both at reception and in GP consultations.

## 10.8 Personal reflection

Whilst the present study has been completed in just over four years, it is the product of a longer ambition to explore in detail African migrant health care. The impetus for this study arose from clinical work in general practice with migrant patients in Glasgow. As well as nearly ten years' caring for asylum seekers and refugees there, I also worked in surgeries with large numbers of non-refugee patients from other parts of the world, such as Pakistan, eastern Europe and China. During such employment, I encountered many of the pleasures and some of the challenges of providing primary care to people from different cultures, many of whom spoke little English. My experience of working with a large population of asylum seekers at Woodside Health Centre and Scotstoun Medical Practice, Glasgow, from 2002, frequently exposed me to situations where interpreters were unavailable. From this, I started regularly speaking to patients in Swahili and French, two languages in which I already possessed an "Ordinary" and "Advanced" level certificate respectively. My command of medical Swahili and (African) French acquired through clinical consultations with asylum seekers opened the door to my conducting qualitative research free from the bounds of using an interpreter. It also led to a self-published Swahili medical dictionary (Eziefula, 2010). A further opportunity arose from my becoming a GP employed part-time by both Greater Glasgow and Clyde Health Board

(clinical work) and Glasgow University (undergraduate medical education). These appointments provided access to networks of GPs who were working with migrant patients. This was augmented through my role as a member of the advisory committee of the Medical Foundation for the Victims of Torture (Scotland).

Specific practical challenges encountered during this study were presented earlier in this chapter. Additional, overarching challenges should be mentioned. First was the diverse nature of the area of research. It was difficult to take findings from the domains of health beliefs, traditional medicine, health service access and organisational policy in the public sector and to bring these together into one “story”. One reason for this was my desire that, where possible, the thesis should present an *African* story. This proved particularly taxing due to the need to read and digest literature in such diverse areas. Identifying sources relating to migrant health in the UK was problematic because they were often located in book chapters, unpublished documents or articles not available online. Alongside that, I learnt that there are both benefits and challenges to having research supervisors with very different areas of expertise.

A second challenge lay in interpreting findings relating to street-level bureaucracy: although simple at first glance, Lipsky’s (2010) theory offers a rich and colourful, yet complex, insight into employees’ behaviour. Nevertheless, the implications of his theory only really became apparent after much discussion with colleagues, including those employed within other public sector services. Exploring a theory that (at face value) had little relation to general medical practice ultimately has proved to be an invaluable and formative experience and one that has informed my own teaching to undergraduate medical students at Brighton and Sussex Medical School. My experience of working as a GP in the south of England and across Scotland’s central belt leads me to conclude that general practice is, indeed and in every respect, a Lipskian street-level bureaucracy. What is more, the pace of clinical general practice work is ultimately determined by those GPs with the most finely honed street-level skills. That is despite the fact that such efficiency can only be maintained by deflecting more complex and time-consuming cases onto colleagues who are perceived as more sympathetic or, perhaps, recognised to be weaker operators on the street-level. This conclusion is, however, impossible to prove not least because GPs are reluctant to voice publicly the street-level decisions and clinical compromises that they must undertake on a daily basis.

A final personal challenge lay in wider pressures on time. This study has been undertaken in the context of a busy family life, including raising three young children (the last being born during the penultimate year of this thesis). On top of this, the final year of the study has coincided with exciting new clinical and academic posts and three house moves. These presented hurdles in terms of maintaining momentum and focus. Despite that, enforced periods away from the thesis proved beneficial by permitting free thought and a refreshed view.

Ultimately, my undertaking this research proved to be a learning curve in many ways: study design, participant recruitment, in-depth interviewing and qualitative data analysis. What I learned was perhaps best exemplified by the fact that my study supervisors were able to identify and to draw to my attention to material within my interview data that was invaluable and which I might otherwise have missed. This experience has informed my supervision at Brighton of masters student research in Africa and with African migrants to the UK.

Interviewing GPs emphasised the hard-working nature of colleagues and, for many, their deep compassion for vulnerable patients. I was struck by the way in which they managed to navigate the complexity of migrant health care in the setting of deprived parts of the city of Glasgow and yet remain positive at the end of their working day. Although it was easier to recruit GPs, these interviews and the subsequent data analysis proved more challenging than with African participants. That may have been because the former were interviewed by a fellow GP whom they expected to understand their perspective. A further reason for my finding GP interviews more challenging was that, in contrast to the African participants, some of these GPs demonstrated considerable caution and significant ability in containing the scope of interviews. Such dexterity, it appears to me, is a fundamental street-level skill that is essential for surviving in busy general practice.

I found the most enjoyable part of this study to be meeting and interviewing Africans. Those who agreed to participate were all refreshingly open and, seemingly, totally honest in their contributions. In contrast to the rather “straight bat” played by some GPs, the African participants took a passionate swing at every delivery. I found this openness to be personally very rewarding. It was also evident that the quality of my research was significantly enhanced by interviewing Africans without an interpreter. Their colourful and very human stories are, ultimately, the foundation of this thesis. Nevertheless, the manner in which interviews were analysed and presented in this study fails to capture the deeply personal nature of such accounts. The human dimension of the lives of African migrants would have been better represented in a narrative form, more effectively capturing and preserving the implicit meaning conveyed both in their body language and in their silences. That is important because their narratives and sentiments – whilst quintessentially African – are likely to represent those of migrants across the globe. Indeed, it is probable that the dilemmas and decisions of African migrants that are documented in this thesis are ones that echo across the centuries:

*“For ye shal nat tarie,  
Though in this toun is noon apothecarie,  
I shal myself to herbes techen yow,  
That shul been for youre hele and for youre prow”*

*(Geoffrey Chaucer, The Nun's Priest's Tale, c1390)*

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# Appendices



## Data collection tables

**Table 4. Purposive sampling frame for African participant recruitment**

|         |           | Male    |       |     | Female |       |     |
|---------|-----------|---------|-------|-----|--------|-------|-----|
|         |           | 18 - 39 | 40-60 | 60+ | 18-39  | 40-60 | 60+ |
| French  | Muslim    |         |       |     |        |       |     |
|         | Christian |         |       |     |        |       |     |
| Swahili | Muslim    |         |       |     |        |       |     |
|         | Christian |         |       |     |        |       |     |

**Table 5. African participant data collection form**

Are you?: Male or Female

How old are you?: 18–24 24--29 30-39 40-49 50-59 >60

What is your marital status?: Single/Married/Co-habiting/Divorced

At what level did you leave education?: None/Primary/Secondary/University/other vocational

How old were you when you left education?: .....

What is your religion?: .....

How frequently do you attend a place of worship?

Daily/Weekly/ Monthly/Annually/Never

How old were you when you came to the UK?: .....

How many years have you spent in the UK?: .....

What is your country of birth?: .....

Do you consider that in Africa you came from?:

A city, a town or a rural village:

What nationality do you consider yourself to be?: .....

What is your Immigration status?:

Asylum seeker Refugee Student Visa Other migrant

What was your job before you came to the UK?: .....

What is your current employment?: .....

***Table 6. GP participant data collection form***

- Gender
- Age group
- Years in clinical general practice
- Nationality (United Kingdom or continent of origin)

## Interview topic guides

### ***Table 7. African participant in-depth interview topic guide***

- Introduction: explanation of project
- Languages spoken and where (e.g. at home, with friends etc)
- Experience of health service, in particular general practice
- Cases of unmet expectations with general practice
- Antibiotics: experiences of use and beliefs
- Use and awareness of self-care and OTC medications
- Use of and beliefs about traditional medications
- Beliefs about major health threats facing African community
- Causes of chronic physical diseases, in particular cancer, diabetes, hypertension, diabetes, and obesity
- Sources of information about health

**Table 8. GP participant in-depth interview topic guide**

- Experience of working with migrants (i.e. what type and how long)<sup>165</sup>
- Experience of using interpreters
- Experience of conflicting expectations in consultations with migrants
- Prescribing strategy for antibiotic requests, particularly without clinical signs of infection
- Unusual requests from migrants
- Ethical issues (if necessary, prompts like “any gifts?”)
- Beliefs about burnout
- In later interviews:
- Perceptions of biggest threats to African patients in UK
- Experience of and beliefs about African patients with chronic disease, including lifestyle advice

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<sup>165</sup> Please note that that in this thesis the GP responses to this question are not provided in detail in order to preserve anonymity

## **Participant information sheets**

### ***Participant information sheet (African participants - English)***

#### **1. Study title**

Health beliefs reported by African migrants

#### **2. Invitation paragraph**

You are invited to take part in an interview research study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and feel free to discuss it with your colleagues or the lead researcher if you wish.

#### **3. What is the purpose of the study?**

The research project aims to use interviews to explore Africans' beliefs about sickness and health. This is important because doctors and nurses in the United Kingdom may not be familiar with the way African's perceive the causes of sickness and health.

#### **4. Why have I been chosen?**

You have been chosen because you are African. I would like to hear the ideas of Africans from all backgrounds. It is intended that there will be about 30 interviews with Africans.

#### **5. Do I have to take part?**

It is up to you to decide whether or not to take part. You have the right to decline.

#### **6. What will happen to me if I take part?**

If you decide to take part you will be asked to participate in a semi-structured interview with the lead researcher, Dr Max Cooper. Only you and Dr Cooper will be present for the interview. You may bring a family member or friend if you wish. The discussion will be recorded (sound only, not video). It will last between 30 and 60 minutes.

You will be asked questions like:

Do people use traditional medicines?

What makes people healthy?

What are the sicknesses that you feel you are most vulnerable to?

How are diseases spread?

What symptoms would make you want to see a G.P.?

#### **7. What happens to the audio recording of interviews?**

After the interview the recording will be transcribed (i.e. written down) by a professional secretary. It will not be possible for any one other than Dr Cooper to be able to identify your contribution. The recordings will be kept securely and when the study is finished will be destroyed. Written transcriptions of the interviews will be kept totally anonymised. It is intended to publish parts of interviews in medical journals. Again it will not be possible for anyone to identify your contribution.

**8. Who is organising and funding the research?**

The study is part of the principal researcher's higher degree (Ph.D) at the University of Glasgow. The duration of the study is from January 2010 to January 2014. Ethical approval has been gained for the study. There is no external funding.

You will be asked to signed a consent form in order to participate. This is a normal part of studies at the University of Glasgow.

Thank you for considering this request.

Contact for further information.

Dr Max Cooper  
Clinical University Teacher  
General Practice and Primary Care  
University of Glasgow  
1 Horselethill Road,  
Glasgow G12 9L

15<sup>th</sup> April 2010

## **Participant information sheet (African participants - French)**

### **Etude sur les expériences des patients Africains: Renseignements pour les participants francophone**

1. **Titre de l'étude:** Une exploration de l'impact de la différence des croyances et ce qu'on espère d'une consultation entre les Africains francophones (ou Swahiliphones) et les médecins généralistes

#### **2. Invitation**

Vous êtes invité(e) à participer dans un entretien d'une étude. Avant de participer c'est très important de comprendre la base de cette recherche et le rôle des participants. Veuillez donc lire attentivement ces renseignements et si vous le souhaitez, soyez libre d'en discuter avec votre famille, vos amis ou le chercheur principal.

#### **3. Quel est le but de cette recherche?**

Ce projet vise à explorer les expériences des Africains chez leurs médecins, particulièrement les médecins généralistes. Cette étude est importante parce que les médecins britanniques pourraient ne pas comprendre très bien la façon dont les Africains perçoivent la santé et la maladie ainsi que la raison pour laquelle ils décident de consulter un médecin. Docteur Cooper est médecin et c'est lui qui entreprend ce projet pour son doctorat.

#### **4. Pourquoi est ce que j'ai été (e) été choisi(e)**

Vous avez été(e) choisi(e) parce que vous êtes Africain francophone ou Swahili phone. Ce projet vise à examiner une gamme large d'expériences des Africains qui habitent dans l'ouest de l'Ecosse.

#### **5. Est ce que je dois participer?**

Non, la décision de (ou ne pas) participer est la votre.

#### **6. Qu'est ce qui va m'arriver si je participe?**

Si vous choisissez de participer vous serez invité(e) à un entretien (interview) avec le chercheur principal, le Docteur Cooper. Cet entretien sera enregistré (le son seulement et pas de vidéo) et durera environ une heure.

L'entretien examinera les points suivants:

- Vos expériences chez votre médecin ici au Royaume Uni et la différence entre une telle consultation et celle en Afrique.
- Quelles sortes de maladies qui sont inquiétantes pour vous et vos familles.



- Ce qui vous amène à consulter un médecin
- Ce qui constitue pour vous un bon médecin

### 7. Qu'est qu'il va arriver aux enregistrements des entretiens?

Les entretiens en Français ou en Swahili seront transcrits par Docteur Cooper. Ceux en Anglais seront transcrits par les secrétaires professionnelles à l'université de Glasgow. Personne d'autre ne pourra vous identifier. Les résultats de l'étude (y compris les citations des participants) seront publiés dans des journaux médicaux. Votre nom ne sera pas utilisé et il sera impossible que quelqu'un puisse vous identifier. Les enregistrements seront détruits après la fin de cette recherche. Docteur Cooper informera les participants les résultats de l'étude à la fin.

### 8. Qui est qui organise et finance cette recherche?

Docteur Cooper poursuit cette recherche afin de compléter un doctorat à l'université de Glasgow. Cette étude ira jusqu'à Janvier 2014. Ce projet a été ratifié par le comité d'éthique à la faculté de la médecine à l'université de Glasgow. Comme tous les projets de recherche, pour participer il est nécessaire de signer un formulaire de consentement. Les participants recevront un remerciement de quinze (£15) livres.

### Nous vous remercions de considérer votre participation.

Dr Maxwell Cooper  
Clinical University Teacher  
General Practice and Primary Care  
University of Glasgow  
1 Horselethill Road,  
Glasgow G12 9L

15th December 2010

Tel = xxxxxx **Les messages seront écoutés deux fois par jour et vous recevrez une réponse le même jour)**

Email = [max.cooper@glasgow.ac.uk](mailto:max.cooper@glasgow.ac.uk)

**Si vous voulez vous renseigner plus sur ce projet ou si vous voulez participer, veuillez compléter et retourner le formulaire ci-dessous au chercheur principal (Docteur Cooper)**

Votre nom: .....

Les langues que vous parlez .....

Votre religion .....

Votre âge: 18-24    24-29    30-39    40-49    50-59    >60

## ***Participant information sheet (African participants - Swahili)***

### **Karitasi la kujumlisha Ufahamuzi wa wasaidizi**

**Asante sana kwa kuwazia kuingia mradi huu unaoitwa: “Kutazama matokeo ya maamini tofauti katikati ya madaktari na Wafrika wanaojua ama Kiswahili ama Kifansa”.**

Thank you for your interest in taking part in our study entitled “Exploring the impact of discordant beliefs and expectations in General Practice consultations with French and Swahili speaking Africans”.

**Tungekushukuri kujaza maswali hapo chini ili kukagua mambo mbalimbali. Hiyo tutajua kama unaweza kuingia utafiti huu. Maelezo haya unatupa sisi asili wako. Hivyo tutaweza kupata wasaidizi kutoka asili mbalimbali kwa mradi huu.**

We would be grateful if you could complete this questionnaire so we may check a few details just to make sure you will be able to take part. This information gives us some background information about yourself so that we can ensure that we have a spread of participants from different backgrounds included in the study.

**Maelezo wako utatunzwa siri kwa sababu tutatoa karatasi lenye jina lako na anywani yako. Hutajulikana na tafiti Mkuu tu. Usipoingia mradi, karatasi hili litabomolewa.**

The information you provide will be kept confidential because we will remove the page with your name and contact details on it. You will not be identifiable to anyone other than Dr Max Cooper. If you ultimately do not take part the sheet will be destroyed.

**Je, wewe** Are you?: **Mwanaume** Male or **Mwanawake** Female

**Una miaka mingapi?** How old are you?: 18–24 24--29 30-39 40-49 50-59 >60

**Je, ni ni hali yako ya kiharusi:** What is your marital status?:

**Peke wako** Single/ **Umeoa au umeolewa** Married/ **Co-habiting** Co-habiting/ **Divorced**  
Divorced

**Kwa kiwango gani umeache elimu?**

At what level did you leave education?: **hukwenda shuleni** None/ **Shule ya primary**  
**Primary/Shule ya sekondari** Secondary/**Chuo kikuu** University/ **masomo mengine**  
other vocational

**Je ulikuwa na umri gani ulipoacha elimu?** How old were you when you left  
education?: .....

**Je, una dini gani?** What is your religion?:

.....

**Je, mara ngapi huenda wewe kusali?** How frequently do you attend a place of worship?

**Kila siku** Daily/**kila wiki** Weekly/**Kila mwezi** Monthly/**Kila mwezi** Annually/**Hendi**  
**kabisa** Never

**Je, ulikuwa na umri gani ulipo kuja hapa UK?** How old were you when you came to  
the UK?: .....

**Je, umekaa miaka mingapi hapa UK?** How many years have you spent in the U.K.?:

.....

**Je, ulizaliwa nchi gani?** What is your country of birth?:

.....

**Huko Afrika, unatoka....** Do you consider that in Africa you came from?:

**Jijini** A city, **Mjini** a town or a **Kijijini** rural village:

**Je, una raia gani?** What nationality do you consider yourself to be?: .....

**Je, umekuja hapa kwa cheo gani?** What is your Immigration status?:

**Msaidizi wa salaama** Asylum seeker **Mkimbizi** Refugee **Mwanafunzi** Student Visa

**Nyingine** Other migrant

**Je, ulifanya kazi gani Afrika kabla kuja hapa UK**What was your job before you came to the UK?: .....

**Hapa unafanya kazi gani?** What is your current employment?:

.....

## **Participant Information Sheet (GP Participants)**

### **1. Study title**

Exploring the impact of discordant beliefs and expectations in General Practice consultations with French and Swahili speaking Africans

### **2. Invitation paragraph**

You are invited to take part in an interview research study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and feel free to discuss it with your colleagues or the lead researcher if you wish.

### **3. What is the purpose of the study?**

This research project uses interviews to explore Africans' experiences of consulting doctors (especially GPs) about their health problems. The study also seeks to explore GPs' perspectives and experiences of consultations with minority ethnic patients (not just African ones). Dr Cooper is undertaking this study as part of a higher degree (PhD).

### **4. Why have I been chosen?**

You have been chosen because you are a GP. The lead researcher is seeking to interview a wide range of GPs, including those with little experience of providing care for ethnic minority patients.

### **5. Do I have to take part?**

It is up to you to decide whether or not to take part. You have the right to decline.

### **6. What will happen to me if I take part?**

If you decide to take part you will be asked to participate in a semi-structured interview with the lead researcher, Dr Maxwell Cooper. Only you and Dr Cooper will be present for the interview. There will be no interpreters. You may bring a family member or friend if you wish. The discussion will be recorded (sound only, not video). It will last between 30 and 60 minutes.

Topics to be covered include

- The kind of relationship ethnic minority patients expect with their doctors
- Strategies used by doctors to deal with unreasonable expectations
- Perceived logic behind requests for interventions like antibiotics/xrays/scans/referrals?

### **7. What happens to the audio recording of interviews?**

After the interview the recording will be transcribed by Dr Cooper or a university secretary. It will not be possible for any one other than Dr Cooper to be able to identify your contribution. Your name will be removed from the written down copy of the interview. The study results (including short, written portions of interviews) will be used to publish research papers in journals. The recordings will be kept securely and when the study is finished will be destroyed. At the end of the project, Dr Cooper will provide feedback to participants on the study results

## **8. Who is organising and funding the research?**

The study is part of the principal researcher's higher degree (Ph.D) at the University of Glasgow. The duration of the study is from January 2010 to January 2014. Ethical approval has been gained for the study by..... There is no financial reward for participating in this study. You will be asked to signed a consent form in order to participate. This is a normal part of studies at the University of Glasgow.

Thank you for considering this request.

Contact for further information:

Dr Maxwell Cooper  
Clinical University Teacher  
General Practice and Primary Care  
University of Glasgow  
1 Horselethill Road,  
Glasgow G12 9L

15th December 2010

Tel = xxxxx (Answerphone checked twice a day and your message will be returned the same day)

Email = max.cooper@glasgow.ac.uk

## ***Participant Information Sheet (Key Informants)***

### **1. Study title**

Exploring the impact of discordant beliefs and expectations in General Practice consultations with French and Swahili speaking Africans

### **2. Invitation paragraph**

You are invited to take part in an interview study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and feel free to discuss it with your family, friends or the lead researcher if you wish.

### **3. What is the purpose of the study?**

This research project uses interviews to explore Africans' experiences of consulting doctors (especially GPs) about their health problems. This is important because doctors in the United Kingdom may not be familiar with the way Africans' understand health and illness and why people need to consult a doctor. Dr Cooper is a medical doctor and undertaking this study as part of a higher degree (PhD).

### **4. Why have I been chosen?**

You have been chosen because you are an African with knowledge of the African community in the West of Scotland. The lead researcher would like to discuss with you some of the findings of the study so far. He would like to ask you to help him understand these findings from an African perspective and to know if they are also issues for the wider African community. He would also like to ask about the wider African community in Glasgow and how their lives may affect their health.

### **5. Do I have to take part?**

It is up to you to decide whether or not to take part. You have the right to decline.

### **6. What will happen to me if I take part?**

If you decide to take part you will be asked to participate in a semi-structured interview with the lead researcher, Dr Maxwell Cooper. There will be no interpreters. You may bring a family member or friend if you wish. The discussion will be recorded (sound only, not video). It will last about 60 minutes.

Topics to be covered include:

- How Africans learn about health and illness in the U.K.
- What Africans expect from their doctor and the health service
- What do Africans do if they cannot get what they are looking for from their doctor
- The use of traditional medicine
- The lives of African migrants in Scotland and how this may influence their health and their expectations of the health service (e.g. types of housing and kinds of jobs undertaken)

## **7. What happens to the audio recording of interviews?**

After the interview the recording will be transcribed (i.e. written down) by Dr Cooper or a university secretary. It will not be possible for any one other than Dr Cooper to be able to identify your contribution. Your name will be removed from the written down copy of the interview. The study results (including short, written pieces of the interview) will be used to publish research papers in scientific journals. Again, it will not be possible for anyone to identify you. The recordings will be kept securely and when the study is finished will be destroyed. At the end of the project, Dr Cooper will provide feedback to participants on the study results

## **8. Who is organising and funding the research?**

The study is part of the principal researcher's higher degree (Ph.D) at the University of Glasgow. The duration of the study is from January 2010 to January 2014. Ethical approval has been gained for the study from the Faculty of Medicine, Glasgow University. There is no financial reward for participating in this part of the study. You will be asked to signed a consent form in order to participate. This is a normal part of studies at the University of Glasgow.

Thank you for considering this request.

Contact for further information:

Dr Maxwell Cooper  
Clinical University Teacher  
General Practice and Primary Care  
University of Glasgow  
1 Horselethill Road,  
Glasgow G12 9L

15th December 2010

Tel = xxxxxxxxxx (Answerphone checked twice a day and your message will be returned the same day)

Email = [max.cooper@glasgow.ac.uk](mailto:max.cooper@glasgow.ac.uk)



## Consent forms

### Consent form (English)

*(Form to be on headed paper)*

Centre Number:

Study Number:

Subject Identification Number for this trial:

#### CONSENT FORM

**Title of Project:** Health beliefs reported by African migrants

Name of Researcher: Dr Max Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated.....  
(version..... ) for the above study and  
have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to  
withdraw at any time, without giving any reason, without my legal rights  
being affected.
3. I agree to take part in the above study.

\_\_\_\_\_  
Name of subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for subject; 1 for researcher

**Consent form (French)****Formulaire de consentement éclairé**

Référence du centre :  
 Référence de l'étude :  
 Code d'identification pour le participant:

**Titre de l'étude:** Une exploration de l'impact de la différence des croyances et ce qu'on espère d'une consultation entre les Africains francophones (ou swahili phones) et les médecins généralistes

**Nom du chercheur:** Dr Maxwell Cooper

**Veillez parapher les boîtes suivantes:**

Je confirme que j'ai lu et compris les informations étant dans le formulaire de renseignements pour les participants au projet (daté le 15 Décembre 2010). Je confirme que j'ai eu l'occasion de poser des questions au chercheur principal.

Je comprends que ma participation est toute à fait volontaire et que j'ai le droit de retirer ma permission à n'importe quel moment, sans devoir m'expliquer et sans que mes droits légaux soient affectés.

J'accepte de participer à cette étude

\_\_\_\_\_  
 Nom du participant

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

\_\_\_\_\_  
 Chercheur

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

Une copie pour le participant et une pour le chercheur

## Consent form (Swahili)

### Karatasi ya Kukubali

Namba ya ofisi

Namba ya mradi:

Namba ya Mshiriki kwa utafiti huu:

### Karatasi ya Kukubali

**Jina la Mradi: Kutazama matokeo ya imani tofauti kati ya madaktari na Waafrika wanaojua Kiswahili au Kifaransa**

Jina la mtafiti: Dr Maxwell Cooper

Ukikubali, weka jina lako sandukuni hapo chini

1 Nimesoma na nimeelewa karatasi ya kuelezea mradi huu (ya Disemba 2010). Pia nimepewa fursa kuuliza maswali.

2 Naelewa kuwa kungia utafiti huu ni hiari yangu halafu nikitaka naweza kukataa bila kutoa sababu. Nikikataa haki yangu haitaathirika

3. Nakubali kushiriki mradi huu

\_\_\_\_\_

**Jina la Mshiriki**

\_\_\_\_\_

**Tarehe**

\_\_\_\_\_

**Sahihi**

\_\_\_\_\_

**Jina la Mtafiti**

\_\_\_\_\_

**Tarehe**

\_\_\_\_\_

**Sahihi**

Nakala moja kwa mshiriki, na nakala moja kwa mtafiti