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Africans in Scotland: Heterogeneity and Sensitivities to HIV

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Submitted in fulfilment of the requirements of the degree of Doctor of Philosophy at the University of Glasgow

MRC/CSO Social and Public Health Sciences Unit, University of Glasgow

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Abstract

Aim: To investigate how diversity within the African migrant population in Scotland affects their understandings of HIV and uptake of HIV testing and treatment, in order to improve HIV-related outcomes.
Background: In the UK, Africans have the worst outcomes for HIV infection, primarily due to late diagnosis. Improvement requires better understanding of the barriers to healthcare engagement. This PhD study investigates how diversity among first generation African migrants in Scotland could affect engagement with general healthcare and HIV related interventions and services.
Methods: I conducted qualitative research, involving participant observation at two sites (an African religious group and an asylum seeker/refugee drop-in centre) and interviews with African migrants attending these and three additional sites (two advocacy charities and a student association). Data were collected in two cities (Glasgow and Edinburgh) and two smaller towns (Paisley and Kirkcaldy). I interviewed 27 Africans, including economic migrants (n=8), students (n=9) and asylum seeker/refugees (n=10) and 14 representatives from organisations with high levels of African attendees (e.g., country associations, community organisations, advocacy groups, commercial establishments and religious based organisations). Thematic data analysis was carried out.
Results:
Diversity of the population and related issues of identity: Participants were highly diverse and reported considerable heterogeneity in the African diaspora in Scotland. The identity of "African" was bound with various negative stereotypes and appeals to this identity did not necessarily have relevance for participants.
Nature of African affiliated organisations in Scotland: There were a wide range of organisations that advertised their remit as catering for the African diaspora. They varied in consistency and sustainability and contributed towards healthcare engagement to different degrees.
Engagement with healthcare: There were multiple experiences and understandings of the healthcare system within the sample as a whole, and to an extent by migrant type. Whilst the majority reported successful and satisfactory service use, distinct barriers emerged. These included: understandings of rights and access to care based on African models of healthcare; the interplay of religious based understandings with ideas about access to healthcare; and assumptions and anxiety about the connections between visa status and health status.
Knowledge of HIV and engagement with HIV related services: Participants had good knowledge about HIV, with some notable exceptions, but there was no patterning by migrant type. They had diverse views about risk of HIV infection, most of which did not align with the HIV epidemiology that identifies African migrants as an at risk group. Most of the sample did not think targeting African migrants for HIV interventions would be successful and were hostile to the proposal for various reasons, especially because they believed it would perpetuate stigma and prejudice towards the African diaspora. There were mixed experiences of HIV related services, and prompts to test for HIV had elicited a range of reactions, the majority negative.
Conclusion: Diversity within the African diaspora in Scotland should be taken into account to improve the salience and relevance of future HIV interventions. Attitudes towards current HIV testing promotion suggest that a more cooperative approach could be taken with African communities to build on existing relationships of trust and understandings of HIV.

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Author's declaration

I declare that, except where explicit reference is made to the contribution of others, that 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.

Mathew Smith

1 Chapter One - Introduction

1.1 Background

HIV prevention is an ongoing priority in Scottish Government public health policy (Scottish Government, 2015d). Since 2001, there has been a rise in reports of HIV infection in comparison to previous decades (Health Protection Scotland, 2015). HIV/AIDS surveillance data suggests that increases are particularly high concerning the number of diagnoses amongst heterosexual men and women. Health Protection Scotland identify the main factors contributing to this as an increase in the numbers of people living with HIV arriving from high prevalence areas, particularly sub-Saharan Africa, and the increase in numbers of people presenting for HIV tests (Prost et al., 2007). In 2013, black African heterosexuals constituted 65% of all heterosexual people living with HIV in the UK (Yin et al., 2014).

In addition to over representation of HIV prevalence in the population, a pattern of late diagnoses among African migrants is a major public health concern across the UK (Yin et al., 2014). Despite health promotion efforts and attempts to increase the availability of services, HIV positive Africans in the UK continue to present late to services and are significantly more likely to present with advanced stages of the disease than other groups (Aung et al., 2010; Burns et al., 2007; Sinka et al., 2003). Africans, in particular those who have been in the UK for less time, consistently present later than British born people, usually with ill health acting as a prompt for service engagement (Anderson & Doyal, 2004; Boyd et al., 2005; Burns et al., 2007). Clinical ramifications of late diagnoses include requiring simultaneous antiretroviral treatment and treatment of acute opportunistic infections, resulting in worse clinical outcomes (Anderson et al., 2008). Whilst mortality rates for HIV in the UK have fallen significantly as treatment and therapy have improved, a high proportion of mortality still results from late diagnoses (British HIV Association, 2015; Burns et al., 2008; Chadborn et al., 2006).

In general the specific health needs of migrants of any ethnicity to the UK are still poorly understood (Jayaweera & Britain, 2010; Rechel et al., 2011). There is still insufficient communication between healthcare providers and migrant

service users, and many health systems in the UK are not prepared to adequately respond to the needs of migrants (Prost et al., 2007). This is often compounded by the multitude of barriers migrants face in access to health and other basic services (Aung et al., 2010).

Improvement of outcomes for Africans with HIV requires earlier service engagement. Increased use of prevention initiatives would also help to lower numbers of Africans presenting with HIV. In order for these to be viable, better understanding of the barriers to service use by African migrants is required. A key, and often underemphasised, aspect of improving services to encourage migrant engagement is developing an understanding of heterogeneity in these populations (Alvarez-del Arco et al., 2012). Taking these issues into account, the next section will outline the aims of this study and its research questions.

1.2 Study Aim

The overarching aim of the study is to contribute to the understanding of the diversity of the population of sub-Saharan African migrants in Scotland, explore understandings of HIV and perceptions of HIV risk and develop knowledge on how to encourage the use of HIV testing and prevention related services in this group.

1.3 Research Questions

1) What are the levels of heterogeneity amongst the African Migrant population in Scotland, and what dimensions of heterogeneity could affect future efforts to engage them with HIV related services?

   From a qualitative approach, how do participants view the African diaspora in Scotland? To what extent is there diversity in the diaspora in terms of life experiences and how does this relate to their use of health services?

2) What organisations claim to represent Africans in Scotland and in what way do they affect African migrants' access to health services?

What are the varieties of organisations that represent Africans at a community level? In what ways do they facilitate service engagement? What types of organisations might have utility in facilitating or being co-producers of future HIV related interventions?

3) To what extent and in what way do African migrants discuss sexual health, HIV, HIV testing and health service use within their social networks?

   What are participants' levels of knowledge and understanding around HIV, HIV related stigma and risk of HIV infection? What are levels of awareness around HIV testing and do participants think these services are relevant? To what extent are these issues discussed in social networks?

4) How sensitive are different sub-populations of Africans to being targeted for HIV related services?

   What is the spectrum of opinion concerning targeting of Africans for HIV related services and interventions? Why do participants have positive or negative views of targeted initiatives?

1.4 Terminology

Throughout the thesis I refer to "Africans", which should be interpreted as sub-Saharan first generation migrants, the subjects of this research.

"Refugees" refers to both asylum seekers and refugees. I acknowledge that they have different legal statuses which affect their lived experience. The distinction of refugees as having successfully received asylum in the UK will be identified when it is relevant to the topic of discussion.

I designated participants into three "migrant type" categories for the sake of this research: economic; students and refugees. I am aware of the huge diversity of different types of migrants that fit into each of these categories, but for ease of analysis and discussion these will be used as of convenience. The "economic" category could contain job seekers or those who migrate for reasons of marriage

or family reunion. It also includes individuals who might have studied here and have stayed on to work in Scotland. The students category are those who have come specifically to study in Scotland. The refugees category are all those who have at some point claimed for asylum. Within each of these categories there are diversity in terms of time in Scotland and routes to Scotland, with some participants coming directly from their country of origin in Africa and others coming via various countries around the world.

African diaspora, or simply "diaspora" should be interpreted to mean the population of African migrants in Scotland.

1.5 Thesis Chapter Plan

In the following chapter (Chapter Two) relevant literature is reviewed to provide context for my research. Key topics outlined in the review are: History of the African diaspora in the UK and routes of migration into Africa; Experiences of racism and xenophobia in the UK; A theoretical overview of stigma; General population engagement with health services; Migrant and Ethnic minority engagement with health services and African Migrant engagement with HIV services.

Chapter Three documents the methods I used in my research and the process of data gathering and analysis.

Chapter Four is titled "Identity and social Networks in the diaspora" and details results concerning various types of identities participants felt affiliation to, and their related social networks.

Chapter Five is titled "The Nature and function of African affiliated organisations". This chapter documents a cross-section of different organisations that claim African affiliation in Scotland and examines to what extent they might influence the healthcare engagement of their African users.

Chapter Six is titled "Engagement with health services and understandings of health" and focuses on participants' experiences of general health services,

their understandings of the healthcare system and influences on these understandings.

Chapter Seven is titled “Awareness and understandings of HIV and HIV related stigma”. This chapter explores participants’ awareness and understandings of HIV, their sources of information for these understandings, and levels of discussion about HIV in the diaspora. It also covers participants’ understandings and experiences of HIV stigma.

Chapter Eight is titled “Perceptions of vulnerability to HIV infection and responses to potential targeting of Africans for HIV related initiatives.” This chapter examines the extent to which participants agreed with epidemiological evidence that African migrants are at higher risk of HIV infection than the greater population of Scotland. It also describes participants’ reactions to, and perspectives on, targeting African migrants for HIV related initiatives in Scotland.

Chapter Nine, the Discussion chapter, explores the key findings of this research and describes how they relate to the literature presented in the initial review. I then consider the implications of research findings and make recommendations for future engagement and intervention design.

Chapter Ten, the Conclusion chapter, outlines the main conclusions of the thesis and describes the limitations of my study approach.

2 Chapter Two - Literature Review

2.1 Introduction

This literature review will cover the main areas of theory and previous research most relevant to my research aims and questions. Many of the areas covered, for example healthcare engagement, stigma and racism, have very large bodies of literature and accordingly only the areas identified as relevant to the results and discussion will be explored in detail. The literature review is split into the following subheadings: Demography, history, and routes of migration of Africans into the UK; Experiences of racism and xenophobia in the UK; A theoretical overview of stigma; the impact of religion of Africans' in Scotland experiences with HIV; General population engagement with health services; Migrant and Ethnic Minority engagement with health services and finally African migrant engagement with health services.

2.2 History and routes of migration of Africans into the United Kingdom

The history of African immigration into the UK is important to explore as it informs and understanding of the context in which Africans live in Scotland today. There is a long history of African migration to the UK (Burns & Fenton, 2006), due to the historical colonial relationships that existed with a multitude of African countries (Killingray, 1994). International movements of people to and from the UK are strongly influenced by links with Commonwealth countries, many of which are in sub-Saharan Africa (Sinka et al., 2003). Gundara and Duffield (1992) suggest that there was very little African presence in the UK pre-18th Century. From the 18th Century the slave trade was the dominant factor determining numbers of Africans in the UK (ibid). After the slave trade in the UK was made illegal, African immigration to the UK was mainly for paid labour and to a much lesser extent higher education (Gundara & Duffield, 1992). Up until the 1980s, only limited numbers of students and highly skilled workers migrated to Europe from Africa, and these individuals usually followed colonial ties (De Haas, 2007). Subsequently the number of migrants has increased to a large scale labour migration of workers to Europe, including the UK (ibid).

In the last two decades, increasing numbers of asylum seekers have looked to escape social and political upheaval, and modern migration patterns from Africa can be argued to be closely related to conflict as well as motivation for labour and education (Forsyth et al., 2005). Many countries in sub-Saharan Africa have experienced war, civil conflict and political unrest since 1990, and this has boosted the number of asylum applications to the UK (Owen, 2009). Most recently this could explain large influxes of immigration from countries such as Somalia, Eritrea and Zimbabwe refugees are an increasingly significant part of the diaspora Ndirangu & Evans (2009).

2.2.1 Relevant findings from Census 2011 Data

Data from the 2011 Census (Scottish Government, 2015a) gives the most comprehensive overview available of the African population in Scotland. The ethnicity categories are ambiguous ("African: African, African Scottish" and "African: Other African") and do not indicate first or subsequent generation. However, these figures do give an estimate of the numbers of Africans in the UK in contrast with the rest of the population, and the extent to which Africans are a minority in Scotland is relevant for this research. The total population of Scotland is estimated at 5,295,403 (Scottish Government, 2015a). The total African population (using both the African ethnicity categories) is 29638, which is roughly 0.5% of the total population. Of these, 54% were men and 46% women.

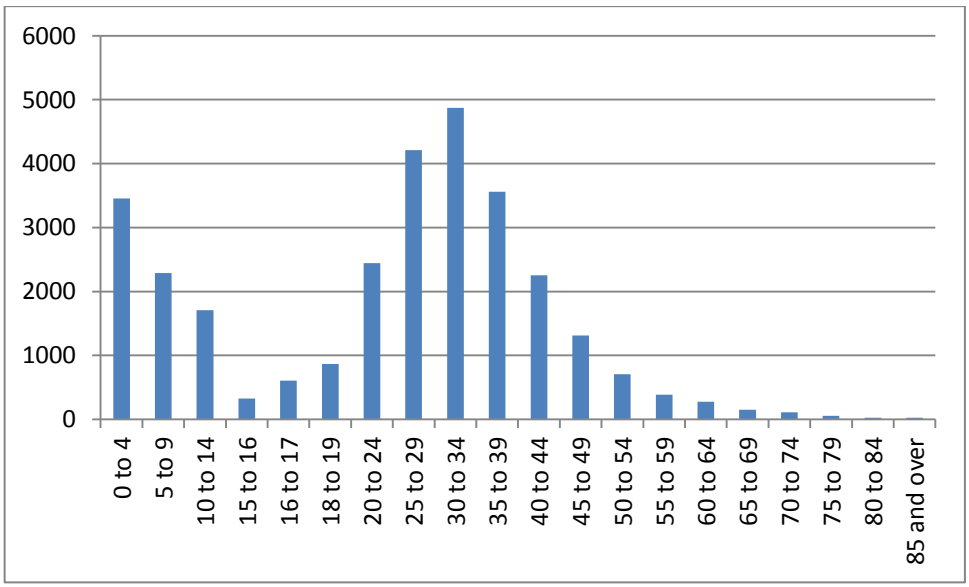


Fig 1. Africans in Scotland by age (Scottish Government, 2015a)

As can be seen from Figure one above, the majority of African individuals in Scotland are between the ages of 24 and 49, with a large number also under the age of 14.

The comparatively small size of the African diaspora in the UK and the distribution of age provide contextual details that are relevant for results and discussion in this research.

2.2.2 Immigration policy in the UK

Immigration policy is relevant to this research as it provides an indicator of the current policy climate regarding immigration, reflecting the broader socio-political environment for immigrants. The UK's immigration policy has been subject to considerable instability in recent history (Mulvey, 2010). Although Mulvey (2010) suggests that this is in part a response to changing international migratory patterns, he and other writers (Gilbert & Koser, 2006; Malhotra et al., 2013; McLaren, 2012) qualify that it is also in response to a supposed social and economic threat associated with immigration. Anti-migrant sentiment can be argued to be rising in the UK (Cochrane & Nevitte) and this trend is often linked to economic recession (Hjerm & Bohman, 2014). Immigration policies may be result of reactive and populist political decision making aimed at meeting the demands of public opinion around the perceived threat that immigration and immigrants represent (Mulvey, 2010; Schuster, 2004).

Public opinion, policy makers, politicians and the media synergise to paint immigrants as a homogenous group and frame them within the lexicon of threat, risk and problematisation of both a social and economic nature (Lynn & Lea, 2003; Malloch & Stanley, 2005). Policy changes are usually weighted towards deterrence of migrants (Schuster, 2004) and successive legislation has aimed to achieve tighter control of Britain's border security and internal controls (Geddes, 2014; Mulvey, 2010). This is applied through increasing stringency and the systematic removal of entitlements and support for new arrivals (Phillips). Immigration policy coalesces with general public anti-immigrant sentiment to develop an environment that is characteristically anti-immigrant, and therefore anti-African immigrant (Sides & Citrin, 2007). This is relevant for the way that immigrants perceive the UK government and therefore public services.

Of particular relevance to this study is the process through which some participants had claimed or were claiming asylum. This is important as it had a considerable effect on both their lived experiences and their perspectives on health services, official entities and Scotland in general. An asylum-seeker is a person who has exercised their legal right under the Geneva Convention (1951) to apply for asylum and is waiting for the outcome of their case (Wren, 2004). The Geneva Convention defines a refugee as someone who "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, or political opinion, is outside the country of his nationality and is unable or, owing to such fear or for reasons other than personal convenience, is unwilling to avail himself of the protection of that country," (Wren, 2004, 392). The state of asylum is a temporary one, but the period of time that individuals spend within the asylum process can vary considerably. Despite statements of intentions to process claims as swiftly as possible from the Home Office, this period can vary from a few months to many years (Da Lomba, 2010; Stewart, 2005).

Through a process of interviewing, document gathering, and questioning of details around the asylum-seeker's circumstances and past, asylum is granted or denied (Da Lomba, 2010). Asylum-seekers exist in a transitory state, as "[they] have been temporarily admitted [and] are not deemed to have entered the UK" (Da Lomba, 2010, 423). Therefore pending their asylum claim, they are not given the right to reside either on a temporary or permanent basis (ibid). In practice and according to section, this allows for detention of asylum-seekers pending a decision or removal from the UK (Wolton, 2006). Whilst seeking asylum, claimants are not allowed to work (Phillips, 2006). They only qualify for housing support if they are destitute, i.e. "homeless or without money to buy food" (Da Lomba, 2010). Accommodation is offered without choice and is often in the most deprived areas (Wren, 2007). Education rights are offered but only between the ages of five and sixteen (Da Lomba, 2010). Asylum-seekers receive income support, but at around half the rate of standard income support (Da Lomba, 2010).

If asylum is granted, the applicant is granted refugee status and access to various services and rights not available to asylum-seekers (Phillips, 2006). Until 2005, refugees were granted indefinite leave to remain. After this date, leave to

remain lasts for five years. During this period the UKBA can reassess the claim for various reasons such as a change in circumstances in the country of origin (Da Lomba). If after five years it is still unsafe to return to the country of origin, then indefinite leave to remain is granted (Ibid).

If an asylum claim is rejected, applicants are expected to leave the UK within 21 days of receiving a negative decision or face an enforced repatriation (Blitz & Otero-Iglesias, 2011). After these 21 days expire, refused asylum-seekers' rights are cut off including denial of healthcare and removal of income and housing support (Blitz & Otero-Iglesias, 2011; Da Lomba, 2010). Blitz and Otero-Inglesias (2011) cite Home Office statistics estimating that some 90% of failed asylum-seekers undergo destitution rather than leave the UK, and they believe this suggests the asylum system is "both inhumane and ineffective" (Blitz & Otero-Inglesias, 2011, p.670).

A key element within the UKBA asylum strategy introduced in the 1999 Asylum and Immigration act was forced dispersal (Sim & Bowes, 2007; Wren, 2004). This as the reason that asylum-seekers have been seen in increased numbers in Scotland (Wren, 2004). Sim & Bowes (2007) claim this policy failed as it took little account of where asylum-seekers actually wanted to live, and therefore created problems of social isolation and issues around integration into local communities. Asylum-seekers may only receive 48 hours notice with a dispersal order, and if they decline the order they face immediate termination of housing, income and legal support (Sim & Bowes, 2007).

This section has briefly described the African diaspora, highlighted some of the processes which lead to anti-immigrant sentiment and described the unique situation of Refugees in this study. These factors all had a considerable effect on the perspectives, understandings and behaviours of participants.

2.3 Experiences of racism and xenophobia in the UK

The conditions of anti-immigrant sentiment described in the last section have led to increased experiences of racism and xenophobia in the UK (NatCen Social Research, 2014). The increasingly hostile anti migrant context in the UK has

fuelled racially motivated attacks across the UK (Healy & McKee, 2004). The experiences of the research participants as black Africans in the UK in engaging with health services are necessarily contextualised by their engagement with society in general. If they experience high levels of prejudice in their day to day lives, this will have a profound effect on their engagement with services.

Of the studies where racism specific towards black Africans in the UK has been examined, it can be suggested that most black Africans will have regular experiences of racism (Burns & Fenton, 2006; Dodds, 2006; Erwin & Peters, 1999; Howarth, 2006). Racism has often been suggested to have a central role in producing and maintaining health inequalities (Link & Phelan, 1995; Williams & Collins, 2001). Research has emphasised how day to day experiences of racism impact health and healthcare engagement negatively, causing social damage and creating barriers to healthcare use (Gee et al., 2009; Krieger, 1999; Viruell-Fuentes et al., 2012; Williams & Mohammed, 2008). Of particular interest for the examination of HIV related engagement is the complex intersecting of racism, xenophobia and stigma around HIV (Dodds, 2006; Viruell-Fuentes et al., 2012). This will be briefly examined below in order to provide context to the experiences of discrimination by participants.

2.3.1 Defining racism

Much of the research on racism in contemporary Britain has focussed on the origins and content of racist belief rather than prevalence and experience of racism (Ford, 2008). Contemporary racism is highly complex and contextually dependent (Goldberg, 1993). It can take many forms, being shaped by a broad range of factors including social, economic, political, geographical and environmental (Neal, 2002). It is not uncommon in contemporary discussions of racism to conflate the term with broad anti-foreigner xenophobia (Cole). This research will take the position of not necessarily separating the two, but instead use the definition of “hybridist racism” promoted by Cole (Cole) or “mosaic of racisms” promoted by Athwal et al. . Both these take into account colour coded racism, anti-foreigner sentiment, anti-asylum sentiment and Islamaphobia. The most important factor in defining race however, is the experience of those who suffer from it. Whilst there is merit in theoretical discussions around the definition of “race” and racism, in this research and in general focussing too

narrowly on theory risks disaggregating racism from the lived experiences of those who are victims of it (Cole, 2009; Rattansi, 2000). As defined by the pivotal MacPherson Report, a racist incident is one which is perceived to be racist by the victim or any other person. This is the definition that will be used throughout this research in understanding the experiences of participants.

2.3.2 Racism in contemporary Britain

As previously suggested, there is a considerable lack of data on levels of racism in the UK. However, some surveys have found a rise in racially aggravated crimes, and have found ethnic minority respondents perceived racism in Scotland to be "frequent" (Clayton) (Bhopal, 2007; Clayton, 2005; Worth, 2006). The British Social Attitudes survey (NatCen Social Research, 2014) reports that 25% of respondents from Scotland said they had some level of racial prejudice. This was an increase of 11% from figures in 2000. According to the British Attitudes survey data (1983-1996) examined by Ford (2008), the form of acceptable discourse around race has changed with overt racism becoming much less publically acceptable. This change in the form of racism is also reported in Allan et al.'s (2004) study in which respondents suggested that racism they experienced in health service engagement tended to be covert rather than in the form of overt epithets. Another shift in the forms of racism dominant in the UK is reflected in the focus of anti-racist efforts moving from public mentalities to institutional racism (Rattansi). As Graham and Robinson (2004) suggest, racism was shown to "permeate the structures and institutions in British Society" (ibid., p.668). This study will not attempt to disentangle the nature of racism that participants experience, but having an understanding of the nature of racism that is present in Scottish society (potentially institutionalised, increasing, and covert rather than overt) is useful in contextualising participants' experiences.

2.3.3 Racism and discrimination in relation to HIV stigmatisation

It is important discrimination with regards to HIV stigmatisation for this research. Like racism, stigma around HIV affecting African Migrants in the UK is complex, multifaceted and extensive (Dodds et al., 2008; Flowers et al., 2006; Ndirangu & Evans, 2009). Dodds (2006)'s in depth study of HIV related stigma in

England found that heterosexual Africans experienced high levels of perceived discrimination in dealing with health services. These were connected to assumptions about their levels of education, levels of risky behaviour, denial of rights to access services and excessive infection control measures. Particularly striking in this research were comparisons with white MSM participants who were shocked that HIV related stigmatisation of this type still existed as they assumed that it had been effectively purged from health services. Dodds (2006) suggests that rather than being removed, HIV related stigma has been "shifted to a different outsider group" (ibid., p.475). Flowers et al. (Flowers et al., 2006) found HIV positive Africans were subject to racial harassment on a daily basis which compounded the distress in coping with their diagnosis. Prost et al.'s (2007) literature review also reported extensive experiences of discrimination that were complex combinations of racism and HIV stigma in engagement with services. Sinyemu and Baillie's (2005) Scottish study suggested that participants experienced discrimination which pushed them to further isolate themselves, exacerbating stigma they already felt due to HIV diagnosis. One respondent reported "people look at you like rubbish. People think you are a beggar, even GPs look at you like you are nothing. We feel small, really small. We keep asking ourselves, is it because we are black? Is it because we are sick people and we are going to die that is why they don't care?" (Sinyemu & Baillie, 2005).

2.3.4 Structurally/institutionally generated mosaics of racism and HIV stigma

There are many institutions that arguably generate or facilitate stigmatisation and racism against African migrants in Britain (Fakoya et al., 2008). However two which were revealed to be most relevant to participants in this research were the mass media and the immigration system, and their influence will be described briefly here.

The mainstream media can be perceived by African migrants to create and reinforce negative stereotypes about black Africans as economically lacking in resources, uneducated and lacking civility (Burns et al., 2007; Dodds et al., 2004; Fakoya et al., 2008). Media discourses linking HIV rates with migration also add to stigmatisation and social isolation of African communities in the UK (Fakoya et al., 2008). The perception of Africans being the vector of HIV into the

UK is exacerbated by media stories like prosecution of African migrants for HIV transmission and of the supposed burden that migrants place on the NHS (Dodds et al., 2004). Perceived anti-African migrant sentiment in the media also contributes to diaspora mistrust of institutions which further exacerbates barriers to engagement due to expectations of discriminatory treatment (Burns et al., 2007; Ndirangu & Evans, 2009).

African migrants in the UK commonly identify the immigration system as a source of anxiety, discrimination and stigma (Dodds, 2006). This is particularly the case for asylum seekers and refugees who are in an even more precarious position with regards to perceived levels of access to services and perceptions that their place in the UK in unstable due to the hostile socio-political environment (Doyal et al., 2009). Whilst the majority of African migrants in the UK are not asylum seekers or refugees there is evidence suggesting that the host population increasingly perceives African migrants to all be asylum seekers. This has been found to be due in part to the mass media and political narrative which uses terms like “invading illegals”, “swamping”, “scroungers” and “criminals” (Dodds et al., 2004; Mulvey, 2010) (Healy & McKee, 2004).

In terms of effect on HIV related engagement and stigma, the immigration system creates an instability of resources and worry concerning perceived entitlement to access (Dodds, 2006). This can heighten negative effects of stigma for people in this position, particularly for those going through the asylum process (ibid.) Many studies cite uncertainties around immigration status heightening fears of potential HIV diagnosis due to uncertainty around access to treatment in the case of a positive result, possible negative ramifications of an HIV diagnosis on asylum claims and visa status and even potential deportation due to a positive result (Doyal et al., 2009; Flowers et al., 2006; Prost et al., 2007). These fears can act as powerful deterrents to service engagement and discourage HIV testing (Prost et al., 2007).

2.3.5 Stigmatisation from within the African diaspora

African migrant experiences of stigmatisation from other Africans can be particularly damaging due to the already perceived hostile environment that the UK presents to foreigners, particularly Africans, as described above (Dodds et

al., 2004). This is because any social action that can separate individuals from their support network in a context of already existing isolation can leave them in an exceptionally vulnerable position (Alvarez-del Arco et al., 2012). Many Africans in the UK rely on African social networks for emotional and practical support (Dodds et al., 2004). Various studies (Burns et al., 2007; Calin et al., 2007; Fakoya et al., 2008; Ndirangu & Evans, 2009) found that in many African diaspora populations in the UK, positive HIV status is understood within a moralistic and judgemental framework. It can be seen as an indicator of promiscuity, immorality, unfaithfulness and inappropriate sexual behaviour (ibid). It therefore becomes a marker of shame, and many assume that if they are diagnosed they will be subject to high levels of discrimination and hostility from their own communities (Paparini et al., 2008).

Some have suggested that HIV stigma is particularly strong in African cultures and that migrants may have brought this stigma with them to the UK, resulting in particularly high levels of stigma within the diaspora (Erwin & Peters, 1999). Others have suggested that due to high visibility anti-stigma campaigns in African countries, there are actually higher levels of stigma in UK based African communities (Burns et al., 2007; Prost et al., 2007). Alternatively Africans in the UK might stigmatise against HIV more as a mechanism to separate their identity from the publically maligned stereotypes of “health tourist” or “HIV positive asylum seeker” (Dodds, 2006). Individuals who are perceived to fulfil these stereotypes could be seen in the diaspora as the cause of discrimination for the whole diaspora (ibid). Those who do not see themselves as fulfilling these stereotypes are likely to try to distance themselves (Viruell-Fuentes et al., 2012)

2.4 Theoretical overview of stigma

Stigma plays a large part in determining the understandings and actions of participants in this research concerning HIV and HIV related services. In this section I will outline the theoretical underpinnings of further discussions of stigma.

Individual HIV understandings and engagement with services are determined to varying extents by experiences of stigma around the disease (Alonzo & Reynolds, 1995). Stigma is highly complex and affects many diseases and conditions which

vary widely in nature and tend to be ambiguous (Dijker & Koomen, 2006; Parker & Aggleton, 2003). This has caused a lack of cross disciplinary consensus and meant that a universal model of the concept has been difficult to develop (Deacon, 2006; Pescosolido et al., 2008) As such this section is not intended to be comprehensive, but to cover the main theoretical approaches with relevance to this research.

2.4.1 Goffman's theory of stigma

Since Goffman's (2009) pivotal work "Stigma: Notes on the Management of Spoiled Identity", stigma has been the focus of attention from various fields, especially sociology, social psychology and anthropology (D'Lane, 2007; Furuya, 2002). Goffman's original definition of "A person who is... reduced in our minds from a whole and usual person to a tainted, discounted one... such an attribute is stigma... It constitutes a special discrepancy between virtual and actual social identity." (Goffman, 2009). Goffman emphasised that stigma is embedded within relationships between people and that it is the social context for stigma that must be examined (Deacon, 2006). The socially constructed stigma discredits those stigmatised and leaves them labelled as inferior and abject (Balfe et al., 2010) which leads to disqualification from social groups to which the stigmatised previously belonged (Castro & Farmer, 2005). D'Lane suggests that some saw Goffman's (2009) definition as overly vague as it considered that any characteristic could be stigmatised, whilst Link and Phelan (2001) suggest that the focus on the social constructive context of stigma is the definition's main strength. Parker and Aggleton (2003) propose that many conceptualisations are misguided in promoting stigma as a static "thing" present in individualistic terms rather than in the society that constructs it.

2.4.2 Social psychology perspective

Whilst social psychology appears to be the main research tradition promoting an individualised understanding of stigma from the perspective of the stigmatiser (Yang et al., 2007), there are also useful models developed from the perspective of the stigmatised (Castro & Farmer, 2005; Lichtenstein, 2003; Yang et al., 2007). Corrigan et al. (2011) summarise the stigmatiser perspective as "examining the social cognitive elements of the stigmatiser, who perceives a

stigmatising mark, and behaves towards the marked group in a discriminatory manner," (ibid, p.481). This can consist of epithets, shunning, ostracism and in extreme cases emotional and physical violence (Herek, 2007). This can be considered "enacted" or external stigma (Herek, 2007). Social psychology also examines how attributes of the stigmatised condition shape the severity of enacted stigma (Mak et al.). One dimension is controllability/responsibility/foreseeability (Corrigan, 2000; Dijker & Koomen, 2003), where if the stigmatised condition is perceived to have been preventable or controllable then the subject is seen as responsible, therefore eliciting a more severe negative reaction (Weiner). This is applicable to HIV where often people are stigmatised as responsible for their own infection due to risky behaviour (Brown et al., 2003). A second dimension is the perceived "seriousness of condition" (Dijker & Koomen, 2003) where "seriousness" or likelihood of substantial harm or mortality has been shown to positively influence the social rejection of ill people. Seriousness is relevant as HIV related stigma is often connected to the perceived mortal consequences of the disease (Duffy, 2005). These two dimensions of stigma are relevant in considering the perspectives of participants on stigma and stigma generation.

The other main area of exploration in social psychology literature is the experience of stigma from the viewpoint of those stigmatised (Yang et al.). An important aspect of this is felt or anticipated stigma (ibid.) Corrigan and Watson (2002) suggest that when individuals know of negative associations with their group it leads to self-discrimination. People do not have to be subject to external stigma in order to be subject to "felt stigma", indeed, individual expectations of the likelihood of being stigmatised can define their perspectives and actions regardless of their perceptions of that stigma being justified or not (ibid). Felt stigma is based on expectations and knowledge that the group they belong to is subject to stigma. Anticipated stigma was revealed to have an important impact on participants' behaviours and perspectives in all discussions relating to HIV.

2.4.3 Sociological and anthropological perspectives

In order to move conceptualisations of stigma away from the individual and towards a macro societal understanding, anthropological and sociological

perspectives are useful. Anthropologists have rejected approaches which focus on individual cognitivist explanatory models of stigma and instead promote understandings taking into account "structural violence" and inequality in which stigma is argued to be rooted (Page-Reeves et al., 2013; Parker & Camargo Jr, 2000). Sociological approaches also emphasise that stigma should be understood within frameworks of unequal relationships of power and discrimination that have political and economic roots (Parker & Aggleton, 2003). In this approach cognitive processes are "necessary but not sufficient" to cause stigmatisation, and instead precedence is given to "myriad of forces" (Pescosolido et al., 2008) stemming from social, historical, economic, political and ideological power differentials which create and influence stigmatisation(Corrigan et al., 2011; Link & Phelan, 2001).

2.5 General population engagement with services

In order to focus on aspects that are specific to the African diaspora in Scotland in terms of healthcare use, a contextual overview of general patterns of overall population healthcare use is vital. In this section I will describe some broad reviews of health engagement available from the literature. Health engagement is a huge area of research and accordingly this review covers small sections that have the most relevant to this my research. It is arguable that there are few sources of robust patient engagement data on a UK or Scotland wide scale, rather than focussing on specific services or specific geographical locations (Parsons et al., 2010). I will focus on primary care, especially GPs, since participants focussed on this aspect of healthcare engagement in their interviews.

2.5.1 Access to services

Precise definitions for access and equity of access are difficult to establish (Dixon-Woods et al., 2005). Norredam & Krasnik (2011) define access as "providing the right services at the right time in the right place" p.68, and there is inequity when it varies by social factors such as age, gender, socio-economic group or ethnicity (ibid). Dixon-Woods et al. (2005) identify some evidence of patterns of access based these factors, but suggest that the evidence is far from conclusive.

However, from the perspective of the patient, accessing services can be a considerable challenge. Access is an exceptionally complex dimension of engagement, affected by a myriad of factors, including transport, distance to service, economic resources and rural or urban settings (Dixon-Woods et al.). Dixon-Woods et al. (2005) suggest that the complexity of the health services in the UK, including variation in organisation types and the unclear boundaries that exist between services, make it difficult for patients to understand where and when to seek help appropriately (Dixon-Woods et al., 2005). Accessing services was identified to be a major concern for participants in the (Scottish Government, 2015c). Four of the top five most negatively answered questions about GP engagement related to levels of access. Only 72% of participants answered that they felt positive in being able to access the GP when they needed to, which is down 9% since the 2009/10 survey (Scottish Government, 2015b). The two largest concerns about access were being able to get through to the GP surgery on the phone and managing to speak to a doctor or nurse within 2 working days (ibid).

2.5.2 Characteristics of GP engagement

The King's Fund meta-analysis of qualitative studies in the UK (Parsons et al., 2010) found that an effective doctor patient relationship was consistently necessary for fostering effecting patient engagement in the consultation. Participants in various studies in the meta-analysis referred to this in various ways. One recurring explanation was the need for GPs to value lived experience of individuals, as was the importance of a feeling of shared decision making (Parsons et al., 2010).

The priorities around patient doctor interaction found by (Parsons et al., 2010) are similar to those identified in earlier reviews (Wensing et al., 1998). Wensing et al. (1998) reviewed 19 studies asking patients to rank in order several aspects of engagement and the five most important were "humaneness", "competency", "patient involvement in decisions", "time for care" and "accessibility".

The majority of studies reviewed by the King's Fund study also found that the idea of gaining "mutual respect" from the perspective of the patient was instrumental in patients feeling satisfied with GP engagement (Ibid). Various

studies positioned this in different ways, but generally defined the process as working together in a partnership, in order to develop bonds which would enshrine trust between the two parties. Trust was central to the definition of a "good" relationship with GPs (ibid).

2.5.2.1 Patient involvement in decisions around their care and treatment

One of the issues that surfaced in the literature with relevance to the current study was the shared decision making process. Defining participation in the decision making process is difficult, as participation can take many forms, especially if being rated by the patient themselves (Schouten et al., 2007). For example patients can be very active in asking questions but still not feel as though they have participated in decision making, and the opposite can also be the case (ibid). The Scottish Health and care experience survey (Scottish Government, 2015b) attempted to ascertain how involved in the decision making process patients felt. Sixty-one percent felt they had been involved as much as they wanted to be, 33% answered they had been involved to a certain extent but not as much as they would like to be, 4% had suggested they had not been involved and they wanted to be, 2% suggested they had not been involved but did not want to be. 37% of patients wanting to be more involved in decision making could be interpreted as a considerable amount. However some studies in the Kings Fund meta-analysis (Parsons et al., 2010) emphasised the problem of patients and GPs having very delineated understandings of their roles in engagement. Concern was exhibited about whether attempts to increase patient involvement in decision making processes would cause compromise of function in the patient doctor relationship. Schouten et al. (2007) also found that research on preferences for decision making had shown that patients often desire to be well informed about their condition but wish to leave decision making to their GPs.

2.6 Migrant engagement and ethnic minority engagement with services

Minority groups' engagement with health services is particularly complex, both due to the reasons outlined above concerning research into health engagement in general but with an addition layer of complexity regarding the categories of

migrant or ethnic minority. Migration and ethnicity are closely intertwined phenomena and the nuances of each lead to inequalities in healthcare engagement (Bhopal, 2012). I will give a brief overview of some of the aspects of literature concerning health engagement by both categories most relevant to the current study.

2.6.1 Migrant engagement

Migrant engagement with services may differ considerably from that of non-migrants as their needs, resources and access to services are affected by factors related to the process of migration. This is especially true for recently arrived migrants (Nørredam & Krasnik, 2011). Here I will address the most relevant dimensions that affect migrant health engagement.

It should be emphasised at this point that it is difficult to collect data on migrant healthcare engagement due to the variability and complexity of migration (Jayaweera & Britain, 2010). The term “migrant” covers a highly diverse group and African migrants are no exception (Rechel et al., 2011). Therefore it should be noted that whilst some allusions to explanations for migrant engagement can be made, the group “migrant” is so diverse that there are few firm conclusions to be drawn. Regardless, the patterns and approaches discussed below have relevance for the experiences of participants in the current study.

2.6.1.1 Newness

Recency of migration represents a deterrent to engagement and a unique set of barriers concerning knowledge of healthcare systems (Dixon-Woods et al., 2005) (Worth, 2006). It is, however, exceptionally difficult to isolate the influence of time in the country from other aspects such as socio-economic category and ethnicity in understanding changes in migrant health and engagement (Jayaweera & Quigley, 2010). One of the central aspects of migration newness that can affect engagement is level of knowledge of healthcare system. However, a study by (Aung et al., 2010) examining migrant registration with GPs found that whilst levels of knowledge of healthcare engagement did have a significant association with engagement, socio-demographics were a stronger

determinant of registration. The exceptions to this were asylum seekers and refugees, where knowledge of the health care system was significantly associated with registration (Aung et al., 2010).

2.6.2 The issue of culture

Much of migrant health research looks to supposed differences in culture between migrant populations and host populations as a critical explanation for barriers to engagement with health services (Thurston & Vissandjée, 2005). Culture itself has multifaceted meanings which make defining cultural barriers challenging. Culture here will be defined "as a set of meanings, behavioural norms, values and practices used by members of a particular society, as they construct their view of the world" (Rechel et al., 2011, 204). Cultural expectations affect people's engagement behaviour (Dixon-Woods et al., 2005). A pertinent example of this is perspectives on what is gender appropriate behaviour. In some cases men might be less inclined to engage on the basis of cultural norms concerning masculinity that develop a perspective that help-seeking behaviour connotes weakness (Dixon-Woods et al., 2005). This creates issues with health care engagement when "cultural dissonance" occurs, i.e. when the cultural norms of healthcare organisations do not align with their users (Dixon-Woods et al., 2005). This can result in alienation of users through a lack of sensitivity or stereotyping, where organisations make assumptions about users in order to bridge the cultural dissonance (ibid). This leads to the idea of cultural competency, where services should have good knowledge of the cultural norms of their users (Nørredam & Krasnik, 2011). (Page-Reeves et al., 2013) suggests that it is common for healthcare providers to lack awareness of the daily lived realities of their patients, and suggests that cultural competency facilitates a greater understanding of patient contexts.

2.6.2.1 Communication and culture

As suggested in the section on general health engagement, good communication and therefore positive relationships between a GP and patient are instrumental in successful engagement. Language barriers are often identified as being difficult to overcome in healthcare engagement for migrants, however communication goes beyond language (Nørredam & Krasnik, 2011). Culture is

often cited as a barrier to establishing effective communication (Harmsen et al., 2003; Schouten & Meeuwesen, 2006). “Culture” issues in communication are broken down by Schouten and Meeuwesen (2006) into five types: “cultural differences in explanatory models of health and illness; differences in cultural values; cultural differences in patients’ preferences for doctor-patient relationships; racism/perceptual biases and linguistic barriers” (Schouten & Meeuwesen, 2006, 21). These issues can result is less compliance to healthcare instructions, and less satisfaction in services even after adjusting for socio-economic variables and education (Harmsen et al., 2003). However, (Schouten et al., 2007) also found that studies they reviewed concerning intercultural medical communication yielded inconsistent results, and stress that there is no complete understanding of the variable nature of inter-cultural communication.

A study in Holland showed that GP communication with migrants tended to be shorter, more verbally dominant and less cooperative (Meeuwesen et al., 2006) and therefore less likely to meet the expectations outlined in the general engagement section of “good” engagement. (Harmsen et al., 2003) found that possible dissonance between westernised medicine approaches and migrant patient understandings of biological, psychological and social issues could hamper communication and lead to misunderstanding and non-adherences to treatment.

2.6.2.2 Counter-arguments to a culture based understanding of migrant health

Culture in public health literature tends to be defined on the basis of individual level attitudes and behaviours (Viruell-Fuentes et al., 2012). Therefore cultural explanations for differences in migrant health and access to services tend to focus on individuals and can have the effect of hiding the role of structural social inequalities on health outcomes for migrants (Viruell-Fuentes et al., 2012). These include the effect of living in communities with low resource levels, low socio-economic position, institutional discrimination leading to unequal treatment, immigration policies, labour practices and overarching anti-migrant sentiment in the wider population (Zambrana & Carter-Pokras, 2010). These aspects and institutional policies are argued to affect the health of immigrants through the perpetuation of poverty and prejudice (Viruell-Fuentes

et al., 2012). Authors have argued that in addition to focussing on individual explanations, a framework of cultural based understandings of engagement also has a tendency to focus on the demand side of engagement rather than the provision side (Nørredam & Krasnik, 2011). This can result in a power imbalance whereby the culture in question is defined by service providers, which then determine who is culturally different (Thurston & Vissandjée, 2005). Thurston and Vissandjée (2005) argue that this obscures the fact that service providers are affected by culture as well, and have their own cultural norms that often are not considered in migrant engagement research.

In addition, the use of culture in explaining engagement or in attempting to tailor approaches to service provision runs the risk of homogenising highly heterogeneous immigrant groups, which in turn can facilitate victim blaming (Abbott & Riga, 2007; Hunt et al., 2004). This is the result of stereotyping about certain cultural traits of various groups by service providers which can lead to negative effects on engagement rather than improving levels of engagement (Durieux-Paillard, 2011). These cultural stereotypes may be reduced to a set of measurable traits that encourage individual level understandings and continue to fail to take into account the culture of westernised medical systems as a factor in non-engagement (Holmes, 2012).

An alternative to a culture based understanding of healthcare engagement of migrants would avoid the emphasis on changing values, norms and beliefs (Abraído-Lanza et al., 2006). Instead it would take an intersectional approach as recommended by (Viruell-Fuentes et al., 2012) by examining the ways in which immigration interacts with “race”, class and gender in order to move away from individualised understandings and challenge the determinant factors of immigrant health and engagement. This approach could focus on more structural barriers including but not limited to income and poverty, issues of housing in high deprivation areas where migrants tend to live, including overcrowding and substandard conditions, lack of access to reliable transport and tackling anti-immigrant sentiment which can affect willingness to engage and knowledge of entitlement (Jayaweera & Britain, 2010).

2.6.2.3 Asylum seeker and refugee health engagement

Asylum seekers and refugees arrive in the UK under conditions that are distinct from any other immigrant group (Jayaweera & Britain, 2010). They tend to come from situations where violence, war, persecution on the basis of gender, sexuality, ethnicity or politics have had a considerable physical and mental impact on their health and wellbeing. The process of fleeing adds to these traumas as the journey itself can be exceptionally damaging for mental and physical health due to violence and coercion from those transporting them and others looking to exploit their vulnerable position (Lindert & Schinina, 2011). Compounding these factors are the further traumas of settlement in the UK, due to social isolation, heightened levels of discrimination, homelessness and a considerable lack of social and economic resources (Piachaud et al., 2009). In addition to this, the often long and convoluted process of seeking asylum has been shown to significantly undermine health and wellbeing of an already highly vulnerable group (Healy & McKee, 2004) . Accordingly Asylum seekers are generally considered to be the most disadvantaged group in terms of resources in accessing healthcare amongst migrants (Rechel et al., 2011), but often also considered amongst those of highest need.

This is especially the case concerning mental health, as Lindert et al.'s (2009) meta-analysis shows. In the majority of studies analysed negative mental health outcomes were more likely to occur for asylum seekers and refugees (Lindert et al., 2009). They are more likely to have experienced trauma and therefore display multiple symptoms of post-traumatic stress and depression. There are also associated increased risks of dental, nutritional, infectious and paediatric illnesses, as well as a higher rated level of self-impairment than the general population (Healy & McKee, 2004). They are also more likely to experience risk factors for mental health issues in the UK such as social exclusion and discrimination (Lindert & Schinina, 2011) (Healy & McKee, 2004). Even those who arrive in good health have a tendency to report depression and ill health later into the process (Healy & McKee, 2004). Refugees are likely to remain at increased risk of mental health issues for many years after their transition to host countries, and as such their vulnerability and requirements for sustained attention to encourage engagement should not be underestimated (Lindert & Schinina, 2011). As Healy and Mckee (2004) suggest, psychological dimensions

of trauma and the unique experiences of migration in this group have profound effects on their abilities to access healthcare. For these reasons, managing the needs of this group and encouraging engagement requires a level of sensitivity above and beyond other migrant or ethnic minority groups. Individuals in this position need considerable support to rebuild their lives and as such they present a unique challenge for engagement (Healy & McKee, 2004).

Asylum seekers and refugees also experience specific institutional barriers to engagement. They have restricted housing and benefit entitlements, but are allowed NHS care as the system currently stands (Stewart & Mulvey, 2014). However entitlement is not equivalent to access, and often asylum seekers meet barriers, particularly lack of knowledge of entitlement, both from themselves and service providers (Healy & McKee, 2004). They also commonly experience overt discrimination and intolerance within the system that cannot be explained away by lack of knowledge of entitlement (Ibid). GPs are often reluctant to register asylum seekers as their temporary accommodation status and increased burden of psychological difficulties are perceived as time consuming, and some feel they lack the skills and support to deal with these patients (Healy & McKee, 2004). The health system is designed for people who understand it, have permanent residency and have a minimum of resources including the ability to communicate their needs, all of which are severely lacking in the asylum seeker refugee population, resulting in poor health care despite entitlement (Healy & McKee, 2004)

As previously mentioned, the asylum process may have some profound consequences on engagement, and one dimension where this is particularly the case is trust of authorities (Hynes, 2009). The dispersal system in particular is argued to create considerable levels of mistrust. As it is forced movement, asylum seekers often feel betrayed when they are dispersed without choice far away from their communities into areas which are inevitably highly deprived with substandard living conditions (Hynes, 2009). This serves to compound the mistrust towards the Home Office, with many viewing it as a highly antagonistic force in their lives (Stewart & Mulvey, 2014).

2.6.3 Ethnic minority engagement with services

Another body of literature relevant to African healthcare engagement is that of ethnic minority engagement. As was previously noted, there are many areas of overlap between the literatures on ethnic minority engagement and migrant health engagement, particularly in discussions of the impact of culture. However, it is clear that that ethnic minorities have distinct patterns of engagement with health services, for example ethnic minorities are more likely to engage with GPs but less likely to go on to secondary services. (Morris et al.). Therefore some of the relevant discussions concerning ethnic minority engagement should be examined in more detail. It is often suggested that issues pertaining to ethnic minority engagement are bound in socio-economic issues (Bhopal, 2007). However, as (Dixon-Woods et al., 2005) suggests "it is probable that the issues that affect utilisation of heath care by highly successful professional people who are second or third generation migrants from the Indian sub-continent may be very different from the issues that affect recent migrants from war-torn regions of Africa." (Dixon-Woods et al., 2005, 168). In the ethnic minority engagement literature there has been limited control for socio-economic variables according to (Dixon-Woods et al., 2005), and therefore it is difficult to show the effects of access by ethnicity. Despite this, continued research suggests that ethnic minorities do have poorer access (ibid).

It is important to be aware of within group diversity as well as between group diversity when defining patterns in ethnic minority health. (Dixon-Woods et al., 2005) emphasise that there are issues of age and gender which delineate different sub groups within ethnicities, and that assumed ethnic effects on engagement may lose power over time once people become familiar with the negotiation of systems of healthcare. They also suggest that issues pertinent to visible minorities (i.e. minority categorisation based on skin colour and the assumptions and stereotypes that go with it) may not be those experienced by non-visible minorities.

2.6.3.1 Access

In Dixon Woods et al. (2005) synthesis it was found that ethnic minorities tended not to have trouble with GP registration, apart from those who were very

recently arrived. Some studies in the synthesis reported registration at rates of 99-100 percent. Other studies found that GP registration is often higher amongst ethnic minorities than the majority ethnic population (Dixon-Woods et al., 2005; Morris et al., 2005)

Much of the literature around ethnic minority access to services beyond registration tends to mirror issues that are discussed with regards to migrant engagement (Dixon-Woods et al., 2005). Indeed some authors argue that it is more pertinent to discuss migration than ethnicity in terms of minority engagement (Prost et al., 2007). As such the often cited issues of minority ethnic engagement are those that have already been discussed with regards to migrants, including mobilisation of lower resources for engagement, potential lack of knowledge of existence of services and how to use them, lack of communication abilities due to language skills, and the previously discussed "cultural" barriers that are used to explain lack of engagement in some cases.

2.6.3.2 The Doctor-patient interaction

Much of the focus of ethnic minority engagement with healthcare services focuses on the doctor-patient interaction. (Schouten & Meeuwesen, 2006) conducted a literature review of European research and found that there was a tendency for ethnic minority patients to be less communicative than their white counterparts, and to feel that GPs were less communicative also. Patients tended to be less assertive, express less friendliness and engage in less social talk. Minority ethnic patients tended to feel more that their concerns were not taken into account. From the service delivery side, research showed that doctors felt that dealing with ethnic minority patients tended to be more demanding Other research has also found that ethnic minority patients have more difficulties meeting "mutual understanding" with doctors (Van Wieringen et al., 2002). Van Wieringen et al. (2002) found that experiences of lack of mutual understanding tended to result in more non-compliance. Studies showing these aspects often appeal to explanations of culture (Schouten & Meeuwesen, 2006; Van Wieringen et al., 2002) as described above in the migrant health section, and are also susceptible to the issues described above. These authors do suggest that structural issues also play a part and appeal to the difficulty in isolating

why ethnic minority engagement is specifically different. (Schouten & Meeuwesen, 2006) also suggest that explanations are lacking, as studies dealing with ethnic minority doctor-patient relationships rarely, if at all, relate communicative behaviour to possible predicting variables apart from ethnic background. Whilst more explanatory research is required, it is still pertinent that some research suggests that interactions with ethnic minority patients are consistently less effective than those with white patients in western countries (Schouten & Meeuwesen, 2006).

2.7 African migrant engagement with HIV services

Whilst African migrants specifically can be affected by all the issues discussed above, it is important for this research to examine the literature dealing with their engagement with HIV services. Little research has been carried out concerning African HIV engagement in the UK outside of London (Ndirangu & Evans, 2009). In this section I will look at specifics of African migrant engagement with HIV services that have not been covered in previous sections. I will then go on to examine at whether there are specific issues concerning HIV engagement for asylum seekers and refugees. It should be emphasised that much of what compels individuals to test for is dependent on their individual contexts, however there are some patterns of behaviour and understandings the deserve further attention (Burns & Fenton, 2006).

2.7.1 Late engagement with HIV services

Whilst there is not a large amount of research concerning African migrants' late engagement with HIV related services in the UK in the literature, there is a more substantial amount of European based literature (Hamers & Downs, 2004). (Anderson, 2008) suggest that Africans "consistently" present later than their host population counterparts, and that they only seek testing when they or their partner experience bad health. It is suggested in some studies that late presentation for HIV is an issue for migrants in general compared to general populations (Sulis et al., 2014). Some authors suggest that there have been regular restatements of this issue, especially concerning African migrants, despite the fact that the phenomenon remains relatively poorly documented and understood (Anderson, 2008; Lapostolle et al., 2013). (Lapostolle et al.,

2013) 's study found that there were significant differences in testing rates according to people's country of origin. Authors suggest that in their study people from high prevalence countries where there were high profile campaigns around HIV and good awareness have a tendency to have higher testing rates than individuals born in the host population (Lapostolle et al., 2013). Those who had comparatively lower testing rates were those from countries where there were strong taboos perhaps connected to religion, or lack of open engagement around HIV, both of which contributed to higher levels of stigma (ibid). (Lapostolle et al., 2013) caution that their results cannot show a causal relationship, but they do suggest that a blanket claim that Africans tend to test later has to be interrogated further. (Gama et al., 2010) found in their research based in Portugal, once they had adjusted for potential confounding variables, it was age and education that were significantly associated with testing engagement for African migrants, so these factors probably have a higher effect on engagement than country, or indeed continent of origin.

Gama et al., (2010) found that age and educational level were significant determinants of HIV testing for Africans in Portugal which is in line with previous research in the area, where being younger and less educated was associated with being less likely to test. The authors suggest that low education might be associated with a lack of knowledge about HIV and therefore a poor understanding of when individuals are at risk of infection and therefore should get tested. Once they adjusted for age and educational level, their results showed that HIV testing was independent of immigration status and time in the country. Other studies, such as (Anderson, 2008) based in the UK found that the migration process and legal status of individuals had a profound effect on their engagement with HIV testing services. Some studies showed that going through the process of migration would mean that health care would be a relatively low priority in comparison to basic needs (Burns et al., 2007), which would also suggest that those recently migrated and less settled would be less likely to be thinking about health care and HIV. So it would be sensible to suggest that there are many influences on African migrants' willingness to test and engage with HIV related services.

2.7.2 Risk awareness

Often cited in literature as a reason for late testing alongside the structural and other engagement issues discussed above (Burns & Fenton, 2006) is the a tendency by African migrants to underestimate their risk of HIV (Anderson, 2008). A lack of perception of risk or similarly lack of perceived benefit of knowing one's HIV status contributes to poor access to HIV services by Africans in the UK (Burns et al., 2007). Burns & Fenton (2006) suggest that level of treatment available and awareness in countries of origin affects the extent to which individuals perceive their own risk. Burns et al. (2007) suggest that these issues could be modified by time in the UK, with increasing time associated with an increased level of knowledge about HIV which therefore leads to better resources to understand risk and possible treatment, and hence higher likelihood of engagement. However, some studies (Burns et al., 2005) have shown that it is actually more likely that those African migrants who have been in the UK for less than five years are more likely to test for HIV, so the effect of time in the country is still unclear. (Burns et al., 2007) suggest this could reflect greater awareness of HIV and acceptability of testing in countries of origin in the recent past, especially when compared to more established African communities in the UK.

2.7.3 Targeting for HIV interventions

Arco et al.'s (2012) literature review identified two main approaches to increasing HIV testing, general population approaches and targeted interventions directed at "higher risk" populations, which includes African migrants. Antenatal screening for HIV is a well-documented and successful intervention (ibid). A study in Canada found that women from HIV-endemic countries preferred to be tested as part of routine testing rather than being targeted. Some countries, for example Denmark in 1995, moved to a targeting approach to antenatal screening, however some individuals slipped through the screening and HIV positive babies were born, so they switched back to routine screening (Alvarez-del Arco et al., 2012). Most of the research in the area recommends mixed approaches of both routine screening and targeted strategies (Gee et al., 2009). Burns et al. (2007) suggest that the most important facet of this type of engagement is community backing and participation in the facilitation of these

types of targeted interventions. Another important aspect that emerged from multiple studies was the importance of developing interventions that are set in community based settings such as outreach services, commercial venues and social clubs (Alvarez-del Arco et al., 2012). Another approach identified by Arco et al (2012) was to target migrants entering the country on arrival. For example the US requires all asylum seekers and refugees to test for HIV, with those living with HIV only able to attain temporary visas (Prost et al., 2007). HIV testing is also mandatory for entrants to Canada, but screening also includes clinical referral and is done in a supposedly culturally, gender and linguistically sensitive way (Zencovich et al., 2006). Zencovich et al (2006) suggest this has led to increased diagnoses among migrants, but also increased uptake of treatment.

Targeting does have drawbacks however, as it can leave those targeted feeling stigmatised as carriers of the disease (Prost et al., 2007). This is particularly the case with Africans and HIV as HIV has often been framed as an African problem (Prost et al., 2007). As (Bhopal, 2007) suggests, it is a historical trend that each new group of immigrants in the UK has been accused of raising population risk of infectious diseases, and as a recent wave of immigration it could be argued that assumptions about Africans connections to HIV might be increased due to targeting this population for HIV related interventions (Prost et al., 2007).

2.8 Conclusion

This literature review has outlined central concepts and contextual information relevant to this research. I have detailed a brief history of African immigration into the United Kingdom, and some demographic details of the African diaspora currently in Scotland. I have set the context of African lived experiences in the UK through discussions about contemporary racism and discrimination, the different forms it can take, and the argument that it stems from structural roots. I have given a brief theoretical overview of stigma, highlighting perspectives that are particularly pertinent to this research. To give a context to the healthcare service use reported by participants, I have summarised some relevant aspects from general health service research, and more specifically some pertinent research concerning migrant and ethnic minority engagement with health services. Finally I outlined relevant research about African migrant

engagement with HIV services in particular. The following chapter, Methods, will detail the processes of carrying out my research project.

3 Chapter Three - Methods

3.1 Introduction

This chapter will detail the processes by which this research was conducted. Initially I will give an overview of the fieldwork and then discuss the methodological approach. I will then recount the preparatory work and report what was learnt, which will lead onto a description of the main studies' two phases. I will then go on to describe and discuss the two main methods employed, participant observation and semi-structured interviews, and reflect on their use. Finally I will discuss the process of data analysis and the ethical issues involved in this project.

3.1.1 Overview of Research

My research consisted of a preparatory stage and two main phases. The preparatory stage involved informal dialogue with other researchers and professionals working in the field of HIV related health promotion, interventions and service provision, and a pilot study. The pilot consisted of semi-structured interviews with four African students based at a large university in Scotland. These interviews were also included in the data set for the main study due to the quality of data that emerged.

The first phase of the main study involved interviewing representatives from 14 organisations in Scotland that had a majority African client base. Organisations were initially selected on the basis of diversity of type, to try and gain as wide a spectrum of organisations as possible. Eventually organisations were also selected on the basis of convenience of access, owing to a range of difficulties in contacting representatives and convincing them to take part in the study. This will be detailed later in this chapter.

The second phase involved both participant observation and semi-structured interviews. Four organisations identified in the first phase were chosen as case study sites. At two of these, participant observation took place, consisting of attendance at weekly meetings over a period of eight months. This participant observation was limited and opportunistic rather than of a prolonged intense

format as is the case in traditional ethnographic field work. During this participant observation I developed relationships of trust which facilitated the recruitment of organisation users for semi-structured interviews. Interviewees were also recruited from two other case study sites, but without the same extent of participant observation. In total 23 organisation users were interviewed in this phase. Organisation attendees were recruited on the basis of a sampling frame in which gender and time in the country were the primary dimensions, as I wanted to gain a spectrum of perspectives from individuals who were newly arrived in Scotland through to those who had lived here for a long time. This was important as I assumed that this dimension would affect participants' experiences of health services and their perspectives on various issues around HIV such as risk and stigma. This was confirmed by my findings. A secondary sampling frame was used to try to gain as diverse a sample as possible on the basis of country of origin and migrant type. Migrant type consisted of three categories: economic migrant, student and refugee.

3.2 Reasons for Choice of Methodology

3.2.1 Qualitative Methods and Underpinning Theoretical Stance

My research aims to explore the heterogeneity of first generation African migrants in Scotland to understand how to improve engagement with health services, particularly HIV testing. As has been explained previously, this heterogeneity concerns participants' views, meanings, values and understandings, therefore an interpretevist approach is appropriate. This is based on an assumption that "reality" exists as peoples' varying internally located perspectives and interpretations (Ritchie et al., 2013). Denzin and Lincoln (Denzin & Lincoln, 2000) theorize that qualitative research aims to uncover the meanings which people ascribe to phenomena within their social worlds. Knowledge and understanding in this paradigm are social constructs which are developed from peoples' perceptions and experiences, rather than an objective external reality separate from these individuals (Ritchie et al., 2013). Taking an interpretevist approach allows a focus on the experiences of participants from their own perspectives and an exploration of how they interpret these experiences (Ritchie et al., 2013). Qualitative methods were essential for this research as I had to access more detailed, nuanced and deeper

information that would not be available using quantitative methods (Mays & Pope, 1995; Silverman, 2006).

Another central aspect of the interpretevist approach is an acceptance that the researcher, the participants and the social world being researched all have mutually influential relationships (Ibid). Findings in my research were influenced by my values, background and perspectives, making claims of objectivity redundant. This does not undermine the value of the research as reflexivity allows these influences to be taken into account in analysis and interpretation of data (Lambert & McKevitt, 2002).

Another underlying perspective that has determined the form of my research is symbolic interactionism, which argues that people behave towards phenomena based on the meaning those phenomena have for them as individuals. (Blumer, 1986). These meanings are generated through social interaction and are fluid and dynamic (Blumer, 1986).

3.2.2 Methods Used

The central data collection method used during this research was one-to-one semi-structured interviews. From this point any reference to "interviews" should be assumed to mean the one-to-one semi-structured format. I also engaged in a limited variant of participant observation. I will first discuss the reasons for use of participant observation, then go on to describe the format and reasoning behind the one-to-one interviews.

3.2.2.1 Participant Observation

Participant observation can be defined as a researcher taking part in the daily rituals and experiences of a group of people as a means to understand their implicit and explicit culture (DeWalt & DeWalt, 2010). Key elements include extended exposure to participants, becoming an active part of the routine actions of participants, informal observation, recording observations in field notes and using both tacitly and explicitly learned data in analysis and write up (ibid). Engaging in close and long term contact with participants can lead to a richer understanding of their experience, beliefs and behaviour that would not

be accessible via interviews alone (Gillham, 2005; Hammersley, 2002). The participant observation utilised in this project was of a limited variant in that the research questions were on specific topics that were not necessarily connected to the setting of the observation site. Therefore field notes had limited utility. However, if pertinent information was volunteered it was recorded in field notes. Participant observation was also limited in terms of time scales, taking part around once a week at each site for a few hours only. This was carried out for around 8 months.

Participant observation was utilised for two reasons. The first was that, as suggested by preparatory discussions with other researchers and community workers, the African diaspora have in the past been difficult to recruit into research, particularly when the topic of research is HIV. Advisors and early participants emphasised I would have to build considerable trust in order to convince people to take part. In addition to this some of the participants were refugees, a group historically wary of involving themselves in research due to political sensitivities, concerns about exposure, and motives and trustworthiness of the interviewer. These barriers can be lessened through the relationship building that can take place using qualitative approaches and participant observation gave me time to assuage these types of fears(DeWalt & DeWalt, 2010).

My immersion into routine activities also provided access to individuals that perhaps would not otherwise take part (DeWalt & DeWalt, 2010; Gillham, 2005). There was also the potential of enhanced disclosure, particularly around sensitive topics, as participants became more familiar with me and more trusting (Gillham, 2005; Mays & Pope, 1995; Ritchie et al., 2013).

In retrospect, participant observation greatly increased the opportunities I had to connect with participants in this research, which arguably resulted in richer data than might be available through interviews alone.

3.2.2.2 One-to-one Semi-structured Interview

Interviews were used in this research to gather the detail required to explore participants' systems of understandings, values and levels of engagement with

health services in general and HIV related services in particular. Focus groups may have been a viable approach in terms of assessing community values. However, I wanted to gather individual perspectives about highly sensitive topics, and group settings might have stifled individuals' abilities to provide their perspectives (Gillham, 2005).

Gillham (2005) suggests that there are three main criteria that define an interview, all of which were important for this research. The first is that the questions asked are "open", with the interviewee free to determine their own answers empowering them to control the focus of the interview (Ibid). This was vital in this research as I wanted participants to focus on the issues which were most important to them concerning the research topic. Whilst semi-structured interviews have more potential to cause distress than a quantitative survey (as respondents would be able to just skip questions they do not like) the interviews' semi-structured nature did generate space to negotiate sensitive issues. If I felt that participants were distressed I could either check it was appropriate to continue, move to a different topic or stop the interview completely as necessary. Through this awareness, more amiable and conducive relationships were formed in the interviews.

The second criteria identified by Gillham (2005) is that the interaction between the interviewer and interviewee is adaptive, allowing for reactive changes in focus and flexibility in clarification and exploration. This allowed me to focus interviews on particular areas of interest. For example, if a participant had experienced a noteworthy event, or had particularly strong feelings about some aspect, I could probe further to gain a more nuanced understanding. It also allowed me to shift focus between interviews. If a particularly relevant or unexpected perspective emerged in one interview, I could seek to clarify and authenticate the phenomenon in subsequent interviews with other participants.

The third criteria identified by Gillham (2005) is that the interviewer has a structure and an aim, even within a naturalistic context and so can be relevant to specific research questions. This research in particular could be argued to cover a very wide spectrum of understanding and experience. The semi-

structured approach allowed me to gain a balance between interviewee empowerment and research focus.

3.3 Preparatory Work

Preparatory work took place prior to the main fieldwork and consisted of discussions with key informants and a pilot study. It was carried out to inform the study design and develop my skills and confidence so as to be both confident and well enough informed to be as rigorous and systematic as possible during the main study interviews. Preparatory work also provided the foundation on which interview schedules were developed.

3.3.1 Discussions with Key Informants

Initial discussions were held with 11 key informants between November 2012 and July 2013. They had either conducted research in a related area, were policy makers (in sexual or public health), or working in HIV-related services supporting African migrants in Scotland. Key informants included NHS Health Scotland workers specialising in black and minority ethnic (BME) engagement, Public Health consultants and advisors whose work was related to HIV, health improvement leads working for HIV prevention programmes, African Health Project outreach workers based at the HIV charity Waverley Care, a researcher from the Scottish Refugee Council and representatives from HIV Scotland. Interviews were not recorded, however notes were taken and on-going dialogues continued throughout the course of the research.

3.3.2 Pilot Study

The pilot study consisted of interviews with four students based at a large University. Students were targeted specifically as a population that was readily accessible.

An African specific student club was approached and representatives of this club were asked if they could provide access to African student attendees. Participants were recruited through snowballing. The interviews covered general

experiences in Scotland, African migrant social networks, experiences of barriers to service engagement, and discussions of HIV/AIDS within the African diaspora. Interviews lasted around one hour, took place at my research unit office in a private space, and with the permission of the participants were recorded and transcribed. Participants were paid £10 in vouchers as compensation for their time.

Analysis of the pilot interviews was exploratory in nature, and aimed to identify key issues and themes to be covered in the main study. The pilot interviews produced rich data and it was therefore decided that they should be included in the main study sample. The data set was re-analysed using the coding developed for the main study data set.
(See appendices 1-3 pages 208-212)

3.3.3 Findings from Preparatory Work

The preparatory research informed decisions on what types of organisations to approach for the first phase of the main study. Religion was reported to be central to lived experiences of Africans in Scotland and results suggested that churches would be very important sites of social networking within the African community, so they were identified as useful sites for participant observation and recruitment for interviews. Several informants thought that it would be important to include commercial establishments that are predominantly African, or have a majority African clientele as these were also reported to form important nexuses in African social networks. Other informants specified specific community groups and African affiliated organisations that would be potentially interested in taking part.

African social networks were suggested to be “tightly knit” by key informants and pilot participants. Experience from the pilot study suggested that the most successful recruitment strategy would be face-to-face and consequent snowballing. Many suggested that Africans, particularly first generation migrants, would need trusted advocates to ‘vouch for me’ in order to convince them to take part, especially as one of the topics of interview was HIV. This was suggested to be the recruitment strategy most likely to convince potential participants of the legitimacy and value of the study.

The close knit nature of social networks was also identified as a problem as it could mean that the possibility of breaches of confidentiality of interview content would be viewed particularly adversely. Therefore it was suggested that participants would need strong guarantees of anonymity and confidentiality in order to feel comfortable enough to take part. However, it was also suggested that the fact I am not a member of the African diaspora would mean that potential participants might perceive me to be less likely to breach their confidentiality than a member of their own community. It was mentioned by both informants and pilot participants that compensation for taking part in interviews would increase willingness to take part in the study, particularly with the refugee contingent.

How the research was presented to potential participants was suggested by key informants and pilot participants to be the most critical aspect of recruitment. In addition to this, recruitment for previous research was said to have been hindered by suspicion of the motives of researchers and what the data would be used for. Therefore my recruitment strategy emphasised the beneficial nature of the research for the African diaspora and was explicit about how the data would be used. It emphasised that my research was not just an academic exercise but also an effort to affect change, and that it would act as a platform from which participants could voice their opinions of current approaches and dialogues with healthcare and HIV related services.

Key informants suggested that potential participants who had recently been through or were still in the migration process, particularly as refugees or asylum seekers, might be especially reticent in engagement with individuals that they perceived to be linked to an official body, and by proxy the government or the UK Border Agency. It was therefore suggested that it would be important for me to be explicit about my independence from these bodies when explaining the research.

On the issue of “HIV research”, key informants suggested they had had more success in engagement when presenting research as being related to general health instead of solely HIV. Pilot participants also suggested that whilst most

people would be willing to discuss HIV/AIDS, they would only be comfortable doing so as part of a wider spectrum of health topics. As such, whilst the research was driven by a need to engage more Africans with HIV related services, it did seek out a range of data broader than that just related to HIV, and was presented as such.

3.4 Main Study

As previously mentioned the main study had two phases. The first involved semi-structured interviews with representatives of organisations. The second involved engaging with four organisations identified in the first phase and interviews with organisation attendees. In the following two sections I will detail descriptions and reflections on each aspect of both phases.

3.5 Phase One: Organisation Representatives

3.5.1 Sample

I interviewed representatives from 14 organisations. These included two commercial organisations (a hairdressing salon and a restaurant in Glasgow) affiliated with Africans, three religious based groups (two based in churches, one with a wider community remit), two integration networks based in Glasgow, one country association, and seven advocacy groups. Organisations were split between large cities (10) and smaller towns (4). Religious groups were those which have at their core a religious affiliation. Two were affiliated with specific African churches and the other was a Scotland wide Christian engagement group with a primarily African membership. Integration networks were set up by Glasgow City Council with specific mandates to react to the influx of asylum seekers and refugees into the greater Glasgow area after their dispersal from London began in 2001. The country association was a voluntary organisation catering to people from a specific country. Of the advocacy groups, five specifically concerned the African diaspora, two of them being women's groups, while the other two dealt with ethnic minorities in general, but had high proportions of African users.

Relevant data from interviews with non-organisation representatives were also used to gain information about the various organisations and broader patterns about those organisation types. In addition to interviews, data from participant observation and repeat visits to organisations were also used.

3.5.2 Table of organisation representative participants

Organisation identifier	Organisation type	Nature of data collection
Religious Organisation 1	Multi-denomination African specific worship group	Interview & Participant Observation
Religious Organisation 2	Evangelical Church	Interview
Religious Organisation 3	Scotland wide African multi-denomination Christian engagement and advocacy group.	Interview
Advocacy Group 1	African Women's association	Interview
Advocacy Group 2	African Women's association	Interview
Advocacy Group 3	African advocacy group	Interview & Repeat visits
Advocacy Group 4	African advocacy group	Interview
Advocacy Group 5	African advocacy group	Interview
Advocacy Group 6	Ethnic minority advocacy with large African user base	Interview & Repeat visits
Integration Network 1	Specifically asylum seeker/refugee	Interview & Participant Observation
Integration Network 2	Wider community remit	Interview
Country Association 1	Somalian country association	Interview
Commercial Entity 1	Restaurant	Interview
Commercial Entity 2	Hairdressing salon	Interview

Table 1: Organisation Representative Participants

3.5.3 Recruitment strategies

Initial recruitment was aimed at organisation representatives, with a starting point being contact details I had gathered at the preparatory stage in addition to details I had sought myself online. This was through phoning and emailing where those details were available. This approach had limited success as often contact details were out of date or organisations had ceased functioning. Many of the smaller organisations had very limited information available on how to contact them. In many cases I had to follow a complex trail of contact details which did not necessarily lead to successful dialogue with a representative of an

organisation. Emails were mostly unsuccessful, with the large majority eliciting no response. More successful was phoning representatives directly, however this also resulted in rejection by the majority of representatives. Reasons commonly given for not wishing to take part were that there were no staff with time available, research was not in the organisation's remit, and that they had previously helped researchers but felt that they had not benefitted.

Snowballing (using contacts from individuals who participated to find other participants) was particularly effective. Often people I was able to interview gave me further contact details either during the interview or afterwards as part of the more informal wrap up discussions that happened. Particularly beneficial was being able to say at the beginning of a phone call or email that I had gotten their details from a named individual. This was particularly effective if I was able to say that the named individual had already taken part in the study as an organisation representative. In some cases people I had interviewed sent emails to potential participants on my behalf. Having an advocate promote the research was highly beneficial in the context of the sensitivities of the research and given the high levels of non-participation in this phase.

When an appropriate organisation representative was reached, the rationale of the study was explained along with how data would be used and how their anonymity would be protected. They were given an opportunity to ask questions, and if they agreed to participate I arranged to meet them for an interview. The interviews explored the remit of their organisation, overviews of social networks in the diaspora, barriers to participation, barriers to health services, the organisation's interactions with health services, and positive outcomes or experiences of the organisation's influence on African communities. Participants were not paid any compensatory vouchers, as they were acting in a professional capacity representing their organisation or group, and it was decided to be inappropriate to provide compensation to individuals acting in this capacity.

3.5.4Interview Process

Once organisation representatives had agreed to take part in the study, I arranged to meet them at a venue of their choice for the interview. In most

cases this was their offices, but in some cases organisations had no permanent offices so I met representatives in public places where it might be possible to conduct the interview. Participants were taken through the information sheet, given an opportunity to ask questions about the study and asked to sign a consent form . Interviews varied in length: the shortest interview was 29 minutes; the longest was 72 minutes and the average interview time was 54 minutes.
(See appendices 4-7: pages 213-218)

3.6 Phase Two: Case Studies Sites

For the second phase of my research, four of the groups identified in phase one were selected as case study sites. Two sites were selected for long term participant observation and two were engaged with in less depth. The case study approach facilitated the use of gatekeepers and advocates to develop better bonds of trust with potential participants.

Sites were chosen to gain as diverse a selection of potential participants as possible and on the basis of practicality in terms of access, numbers of regular attendees and cooperativeness of the gatekeepers. I had previously interviewed gatekeepers for the case study sites in phase one. In subsequent communications I ascertained the viability of using their organisation as a case study site. Below I will give further details of the case study sites.

3.6.1 Advocacy Group (lesser engagement)

The advocacy group was a council funded organisation based in a town outside of Glasgow, the remit of which was to encourage ethnic minority integration and participation. It also acted as an intermediary between locals and the council and NHS, gathering feedback from ethnic minority communities and submitting this information to these bodies. This particular site was chosen for a case study as when I spoke to the representative they suggested that there were large numbers of African clients and that the issues they faced in accessing healthcare were different to those faced by African migrants in Glasgow and Edinburgh. I thought it would be important to try to capture some aspects of this differential nature. However, it was difficult to recruit in this area, both due to the

inconsistent nature of the organisation (a lack of weekly meetings for service users, reactive rather than preventative or systematic work) and the apparent reluctance of the gatekeeper to facilitate recruitment. Eventually I was only able to recruit three people from this site.

3.6.2 Ethnic Minority Empowerment Group

This organisation has a similar remit to the advocacy group. It helps to advocate for individual minority ethnic service users. It also organises events such as large cultural awareness/exchange days, outdoor parties and educational activities. It is funded as a charity and receives no guaranteed regular income. This organisation was chosen as a case study group as the representative suggested that due to its situation in a smaller town, it was more difficult for their clients to engage with healthcare, and as Africans they were more isolated due to a lack of African specific groups and social networks. Like the advocacy group it was inconsistent, so it was difficult to get to know people who were engaging with it to build relationships which could lead to recruitment. As such only three interviews took place with service users.

3.6.3 Religious Group

This is an interdenominational African and Caribbean Christian group. It meets on a weekly basis and discusses various biblical and religious issues, as well as sometimes having outside speakers to discuss issues affecting the diaspora or more general issues. Whilst the discussions that take place are particularly varied in topic, they are always situated within a Christian perspective. This site was one of the two in depth case study sites. It was chosen because it had a large and diverse group of African attendees, because the gatekeeper was keen for the study to take place, had a weekly meeting to which I could attend and it had a good variety of people of different ages and backgrounds so was a useful case study site.

3.6.4 Refugee and Asylum seeker Drop-in

This group is funded by the council and provides front line support for refugees and asylum seekers in a particular area of a large city. Support provided ranges

from handing out food parcels and bus pass vouchers to supporting the progression through the asylum process, helping with issues with housing, the council, job applications and a wide variety of other issues. The group has a drop-in session once a week that I attended as a volunteer worker. This group was chosen as a case study site as it was decided on the basis of previous studies and advice from workers and researchers in this area that African asylum seekers and refugees would have different experiences and health needs in relation to the research questions than other Africans.

3.6.5 Organisation Users Sample

The sample for this research was diverse along several demographic variables. Concerning the organisation users (n=27), the three main reasons to be in the UK were evenly split within the sample, with eight economic migrants, ten asylum seekers/refugees and nine students. Countries of origin included Cameroon, Congo-Brazzaville Democratic Republic of Congo, Eritrea, Ghana, Guinea, Kenya, Malawi, Mauritania, Nigeria, Rwanda, Sierra Leone, Somalia, Tanzania, Uganda and Zimbabwe. Nine of the 27 organisation users were Nigerian, this could be attributed to the large proportion of Nigerians in the African diaspora in Scotland (roughly 23% of the diaspora, second largest national group after South Africans) and due to the convenience sampling necessarily used for this study. Thirteen of the 27 organisation users were female, 14 were male. There were a wide range of times in living the UK. Fifteen participants had been in the UK five years or less, nine 6-10 years, and three 11 or more years. Levels of education were more difficult to ascertain, however only a small minority (five) were not educated to a university level education or currently at university. All five were in the asylum seeker/refugee category. Socio-economic class was also difficult to ascertain, as questions concerning this aspect were not broached due to associated sensitivity. However, I am confident to state from participant observation data that all the participants who were asylum seekers or refugees were experiencing very high levels of deprivation.

Figure 2: Organisation users sample

Site	Pseudonym	M or F	Country of Origin	Migrant Type
Religious Organisation One	Joy	f	Nigeria	Economic
Religious Organisation One	Theresa	f	Nigeria	Economic
Religious Organisation One	Benjamin	m	Nigeria	Economic
Religious Organisation One	Stella	f	Nigeria	Economic
Religious Organisation One	Christopher	m	Malawi	Economic
Religious Organisation One	Emmanuel	m	Nigeria	Economic
Religious Organisation One	Tamilore	f	Nigeria	Economic
Religious Organisation One	Cedric	m	Cameroon	Student
Religious Organisation One	Linda	f	Nigeria	Student
Advocacy Group Three	Kodzo	m	Ghana	Economic
Advocacy Group Three	Yaema	f	Sierra Leone	Refugee
Integration Network One	Alain	m	DRC	Refugee
Integration Network One	Aaban	m	Rwanda	Refugee
Integration Network One	Kheyre	m	Somalia	Refugee
Integration Network One	Ruta	f	Eritrea	Refugee
Integration Network One	Filsan	f	Somalia	Refugee
Integration Network One	Ousmane	m	Mauritania	Refugee
Integration Network One	Faith	f	Uganda	Refugee

Integration Network One	Oudry	m	Congo	Refugee
Integration Network One	Souleymane	m	Guinea	Refugee
Pilot	Deborah	f	DR Congo	student
Pilot	Susan	f	Kenya	student
Pilot	Joseph	m	Tanzania	student
Pilot	Fatima	f	Nigeria	student
Advocacy Group Six	Isaac	m	Uganda	Student
Advocacy Group Six	Victor	m	Nigeria	Student
Advocacy Group Six	Cynthia	f	Zimbabwe	student

Figure 2: Organisation Users sample

3.7 Phase Two: Research Processes and Reflections

In the following section I will discuss and reflect upon the processes involved in participant observation, recruitment, and the semi-structured interviews.

3.7.1 Participant Observation

3.7.1.1 Gaining Consent

A particular issue with my participant observation was how to gain participants informed consent. Participant observation generates particular difficulties in gaining traditional informed consent (DeWalt & DeWalt, 2010). Taking the same approach as for an interview, i.e. asking everyone who might be involved through an information sheet and having them sign a consent form, is both impractical (it would be laborious, if even possible, to have everyone that could be present during long term participant observation to sign a consent form) and could negatively affect the participants perception of the researcher. This approach could have acted as a barrier to my integration into the group and

raised suspicions as to my presence (DeWalt & DeWalt, 2010). Instead I approached informed consent as a process rather than an instance. As Dewalt and Dewalt (2010) suggest, in order to avoid covert research, I took every opportunity to remind the participants at case study sites that I was there to do research, and always took time to answer questions regarding my presence.

3.7.1.2 Religious Group - Description of Participant Observation Process

The leader of the group was a participant from phase one, and subsequent to the interview we discussed whether or not it would be appropriate for me to start attending the meetings and attempting to recruit for interviews. I was given permission to attend and began to go to weekly meetings. I did not feel the need to identify myself to the whole group immediately, but answered questions and took opportunities to speak to individuals about what I was doing there. Whilst there were no restrictions on non-Africans attending, I was the only non-African, and was therefore relatively conspicuous. People quickly, in an entirely non-hostile manner, asked me who I was and why I had decided to join the religious group. I explained that the I had spoken to the pastor and was carrying out work regarding the African diasporas' engagement with health services, and the pastor had suggested I attend meetings as I might be able to speak to some people. Later in the engagement (two months in) I was asked to do a talk concerning health engagement and HIV to the entire congregation. This became more of a forum of discussion, and was useful in generating interest in my work. The meetings took the form of a sermon or discussion, prayers and songs, and time afterwards for conversation and tea. I wrote field notes immediately after the meetings. Field notes covered what I had experienced during the sessions, synopses of any relevant conversations I had had and how I felt afterwards.

3.7.1.3 Drop-in - Description of Participant Observation Process

During the interview with the representative from the advocacy group I discovered that they were looking for volunteers for their weekly drop in session with asylum seekers and refugees. The representative also said that there were a high number of African asylum seekers and refugees in attendance. After discussion with supervisors it was agreed that this would be a good case study

site. I signed up as a volunteer and attended the weekly drop in sessions. In my capacity as a volunteer I provided advice and support related to housing, health, dealings with the council and dealings with the UK Border Agency. In the majority of cases this consisted of signposting to other organisations that could help and facilitating that engagement. I also acted as a "befriender" which consisted of more informal conversations and discussions, and sometimes taking part in activities with art and music. I also helped to run the drop in itself with practicalities like set up and making food. Being a volunteer was facilitative of building relationships of trust. It was also a useful way to reciprocate to the advocacy group for the opportunity they had given me in accessing their users.

Like the religious group, I did not feel it appropriate or necessary to gather everyone initially in a formal manner and explain who I was, as I was concerned this would dissuade people from interacting with me. However, I did answer all questions about why I was there. This information was also spread by people I had spoken to in interviews. Field notes were made immediately after attending the drop in.

3.7.2 Reflections on Participant Observation

Participants voiced concerns and suspicions both during initial recruitment efforts and early interviews about whether information collected would be used for their benefit or to single them out in order for some particular differential treatment. This suspicion was considerably allayed during the participant observation process as it allowed participants to get to know me as an individual. I was accepted into both groups within a matter of weeks, but at both participant observation sites there were some individuals who did not interact with me or, when they did, were brief and did not have any substantial conversations with me. It is difficult to say why this might be without making assumptions, however they were perhaps not as confident in talking to me as others might be, or perhaps had heard that I was doing research and therefore wanted to avoid me. In retrospect I did tend to approach and interact with people that I felt at the time were more approachable. At the beginning of the study I tended to speak to people who I perceived I had more in common with, i.e. who were fluent in English and were perhaps closer to my age. Towards the

end of the participant observation I was interacting with the majority of people at both sites.

The religious site was more difficult for me as a researcher as I felt I was in some way deceiving participants by taking part in religious ceremonies when I am not religious myself. I felt more acutely at this site than at any other that I was perhaps taking advantage of people, and I wrote in my field notes "How did it feel pretending to pray? Selfish, duplicitous, immoral, exploitative…" The feeling that I was taking advantage of the religious group by lying to them and falsely taking part in their ritual never dissipated. Particularly guilt inducing were moments when I arrived at the meeting and people greeted me as a friend and were happy to see me.

By way of an exit strategy after I had finished recruiting here I started to lessen my attendance, at first every two weeks, and then once a month, stopping altogether around July 2013.

My attendance at the integration network drop in was of a different nature. The engagement at this site was particularly extensive. Being a volunteer and helping people at the drop in accelerated the relationship building process within participant observation. In retrospect it would have been useful to have had even longer to participate and observe before starting interviews, as I learnt much through regular interactions that I could have gone into detail about within interviews. Unlike the religious site there was no pressure for me to participate in something contrary to my beliefs, so it was much less duplicitous from my perspective, and therefore much more comfortable. This may have been because as a volunteer I felt I was contributing rather than just observing. I had a similar exit strategy for the drop in, to slowly lessen my attendance over the course of two months.

3.7.3 Reflection on Recruitment for Interviews

3.7.3.1 Recruitment at non-participant observation sites

At the short term sites recruitment was highly opportunistic. I did not have time to approach people, and inevitably people were busy doing other things as I

usually was engaging with groups at an event. Recruiting at these events was difficult and relatively unsuccessful, mostly due to the pressure of limited time scales. Often it was difficult for the advocate/gatekeeper figure to connect me with potential participants as they would be busy working at the event or meeting and therefore did not have time to make introductions.

Recruitment consisted of explaining who I was and the nature of the study, and attempting to get contact details in the form of email or telephone number. Once a phone call or email dialogue had been set up, I gave the potential participant an opportunity to ask further questions about the study. If they were satisfied I arranged to meet with them at the venue of their choice.

3.7.3.2 Recruitment participant observation sites

It was clear that the longer I was embedded within sites the easier it was to recruit. Longer engagement tended to result in less suspicion about my motives and therefore a more straightforward recruitment process. The extended engagement also allowed me to access participants who may not have been enthusiastic about taking part otherwise. The participant observation gave me the opportunity to be more nuanced about those who I had the opportunity to recruit. I could target particular individuals who I learned through the observation period had used the health services.

In the same way, spending more time with the pool of potential participants at both sites allowed me to be less reliant on the gatekeeper figure in the recruitment process. Internal friendships and politics were apparent at all case study sites. It could be argued that gatekeepers would be more likely to recommend or facilitate recruitment of people with whom they had better quality of relationships or whom they perceived to be more able to take part. My independence from these figures was enabled by the long term participation and I believe this allowed me to recruit a wider range of individuals than if I had been engaging with groups in less depth.

3.7.3.3 Recruitment at the Integration Network

The recruitment process at the asylum seeker drop in was necessarily different due to the vulnerability of potential participants. I had to balance the need to recruit with the potential stress that interviewing an unstable interviewee might cause them. I therefore recruited carefully, and in the majority spoke to people who I thought would be resilient in the interview situation and to whom I would not cause too much distress by talking to about the sensitive subjects covered in this research.

Another central factor in recruitment here were potential language barriers. Many of the potential participants at this site had very poor English and were therefore not suitable for the study, as I did not have access to funding for translators. Getting to know people over the length of the long term participant observation period allowed me to make a more informed decision concerning this.

As the majority of the people at the drop in were in particularly vulnerable financial circumstances, the vouchers were a much larger incentive. To those living on food vouchers, £20 of disposable income was a considerable amount of money. This raised the question of whether it was ethical to use vouchers in these circumstances. It is hard to say to what extent people participated only to get the vouchers. On three occasions participants did express disappointment that the reimbursement was in voucher rather than cash form, however this is not conclusive in itself.

The combination of the economic poverty of the group and the vouchers created another problem. On several occasions people asked me if they could take part and about the vouchers. On some occasions I had to turn people down, as I had others in mind who I felt would be more suitable in fulfilling the sampling framework. This upset the potential participants, and they asked me questions such as “why can I not take part?” and “don’t you want to hear about my experiences?” This was difficult to deal with as the researcher, particularly given my position as a volunteer trying to help the organisation users.

In recruiting from this group, in hindsight, I believe I was guilty of recruiting those who I saw to be "good" as opposed to the "bad". The "bad" were those who perhaps did not have good personal hygiene, who I had witnessed being difficult within the drop in, or those who I thought might be mentally ill. The "good" were those who were more eloquent, perhaps more respectful in the drop in and easier for me to interact with. I regret not engaging with more of the "bad" as I think some of them may have faced different barriers to services than the "good". However, I also realise that pragmatism often took precedent, as I had to make judgments as to whether or not certain individuals would be conducive to interview.

3.7.4 Reflections on Interviews

I usually started interviews with informal rapport building in order to dispel any tension. I would then work through the information sheet and ask the participant if they had any questions. These questions were answered and I then moved on to the signing of the consent form. Once the consent form was signed the interview began.

Due to the sensitivities of the subject matter, interviews usually had an extended period of rapport building where I would ask more general questions about people's lives in Scotland and their background. Questioning then was directed towards issues of health and if I felt sufficient rapport had been built, I would move on to issues concerning HIV. There were particular individuals with whom I found it much easier to build a rapport. These tended to be younger people primarily. I believe this was more to do with my disposition than the participants, as I felt more at ease or less under pressure in the interview situation when talking to someone of similar or younger age. I was perhaps less concerned with offending people, meaning I was more relaxed. This effect lessened as I became more confident in my own interview technique. Whilst gender did have a slight impact, particularly concerning sexual health related discussions, I found that I was able to build similar levels of rapport with both men and women.

Interviews with participants I had recruited from the participant observation sites were easier to conduct. It was apparent that the better I knew participants

from previous participant observation, the less the rapport building was required. It is difficult to measure this beyond my instinct within an interview situation, but both the participants and I were certainly more comfortable in negotiating discussions of sensitive issues on a faster time scale. This was particularly the case in discussions of elevated risk of HIV within the African population in Scotland and reasons for this. With participants who I had not had extended engagement with, this was always a difficult topic of discussion.

Interviews at the integration network had several aspects in common with other interviews but some which seemed accentuated due to the circumstances of the respondents. There were two determining factors in how these interviews proceeded: the level of power imbalance between myself and the interviewees as asylum seekers and refugees, and the traumatic nature of the lives of the participants.

Whilst the power imbalance between myself as the researcher and the participants will always have had a bearing on the nature of the data collected, the imbalance was particularly powerful when interviewing participants from the integration network. Not only am I a relatively well off and well educated person, but I was also a volunteer/staff member at the drop in. I endeavoured to put participants as much at ease as possible in conversations during participant observation and in the interviews themselves, reassuring them that there were no right or wrong answers, reiterating that I was there to hear their perspective and emphasising the protective measures inherent in the research process concerning confidentiality.

Another aspect of this particular group that may have made their response different to that in other case studies is their previous relationships with the interview process. As part of the asylum process they have to go through substantive interviews, and these are the main determinants of whether or not they are granted leave to remain in the UK. Interviews can therefore have a particular connotation which may have affected these participants' experiences in this research. There were numerous occurrences when the interviewees intimated that they had to perform to a certain standard, or that they were being in some way tested. Several interviewees also asked for time to prepare

before I turned on the audio recorder. It is difficult to ascertain what effect this perception of a need to perform might have had on the interviews, or to what extent they were telling me what they thought I wanted to hear.

The associations inherent with interviews for this particular group could also explain the increased suspicions around audio recording. I found that I had to explain in further detail the confidentiality clauses particularly when I asked interviewees if I could record the exchange. Many said that they did not want their name to be given, and asked why I needed to record them. Once I had explained the anonymisation and data protection processes they seemed more at ease, and I was eventually able to convince everyone to consent to audio recording, but it was this group in particular that had most resistance to recording.

As mentioned in the recruitment section, language barriers were an issue at this site. The majority of participants I interviewed were still learning English. The tension around the power imbalance and previous experiences with interviews may have caused stress which I believe may have worsened language and communication difficulties. With some participants I was able to communicate well during participant observation, but during the interviews their abilities to communicate degraded considerably. This also may have been because of the more complex nature of the discussions.

The language barrier led to inevitable frustration in the interviews. I would become frustrated that I was not able to explain particular things, and interviewees became frustrated when their English was not sufficient to understand or to portray their own perspective. Interviewees' frustrations would sometimes build to the extent where I would have to change the subject of discussion. This meant that I was not able to speak to everyone about particular topics that I wanted to. These interviewees tended to start to show fatigue and frustration more often and earlier than others. Due to the vulnerability of this particular group, I felt it particularly necessary to avoid undue stress, so I often sped interviews up if I could see that the participant was becoming tired or frustrated.

Whilst the sensitive topic of this research affected all the respondents in different ways, I feel that in this particular group I was more aware of the importance of negotiating sensitive topics for a variety of reasons. For one, I learnt during the participant observation period that most people in the drop in had lived through highly traumatic incidents. These included gang-rape, ethnic cleansing, civil war, deaths of loved ones, missing children and a multitude of other traumas. Added to this was the stress caused by the physically and mentally dilapidating asylum process. Quite often in discussion of health issues, their circumstances here in the UK and therefore the process which led them to be here became the topic of conversation. The nature of these discussions were traumatic for the respondent and for me as the researcher. Often I felt that the nature of the discussion became entangled with the traumas that people had experienced. I felt it would have undermined or trivialized their experiences if I had then gone on to ask about their opinions on HIV, or their experiences with the health services here, so I often cut interviews short when this happened.

I also felt that there were occasions after these discussions when I and the participants were too emotional to continue, again leading to interviews being shortened.

Some of the topics were of such a traumatic nature that I found they negatively impacted my interview technique, not only in those interviews but in subsequent interviews also, even out with the drop in. My emotional resistance to these discussions of trauma increased over time, but I still find it difficult to discuss these issues even whilst in the process of writing them up. There is a phenomenon known as “vicarious trauma” whereby working with people who have experienced trauma can trigger reactions similar to those experienced by those people (Dunkley & Whelan, 2006; Sexton, 1999). Whilst I certainly did not feel reactions anywhere approaching that which the participants had suffered, I was deeply negatively affected by this part of the fieldwork.

3.8 Analysis of Data

Interviews were digitally recorded and transcribed verbatim. Ethnographic field notes were written up. A coding schedule was developing using the interviews and then applied to field note data. The data were organised using NVivo.

3.8.1 Coding

Codes were developed via two strategies. First, I developed codes relating to the topics of the research questions. Second, four transcripts were selected (two each of interviews with organisation representatives and organisation attendees) and used to develop a code list in addition to the codes generated on the basis of the research questions. This coding frame was then refined to generate broader codes which could at a later stage be broken down into sub codes. The broad coding frame was then tested with a coding pilot, applied to six diverse transcripts. These consisted of two representative transcripts and four attendee transcripts, one from each recruitment site. During the coding pilot, some further codes were required, and these were added to the final coding list to be used for the coding of the rest of the data set. The coding pilot was developed to attempt to minimise changes to the coding list throughout the coding process. Some codes naturally emerged as I become more familiar with patterns in the data, however I attempted to minimise the extent to which the list was amended, as if too many changes were made it mean that codes that did not exist at the beginning of the process would only be applied to transcripts close to the end of the process. This process took place after recruitment had finished.

Classification codes were developed so as to be able to later analyse the data by type of participant. Classification codes denoted whether or not the participant was a representative or an attendee, their gender, their educational level (none/higher/university and above/unknown), their time in the country (less than 3 years/3-10 years/over 10 years), their reason for being in the UK (Student/Economic Migrant/ Asylum seeker/refugee), their age (18-29/30-39/40-49/50+), their country of origin, the site at which they were recruited and their participant number. Many classifications only had relevance to the interviews with attendees. Therefore only “representative” and country of origin

classifications were applied to the representative interviews. These classifications were developed at an early stage in the coding as my familiarity with the datasets allowed me to hypothesise which dimensions of diversity would generate patterns of response. These classifications were added to throughout the coding process, particularly if another pattern was recognised whilst coding.

3.8.2 Data Analysis

I used thematic analysis based on a framework model. Framework analysis involves six stages: familiarisation with the data, identification of a coding schedule, coding the data according to the schedule, condensing this data into a succinct summary, and then adding the summary to the framework and interpretation of the data (Ritchie et al., 1994). Whilst key themes were determined in the early stages of research on the basis of my research questions and initial coding pilots, a number of themes and sub themes emerged during the close and multiple readings of transcripts and application of codes, for example, the power of rumours and the extent to which participants believed sources of information within their social networks had as much legitimacy as "official sources" such as medical professionals. The NVivo software allowed me to return to relevant sections of data easily to test hypotheses and confirm patterns. It also allowed me to identify and code, and therefore organise together, deviant cases and contrasting experiences.

Various spreadsheets were then created on the basis of both the broad themes that were decided upon in early stages of research and for the emergent themes that developed as described above. Each broad theme had a table, with some emergent themes in the same table if they were closely linked. Interviewees were listed in rows and codes and sub-codes in columns, with relevant data summarised in each cell, and with key quotations also. This allowed straightforward comparison of themes across the entire sample. Using codes and sub codes as columns also allowed me to quickly return to the relevant point in transcripts. When other themes emerged during coding and analysis, new tables were made of the same format so as to be able to quickly access relevant data. Framework analysis is a method by which to organise data, but does not provide analytical output. As such I will describe the process of analysis below.

I made notes of key ideas and issues that emerged as significant for each interview, and these were used to develop maps along with the broad themes that were decided upon in early stages (See appendix 8, p219 for an example thematic map). These maps organised my thoughts and allowed definition of further themes, exploration of associations between themes and developing of explanations to address research questions. The maps helped me organise emergent themes, and then I was able to develop notes and confirm hypotheses using the spreadsheets developed for framework analysis. This meant I could easily see what participants had covered concerning particular aspects across the entire sample. If sufficient data was available for particular themes, and these themes were of relevance to the research questions, they and their connected themes identified using the thematic maps formed the basis of results chapters. NVivo was invaluable in allowing straightforward organisation of all the data and quick and easy access to pertinent sections of interview transcripts.

This entire process was iterative and was not carried out in isolation. With the help of colleagues and supervisors I was able to develop themes and the final results structure contained in this thesis. During this period I also presented early findings at conferences and feedback from these allowed me to identify weaknesses in certain areas of analysis. Similarly to critical input from my supervisors, if feedback focussed on why particular perspectives were held or why certain patterns of behaviour emerged I was able to go back to the relevantly coded transcript sections and look at context, allowing me to elaborate where possible.

3.9 Ethics

The process of gaining ethical approval for this project was completed through the Glasgow University of Social Sciences Research Ethics Committee. The initial application was rejected on the grounds that I was deceiving participants into taking part. The central issue here was that I was not telling participants directly that I was primarily interested in issues concerning HIV/AIDS. As suggested in the preparatory stages of this research I was advised not to promote this research as HIV/AIDS research as this would immediately deter

large numbers of people, particularly African migrants, from taking part. The ethics committee suggested that framing the research in any way apart from saying it was HIV specific was deception and therefore ethically suspect. To solve this issue I reassured the ethics committee that I was not solely interested in HIV/AIDS related matters, and whilst they were a central aspect to the research it also covered other areas. I also amended the information sheet to be handed to participants to include that I would be asking questions in relation to HIV/AIDS. This was deemed sufficient and the project was given approval.

As the study was highly sensitive, one of the most pressing ethical concerns was confidentiality. Data from interviews and field notes were handled as securely as possible. Recordings were stored on a password protected hard drive which only I had access to. I also transcribed field notes into Microsoft Word as soon as possible and disposed of the paper copies. Transcription of the interview recordings was carried out by a professional transcription service with their own guarantees of confidentiality, and sound files were uploaded to a password protected server for access by the transcription service. Any identifiable details were kept separately from the transcripts and field notes, and participants were given a participant number and pseudonym.

3.10 Conclusion

This chapter has described the methodological choices and research process for this project. The process of design, data collection and analysis was not linear, and these aspects intermingled and were iteratively informed. During this process the guidance of supervisors and others allowed me to develop a systematic as possible approach to data that was often not systematic due to the sensitivities and difficult process of interviews detailed in this chapter. The following chapters will present what my participants shared me with about their lives and perspectives.

4 Chapter Four - Identity and Social Networks in the Diaspora

4.1 Introduction

My first research question is "What are the levels of heterogeneity amongst the African Migrant population in Scotland, and what dimensions of heterogeneity could affect future efforts to engage them with HIV related services?". The central dimension of heterogeneity revealed in this research was identity. Heterogeneity of identity in the diaspora has consequences for the design of future efforts to engage Africans with HIV-related services and health promotion. Understanding how targeted individuals perceive themselves is an important precursor to understanding how to appeal to them. Increasing relevance of services to individuals is one way to encourage uptake and engagement. Therefore, I will examine different identities that participants felt affiliated to. The central identity that will be examined in this chapter is that of "African", as this has been the identity appealed to in previous efforts to engage Africans with HIV-related services. Participants were asked to what extent the African identity had relevance to them as individuals and their communities, whether there was overall African solidarity or unity in Scotland, and what other identities were important for the diaspora. Participants were also asked about the social networks connected with these identities. The term social network was well understood to mean the network of people with whom participants interacted directly.

Identities were deployed in fluid ways, and participants positioned themselves according to their particular context at the time, as Theresa's quote illustrates:

> "If an event was taking place then I could identify with that as being African, or if it was Nigerian then I could go to hat as being Nigerian, but if, you know, there was no ethnicity defined then happy to go as Nigerian or as British or whatever." *(Theresa, F, Economic Migrant, Nigeria)*

Despite the inconsistency in identity use, patterns emerged from the data which provide an insight into several important nuances of identity for the participants.

4.2 The "African" Identity

As demonstrated in the literature review, the category of "African" is widely deployed in HIV epidemiological research and health services engagement. However, there has been limited questioning of the validity of the term "African", and its salience for potential service users. Results from my research show that participants had a diverse range of views on the African identity.

4.2.1 The existence of an "African" Identity

I first asked whether participants thought that the African identity was real and distinct from other identities. The large majority agreed that the African identity was important, distinct and had meaning:

> "It is also true there is a desire amongst the Africans that to be… to maintain an identity that we're Africans. Which is… OK, it's true, we can't run away from it. I always say the Ethiopian cannot change his skin. So, it is… it exists…" (*Emmanuel, M, Economic Migrant, Nigeria*)

Emmanuel gave an indication of the indelibility of the "African" identity, appealing to the unchangeable visual aspect of skin colour. However, for participants including Emmanuel, African concerned more than "race" or ethnicity. It also encompassed culture, geography and a broad range of values and understandings. Emmanuel also emphasised that there is a will among the diaspora to maintain or "preserve" this identity. Other participants also discussed having pride in this particular identity and the will to use it as positive.

One of the ways the legitimacy of the African identity was justified by participants was in perceptions of differences between Africa and Europe:

> "The fact remains that Africa and Europe are totally different." (*Victor, M, Student, Nigeria*).

A small minority of participants provided other justifications on the basis of inherent commonality amongst all Africans:

> "As long as you're African. We're technically from the same place. Especially in this country, well this continent I should say, it's such a long way from Africa. Too far away to say, well I'm only going to hang out with [people from your own country]... There is some difference between Africans, there are some things that I might not get that they get or the other way round, but eventually you get round that." (*Fatima, F, Student, Nigeria*)

Here, African was a master identity which cut across other identities such as nationality. Participants in this minority suggested that isolation from Africa was one of the reasons that the African identity was beneficial, as it allowed mutual support and association, particularly in Scotland due to the small numbers of Africans perceived to be here. One of the students who had been involved in an African society suggested that their lack of numbers solidified the importance of the "African" identity:

> "Susan*:* We want people to be brought in, because we have an identity, and be together, and you know...
> **Researcher***:* What do you mean when you say you have an identity?
> Susan: Like as Africans, you know, we have something... so we have the society, Africans... and I think you know, being around uni and stuff, we're not that many either, so... maybe 40 or 50 African students at all." (*Susan, Student, Kenya*)

Here the African identity was a tool with which to bring people together in an environment where they were different from the majority, and therefore it was a source of pride and highly beneficial.

Four participants spoke about the African identity being so strong as to supersede other identities:

> "I give you an example of a guy I met the other... he's got a kind of Canadian immigration status now. So I was with a friend who asked him where he was coming from. He said... he is Canadian who was born in Nigeria. This is not funny at all! This is an African man… and because he has Canadian status he says he is a Canadian who is born in Nigeria. But Africa comes before Canada." (*Cedric, M, Student, Cameroon*)

Cedric appeals to the importance of African heritage above other kinds of identities, particularly those that may have been adopted as a migrant, but this type of hierarchical prioritisation was rare, with only three participants making similar appeals. Participants who spoke of feeling the strongest affiliation to the "African" identity tended to be those who could not depend on other forms of identity as a means of connecting with other people. For example if there were insufficient numbers of people from the same country as a participant to form a group on this basis, then they would appeal more strongly to the importance of connections with other Africans.

For the participants who extolled the benefits of an overarching African identity, strategic essentialism (as defined in the literature review) took place, where they willingly overlooked diversity within the diaspora to present a unified community, and were able to enjoy the benefits that come from unification, including increasing potential for networks of support. One commonly reported example of this was when individuals were looking for help and received it from fellow Africans. Oudry, an asylum seeker from the Democratic Republic of Congo, was made suddenly destitute by the Home Office, but was able to quickly find a spare room with a friend of a friend, who was from Mozambique. He believed this only took place because of a shared African heritage, as this individual did not have any other connection to him.

Organisation representatives also emphasised the specific importance of the identity in mobilisation to affect change and better the position of Africans in Scottish society:

> "There is an importance when engaging with the system in speaking with one voice. I mean if you're from Zambia or from Tanzania or from Mozambique or wherever you understand your country better than I will. But when we're talking about the overall coming together for you know, speaking in one voice, you have to come in, you can't just be able to do this outside." (*Representative, Advocacy Group 5, pan-African)*

This representative argued that there was more power in a unified voice. She also suggested that people were facing similar issues, "discrimination, whatever, isolation, barriers, whatever", and therefore it was sensible to try and engage as a unified group. Others also suggested that an "African" identity could be a useful tool to raise the profile of Africa.

> "It is useful if it helps people to look to Africa, to try to lift up Africa in my opinion, it will be a useful thing… yes there is an African identity but it is useful to have more, for people to think about Africa." (*Emmanuel, M, Economic Migrant, Nigeria*)

Whilst many participants agreed that the African identity had benefits, these were mostly when it was employed by Africans themselves. However, not all participants were in agreement with this.

4.2.1.1 Problematisation of the African identity

No one in the sample suggested that the African identity was without issue. Four representatives and five organisation users claimed that the African identity should be challenged due to the massive amounts of diversity in all dimensions across the continent, even within individual countries.

> "Africa is not one country. Me, my country, has over four hundred languages. In Nigeria we don't understand each other... someone from the south east of Nigeria, someone from the south west..." (*Joy, F, Economic Migrant, Nigeria*)

This directly contradicts the position of the participants promoting the use of the African identity, and suggests that for Joy internal diversity is too substantial

to deploy strategic essentialism. The other participants taking this position also alluded to overwhelming diversity, for instance suggesting that different colonial backgrounds had created different cultural norms in different countries.

> "We were shaped by colonial masters... so these things come to play when you see the lifestyle, the world view of... people, even we do when they're in the west... so it tends to influence the way of life of such people" (*Representative, Advocacy Group 5, pan-African*)

This participant was a representative from an African advocacy group, so it is notable that she would challenge the idea of a unified African identity, as it is the remit of her organisation to advocate on behalf on the "African Community" in Scotland as one entity. As demonstrated by her quote on page 77, she recognised the usefulness of the African identity in mobilisation, but it appears that she also thought it lacked alignment with the lived reality of African migrants in Scotland.

Another representative from an African advocacy group complained that attempting to harness the diaspora as a whole, or to "speak" with one voice, is difficult due to the disjointed nature of African communities in Scotland.

> "I don't think they understand though. They think their own problem is greater than yours. There are quite a lot of African groups who wants to compete with each other..." (*Representative 5, F, Advocacy Group, Women's)*

Here "they" are other members of the diaspora, and this representative suggested that people had difficulty conceptualising commonality and mutual goals. Participants who discussed trying to unify Africans across Scotland all spoke of the inevitable breakdown of organisations, and what they perceived to be the limitations of trying to deploy the African identity in a sustained practical sense. These participants usually gave the explanation of too many competing interests and a lack of will to unify objectives for all Africans in the diaspora.

For those that espoused the benefits of the African identity, it was beneficial when they decided to utilise it themselves than it being imposed on them by others. Many participants reported that the large majority of issues with the African identity came when it was imposed on them by non-Africans. There was concern that it resulted in homogenising assumptions being made about Africans as a group, which in turn reflected on them as individuals.

> "You can look at me as an African now, in this regard, okay, but in terms of me, my own peculiarities, they don't look at you... They tend to look at you as an African, not as an individual." (*Victor, M, Student, Nigeria*)

Inevitably, participants viewed assumptions that non-Africans made about them as Africans to be negative. They also highlighted that the reduction to "African" obscured other identities at a more individual level, which was an process they found to be upsetting.

One participant felt the benefit, in Scotland, of having African friends in contrast to non-African friends was that they would not judge her on the basis of being African, but on her individual qualities.

> "I wish I had more Africans around me… I don't know… but in terms of you know, the [African] friends I've mixed with, they have not – the treat me as a friend, not as an African or something." (*Tamilore, F, Economic Migrant, Nigeria)*

For Tamilore this might reflect that she feels that she is being judged on her attributes as an individual rather than on the basis of assumptions about Africans.

I asked how participants thought that they were perceived by non-Africans, and the majority thought the way non-Africans in Scotland perceived them was overwhelmingly negative. Scottish people when discussed at an individual level were said to be friendly and hospitable, but when talked about on a societal level they were reported to have negative attitudes towards Africans. This was often discussed in connection with the portrayal of Africa in the UK media. A few

participants pointed out that this portrayal often involved assumptions of homogeneity, particularly in charity appeals or news items. Predominant reported themes were poverty and lack of development, a lack of resources, and a lack of education for the entirety of Africa and therefore African migrants.

> "The photos they see are the photos of African children that Plan or Shelter or any of these good charities that are looking for funding, usually put up. Photos of sick, diseased, hungry, poverty ridden children who have flies all over their face, big heads... they don't also see that happy smiley face." (*Linda, F, Student, Nigeria)*

These perceptions were connected to specific incidents when participants felt they had been treated badly on the basis of these stereotypes. Examples include subtle acts of racism, like being scrutinised to what was perceived to be a disproportionate level when paying for goods and services, or being on the receiving end of explicit racial epithets, such as accusations of scrounging or seeking to take advantage of the UK's welfare system.

> "Many people think Africa is synonymous with poverty, it is synonymous with disease, it is synonymous with corruption, bribery, stealing, robbery; anything and everything…" (*Joy, F, Economic Migrant, Nigeria*)

It is clear that the "African" identity is highly complex, and had particularly contrasting acceptability when deployed by Africans compared to when deployed by non-Africans. I will now discuss the extent to which participants used the identity in the development and maintenance of their social networks.

4.2.2 "African" related social networks

As noted in the literature review identities and social networks are inter-woven and complex. The quality and meanings of networks might provide appropriate contexts for future engagement efforts.

When asked about the nature of their social networks, a majority of participants reported having mainly Africans friends. This phenomenon was explained by participants with reference to an African "understanding" or analogous notion:

> "There's a reason for [mostly socialising with other Africans], there's an underlying principle that we understand each other better. Africans just understand each other. They're just on the same wavelength. In terms of what's funny to me and what's funny to you. You need to relate to people like that." (*Benjamin, M, Economic Migrant, Nigeria*)

This aspect of understanding between Africans was also reflected in perceived lack of understanding of Africans by Scottish people in some cases. Participants felt that it was easier to make networks with other Africans because of this. This "understanding" also affected the nature of these networks, and participants consistently emphasised the "African" character of their networks in contrast to how they viewed Scottish networks. African networks were more social and informal and more closely knit from these perspectives. These were seen to be artefacts of "African" culture. One example given was that guests were always welcome, even without invitation, and this was portrayed to be a specifically African value.

Another aspect of the African social networks that participants emphasised was the unplanned nature of meeting new people. If participants already had a connection through a family member for example, then networks tended to grow from there. However these participants and others also recalled chance meetings on the basis of visual identification of other Africans, and subsequent word of mouth, as how they found out about networks.

> "Researcher: Can you tell me about how you met people?
> Oudry: I arrived here in this country, in hotel, I'd found two, three people from Africa, okay not so from my country. In hotel. So you know, and breakfast we must go downstairs a restaurant just to take something to eat. So, 'how are you?'" (*Oudry, M, Asylum Seeker/Refugee, Congo*)

This tended to be the experience of participants when they had not been in the country for long, and therefore seeking to establish any kind of social network. However, people who had been in Scotland for longer (over five years) also discussed this mechanism for joining social networks. Contexts for this were mainly in meeting other Africans in day to day life such as in public transport, in shops, or in accommodation. Usually once they had made a few connections, their networks expanded to take in other Africans that were proximate to the original contact.

Of interest is that those who were critical of the validity of the African identity did have social networks with Africans in them, but it was difficult to ascertain if this was to a lesser extent than others. However, these contacts could also have been made on the basis of national, rather than continental, identity, as discussed in the next section on alternative identities.

4.3 Alternatives to the African identity and associated social networks

The alternative identities that participants presented were: identity as a foreigner; nationality based identities; the ethnic identity of "black"; religion based identities and migrant status based identities. Each, like the African identity, is complex, fluid and interwoven. The responses to questions about these identities provide data which leads to discussions about what kind of identities would be useful in developing salient and relevant appeals for engagement for different sub-groups within the diaspora.

4.3.1 Identity as a foreigner

Self-identifying as a "foreigner" was very uncommon amongst participants. It was most salient for participants who were relatively new arrivals in the UK, such as Cedric who had been in Scotland for less than one year when interviewed.

> "When I came here I had to grapple with the issues of identity in a new context… I was foreign… and the place was… uh… new…" (*Cedric, M, Student, Cameroon*)

The identity of foreigner was implied to have an inherent disadvantage around knowledge and resources connected to challenges in Scottish society for Africans. Practical problems were usually related to dealing with issues around housing, finance and using services. Emmanuel, who had been in Scotland for five years, recounted his experiences of being newly arrived, and struggling with cultural and practical lack of experience and knowledge.

> "Because this one, we're foreigners here we did not know much about – we did not know enough about what we should know. And we got some knocks that we did not like." (*Emmanuel, M, Economic Migrant, Nigeria)*

Participants seemed to be happy to move away from this identity towards the other alternatives when they were more settled in Scotland.

More commonly participants saw the "foreigner" identity as something applied to them by others. Although most participants were keen to qualify that they had themselves been treated well by most individuals, the majority were aware of a negative view of foreigners in the UK, similarly to how they thought about Scottish perspectives on Africans.

There were no instances of participants reporting that they were part of social networks or social connections on the basis of being foreign. There were reports from the refugee cohort of being friends with people who were also of foreign origin, but this was primarily on the basis of common status of either going through or having completed the asylum process.

4.3.2Identity based on Nationalities

For most of the sample, national identity was more relevant to their lived experiences than African identity. One explanation for this increased relevance was that there were more likely to be common characteristics between people from the same country than the same continent. For example, Theresa (*Economic Migrant, F, Nigeria*) suggested that Nigerians were shaped by their mentality of cunningness, whereas Ghanaians were more "intrinsically honest" and "straightforward" and these aspects meant they were naturally drawn to

each other. Similarly, common experience within national groups was perceived to be a strong bonding force.

> "Cultural aspects differ between countries, so it's natural that people would tend to use nationality as an identity… people are more comfortable… than if it's more diverse [in terms of nationalities]." (*Representative, Religious organisation 2*)

Nationality based identities were suggested by participants to be contextually dependent, as were African identities. It appeared that those who cited nationality based identities with more strength of feeling tended to have a relatively strong or numerous national diaspora. Strength of feeling was judged by how animated participants were during these specific discussions, how much they raised their voices and were enthusiastic about these particular ideas. One group citing strong national ties were the well-established Malawian expatriate group in Edinburgh. They were a large group of Malawians who had good connections to the Scottish government, were well organised and had been in Edinburgh for decades. This supports the idea that there has to be a particular threshold of numbers and level of establishment before national identities become dominant. None however, suggested that "Scottish" was amongst their identities. Only one person said they felt British on occasion.

Participants also suggested that there were defined differences between nationalities in the diaspora, another factor in strengthening nationality based identities. An example of this was recounted by one of the representatives from a commercial outlet who found they may have alienated one nationality by associating too much with another.

> "Then they're saying, "oh no, I can't really do anything with that crew because it's the Zambian crew, or the Malawian crew." But I mean... Maybe it exists because we had a problem because some of our core customers just all of a sudden stopped coming. And we didn't realise why. We didn't know why for quite a while. But, only after... quite a long period... did we understand that maybe someone had you know, caused

> some sort of divide by associating with us, too close with one segment of the community than the other." (*Representative, Commercial Establishment 1, Restaurant)*

The segmentation of the African "community" was a recurring theme with the majority of participants when asked about the nature of African networks in Scotland. The exact nature of these "segments" was ambiguous, but the most common explanation was that they were based on nationality.

Among a small minority, there were admissions of tension between national "segments" and subsequent negative stereotyping. This was particularly the case concerning Nigerians and Somalis:

> "Fatima: I know in general people tend to discriminate against Somalis. Even Somalis don't like to call themselves Somalis. I just have no idea [laughs], I think because it's because they all look the same maybe?
> Researcher: Why do people look down on them?
> Fatima: I dunno, I think maybe it's the pirates. They... stick to themselves. That's definitely true. They don't branch out. They don't really mix with other people."(*Fatima, F, Student, Nigeria*)

This was the most extreme version of perceived divisions along national lines, but it is notable, as Fatima reports, that perhaps these perceptions are generated by the lack of mixing with other nationalities. Nigerians were also reported to be negatively viewed by others in the diaspora due to their perceived cultural tendencies towards loudness and anti-social behaviour. This indicates the complexity of nationality based identities, with some clearly stigmatised heavily by others, as well as by their own members.

4.3.3 Nationality related social networks

Participants proclaiming stronger affiliation to national identity were more likely to report engaging in country based networking and vice-versa, with both characteristics likely influencing each other. In contrast to the African based

social networks, nationality related social networks were reported to be more distinct and well defined.

> "Researcher: Do you have friends here who are Congolese then?
> Alain: Yes, I'm friends... we have, yes, particularly myself I'm involved in the Congolese community. Yeah, country associations, yeah, a lot of Congolese are here, yes." (*Alain, M, Refugee, DRC*)

When Alain referred to the "Congolese Community", his meaning was ambiguous. On further questioning he was referring to all the local Congolese people in abstract, rather than an officiated group. The officiated group was the "country association". As with nationality based identity, participants who tended to refer to country based networking were members of nationalities that had a larger presence in Scotland. However, there sometimes appeared to be more than one country based network for the same country even within the same city.

The genesis of nationality based social networks were similar to those for African based networks, in that people tended to just encounter those who they saw to be African in their day to day lives, and then they were guided to people who were from the same country if those individuals were available. Sometimes participants found others from their country as initial contacts, and in contrast to the visual cues discussed in the facilitation of "African" identity based networks, country based networking connections were often reported to be facilitated by shared language.

> "Yes, she was talking my language – both of them were walking... I was passing so I heard... I had to come back. And I started walking behind them to listen. So I'm like, "oh, wow". Then I say hello to them, and then, they told me, "oh, do you know us?" I said, "no, because I hear you speaking"..." (*Yaema, F, Refugee, Sierra Leone*)

As suggested above, however, there seems to be a threshold below which nationality based networking doesn't occur. There were a few participants who

had never met anyone from their country of origin (*Aaban, M, Refugee, Rwanda; Ousmane, M, Refugee, Mauritania; Cedric, M, Student, Cameroon*). In addition to this, people who lived outside larger population centres of Edinburgh and Glasgow had not experienced nationality based networking.

> "Researcher: So maybe they gather round a country association or something like that?
> Cynthia: Never heard of that in [small town outside Glasgow]... Like there are people from the same country, and having a... they meet... hmmm... never heard of that." (*Cynthia, F, Student, Zimbabwe*)

4.3.4 Ethnic Identities: "Black"

14 of the 27 organisation users and 9 of the 14 organisation representatives used the term "black" at some point in our interviews. It should be noted that only five users and 3 representatives made repeated use of the term in the interviews. This was unprompted because I regarded it as contested and possibly less preferable than "African". The term was applied in diverse ways.

Black was not used as a synonym for African, it was a wider term that took into account all "black" people in the UK not necessary of African origin, including black British and black Caribbean people. When Linda (*F, Student, Nigeria*) was asked whether Scottish people make assumptions about Africans in general, she suggested:

> "Not even Africans in general. Blacks in general, put it that way... They kind of feel that maybe... that the whites have more IQ than the blacks, which I don't think is true." (*Linda, F, Student, Nigeria*)

As Linda demonstrated, black was often used in an oppositional form to white, particularly when visual indicators were important. Much like the identity of foreigner, it was often deployed to contrast themselves to the majority population.

As suggested above, “black” was also described to be used by the ethnic majority, usually pejoratively. Tamilore (*F, Economic Migrant, Nigeria*) related incidents in which she felt she had been followed by security in shops because she was “black”. Whilst the participants tended to use the “black” identity to describe an outsider’s view, they did not problematise the term when we were discussing their own identities. I did not ask directly if they were comfortable with the term, because I wanted them to voluntarily state if they had discomfort with the topic. However only one person identified themselves explicitly as “black”, particularly black British (*Theresa, F, Nigeria, Economic Migrant*). However, she immediately went on to suggest that she also identified herself as African and Nigerian, and that these were more important.

Furthermore, there were no reports of participants being members of social networks on the basis of the “black” identity, with the exception of some discussion of African and Caribbean organisations. However, in these cases it was those who attended the organisations that were identified as “black” rather than the networks themselves, and it appears that “black” was simply used as a strategic convenience rather than an indicator of identity.

4.3.5 Religious Identity

Religion and by extension, religious identity, was important to the majority of participants. Whilst I recruited nine (of the 24) from a church based group, the majority of the rest of the sample also displayed a religious identity. Participants thought that on the whole the diaspora was mostly Christian, but of a wide variety of denominations. They also suggested there was a Muslim contingent, primarily Somalis.

Most participants reported that religion was a very important dimension of social life for the majority of Africans in Scotland. Many also suggested Africans would look for churches “to identify with” on arrival in Scotland. This is because churches were known by new arrivals to be sites of social networking for Africans and a place where they could find people to connect with quickly and easily. Participants suggested they were aware of this both because of the nature of religious networks in their countries of origin and because of reports they had heard before arriving in Scotland.

Several participants suggested religious identity cut across nationality, migrant status, and tribal-based divisions within the diaspora.

> "So here, yeah, there is a division between whether it's Ebo [Nigerian tribe], or something or another. But what unites most for all of them is if they Christians, it doesn't really matter much – too much. OK it does matter, but it just doesn't matter too much to them. It just matters that this person is a Christian." (*Emmanuel, M, Student, Cameroon*)

In this way the religious aspect of identity did not have the same potential for segmentation that other types of identities were vulnerable to. The same unifying affect was cited by Muslim participants and there was a sense that it eclipsed even the "African" identity, in terms of generating connections.

> "In the mosque, we meet a lot of people, different people, you know, of different backgrounds, but we pray together... All Muslims. We pray with each other, you know Arabians, British Muslims, Africans... Yeah so there is no difference, you know, you can see. This is good." (*Kheyre, M, Asylum Seeker/Refugee, Somalia*)

The same particularity was reported by those who attended churches that were not specifically African. Through these churches participants had developed considerable networks with Scottish people, and some stated that they would not have been able to make connections with Scottish people otherwise.

Whilst most of the sample described themselves as religious, it should be noted that there was a wide spectrum of levels of religiosity and enthusiasm for religious discourse. This was observed through participant observation in the religious group meetings. It appeared that some of the congregation took highly evangelical preaching very seriously, whereas others reacted in disbelieve or laughed at the tone. Whilst religion is apparently highly present in the lives of the African diaspora, it should be considered that religion might have a variety of meanings and influence.

Some, mainly younger participants, did not prioritise religion as an all-consuming aspect of identity.

> "I think just Africans go to church because they are just – they grew up knowing that you know, you just have to go to church. It's something you have to do. That's all, yeah." (*Cynthia, F, Student, Zimbabwe)*

As suggested by Cynthia, a few participants reflected on engaging with religious institutions, identities and networks by default rather than in a more meaningful way. Isaac went further and was the only participant to refute the idea that religion is important for Africans in Scotland.

> Researcher: Do you go to church regularly and stuff?
> Isaac: No, not regularly, but I do go yeah.
> Researcher: OK. And is that something from your family and things?
> Isaac: Yeah, it's a family thing, yeah. Most of them are Catholic.
> Researcher: And you know, kind of most Africans... do you think most African here are quite religious and things?
> Isaac: No... It's also a breakdown, you know... well, when they come over here... I don't know what happens. It's maybe they just tend to lose that religious bit... so I wouldn't expect them to be religious… You come over when you're young, there's not too much pressure on you from your family side... because over here there definitely is not that family factor. So there's no drive. (*Isaac, M, Student, Uganda*)

He suggested that if one is not engaged with religious activity, one is unlikely to have a religious identity.

4.3.5.1 Religion Related Social Networks

Religious networks were prominent in the sample, although there were also exceptions to this pattern. Those who did attend religious institutions were adamant about their centrality in social networks within and out with the diaspora.

> "I think it is [an important social aspect] though. I think like now if... people either meet in – the way I see it – people either meet in clubs or church. So, I think yeah, it is a social aspect some way for me. Most people they do meet when they go to church like, and like doing stuff. Like, but our church, you see loads of Africans." (*Cynthia, F, Student, Zimbabwe*)

Places of religious worship were referred to as "bedrock" for African communities and social networks by Theresa (F, *Economic Migrant, Nigeria*) which is a useful term in understanding the place of these religious institutions in the social networks of the diaspora. However, it was also emphasised that religious institutions were by no means the only settings for social networks, even among those who were very religious. Instead it was reported that these institutions were more likely to link individuals and networks, and often acted as gateways to other networks.

> "Well I think there's a church, a lot of us go to the same church, and I also guess it just happens naturally. You meet one person who introduces you to another person, and that sort of just goes on like that." *(Deborah, F, DR Congo, Student)*

4.3.6 Migrant status as part of identity: the unique position of refugees

Migrant status only appeared to have a significant influence on the identities of refugees. The only other group that mentioned migrant status were students, and this was in relation to whether or not they would return to their country of origin and their chances of gaining work visas after they graduated. Economic migrants did not deploy their migrant status as part of their identity in this research. For a few participants, there was a perceived separation between refugees and the rest of the diaspora.

> "Researcher: How do [the rest of the diaspora] think about Africans who have come here through the refugee system, is there any ideas about them?

> Fatima: No, it's just that, most of them come to a particular club. That's the only thing we know [laughs] so we brand this place as a refugee camp. Well they do... well it's just for a laugh. The thing is we tease a lot, don't mean we're taking it personal." (*Fatima, F, Student, Nigeria)*

Whilst Fatima was the only participant to display derisory views of refugees, the general sentiment of their distinctness from the rest of the diaspora was echoed by two others. For these three participants they were distinguished by the route through which they had come into the country.

It was difficult to gain insight into what extent migrant status had an effect on refugees' own identities through interviews alone. All were reluctant to go into detail about the process of seeking asylum or the effects it had on their lives and I did not want to dwell on this since it seemed to have caused them considerable trauma . However, participant observation at the asylum seeker and refugee drop-in centre suggested that this group's identities were dominated by their involvement in on-going asylum processes or the repercussions of having been through it. Their lives necessarily revolved around their interaction with the Home Office. People described to me that they existed in a state of limbo, waiting for their status to be determined and unable to continue with what they would consider to be a normal life. For example, they were not allowed to work or engage in education beyond learning English during the asylum seeking process. This could last for many years, with examples related to me of 10 years of waiting before refugee status was gained. There were some discussions by refugees and asylum seekers during participant observation concerning strong connections with their home countries. However, they had little space in which to enact their national identities, as will be explained in the subsequent section describing their social networks. Conversely, many made substantial efforts to avoid talking about where they were from or their previous circumstances, possibly due to trauma they had suffered in those environments. For the latter, there did not seem to be any interest in presenting or conserving a national identity.

4.3.6.1 Refugee Social Networks

The limited resources available to refugees were reflected in the nature of their social networks. Financial constraints created practical barriers to networking. For example, during my participant observation, I noted that the overwhelming majority could not afford to travel more than short distances unless given bus pass vouchers. Due to these resource constraints, refugees often reported considerable social isolation. The large majority also suggested that they were entirely dependent on charities, drop-in centres and other sympathetic organisations to facilitate the generation of social networks.

> "Yes, since I come here, I get friends now. The people who I can see on the drop-in, like I meet people integrating, integrate here, or sometimes some positive action." (*Souleymane, M, Refugee, Guinea*)

Another reason for the lack of opportunity to build social networks was geographical instability. People going through the asylum process are often forced to move to different accommodation at short notice and frequent intervals. This also meant that refugees were unwilling to invest in social networks as they might be moved on shortly.

> "Yeah, house now for this one. Yeah, there's a house here, you know, before, yeah very hard. Hard. My lawyer not talk to me, ok my lawyer is just talking after you go to him every day. My house before, I live today, tomorrow out. Just I am going. I can't stop OK? After two months, come again. Now I am going this building. I don't know what." (*Ruta, F, Refugee, Eritrea*)

Another distinctive aspect of refugees' situation was that engaging with country based networks could be problematic if they had escaped their home country to avoid political or religious persecution. Ruta (*F, Refugee, Eritrea*), when asked if she socialises with other Eritreans, became upset in the interview, and suggested that there were "Too much!" Eritreans in Scotland. When probed further during participant observation, she reported that she had left her

country under terrible circumstances, and was fearful of socialising with other Eritreans due to this trauma.

4.4 Summary

In this chapter I have demonstrated that wide levels of diversity concerning identity exist, and that previous strategies appealing to all Africans may not resonate with sub-groups of the diaspora. In some cases participants suggested that the identity of African, when applied by those external to the diaspora, has many negative connotations and may act as a barrier to potential engagement.

Alternatives to the African identity were explored, with nationality based and religious based identities having the most relevance. Accordingly these were also the social networks that were most commonly reported. However the values of these networks were often ambiguous and participants reported a diverse spectrum of meaning and influence from these identities and networks. Only the refugee quotient reported having a singularly dominant dimension of identity, that of their migrant status as refugees.

5 Chapter Five - The Nature and Function of African Affiliated Organisations

In this chapter I will describe a cross-section of different organisations that claim African affiliation in Scotland, and examine to what extent they might influence the healthcare engagement of their African users. This relates to the research question "What organisations claim to represent Africans in Scotland and in what way do they affect African migrants' access to health services?" I will explore whether organisations could have a role in future engagement.

Based on my interviews with representatives and users of three religious organisations, six advocacy groups, two integration networks, two commercial entities and one country association, I will describe reports of how organisations developed, with particular focus on how they tend to recruit new members. To explore their potential reach, I will then address who attended the various organisations and describe their levels of activity and functionality; i.e. the main activities they are involved in, with particular reference to connections to health services. Finally I will address the extent to which organisations engage with health services and could facilitate health-related behaviour of their attendees.

5.1 Origins of Organisations

Organisations developed in different ways depending primarily on the extent to which they had specific remits or access to funding.

Country Associations and Advocacy Groups were reported to develop organically, in most cases due to a lack of formalised funding, evolving from more informal social networks. The process by which this happened was described as vague, but dependent perhaps on reaching a threshold of acceptable numbers before attempts to formalise could be made.

> "Researcher: How did you develop this, the Malawian network then?

> Christopher: ...it's like our life was in a small area, like we didn't know a lot of, most of Malawians so it was for the first, well there was a day when I was in a shop, one of the shops with my wife, and anyway, I was talking then some other woman... and recognised, so it was, we met them and talked. So after that again they introduced us to other Malawians, and then from there now we started mobilising some of the Malawians. So at the moment I can say that's how we got to know the Malawians staying... We just meet as Malawians, we formally could be referred to as an association." (*Christopher, M, Malawi, Student)*

In general, what a "formal" Country Association consisted of varied for different participants. However, of those who did attend a formal association, a website, prescribed positions within the association such as chairs, treasurers etc. signified formality. Christopher and other participants spoke of seeking out new people to join the associations, and aspirations to have more regular meetings. According to those in the sample who were involved in country associations, there was a tendency for meetings to be infrequent, and country associations that met regularly were relatively rare. This was reported to be a contributing factor in the difficulty of Country Associations establishing themselves, and more importantly sustaining themselves over a long period of time.

Advocacy Group members and organisers had similar experiences, differing in that some had more specific agendas. For a minority of Advocacy Groups, their remit was decided by local authorities which then provided limited funding and hired workers to fulfil the objectives of the particular organisation. An example of this is Advocacy Group 4 based in Fife, which was developed to facilitate ethnic minority integration in the Fife area. More commonly however, Advocacy Groups developed due to a small group of people or particular individuals pushing to formalise an existing network of individuals.

The Integration Networks that I had contact with were formal in nature and had core funding. They were originally set up by Glasgow City Council in collaboration with the Scottish Refugee Council to increase reactive capacity for dealing with issues refugees might have as more arrived in Glasgow due to their dispersal from London.

Concerning religious groups, it was difficult for members to trace their origins, but a similar process took place; once numbers met a certain threshold, particular individuals felt they could set up a religiously affiliated group. Many Christian groups were affiliated with particular churches that already existed in Scotland, and some were reported to have been directly set up by religious groups in countries of origin by migrants subscribing to that particular sect. The Mosques at which large numbers of Africans attended were reported to already exist. There did not tend to be mosques dedicated to people from particular places, they catered to all Muslims regardless of country of origin.

African affiliated commercial entities were established in the same way as any other small business.

5.2 Recruitment into Organisations

For all of the organisations, word of mouth was exceptionally important in recruitment. This was particularly the case with the Advocacy Groups and Country Associations which relied on it almost completely. Several participants did report that Country Associations associated with a large refugee population (Sierra Leone and Somalia being two examples) sometimes had individuals referred to them by the Scottish Refugee Council and other refugee engagement groups, but this was unusual. More commonly recruitment was facilitated by word of mouth that someone from a particular country had arrived in a neighbourhood, the new recruits having some previous connection with a member of the association, or very occasionally through events like celebration of independence days. Advocacy Groups' users spoke of being told of the Advocacy Groups existence and being encouraged to engage with them by other members of the diaspora. I found that Advocacy Groups had very little in the way of searchable details or online presence when looking for potential participants for the study. Victor's experience was typical:

> "Researcher: And when you first came here, how did you sort of meet people, and how did you find out about [Advocacy Group] and so on?

> Victor: Yeah well, I've always… there's this, there was this African event, I can't remember the name, you know, this Black History or what do you call it, so there I met [a volunteer for the Advocacy Group] and we kept taking about the ethnic minority thing, and… I felt, OK, let me just participate in what they are doing. So I thought, it's interesting, it's going to be helpful to the community. That's why. I'm involved in it." (*Victor, M, Nigeria, Student*).

Recruitment at Integration Networks was done through word of mouth in many cases, as with the Advocacy Groups and Country Associations:

> "I don't know if it's kind of, friendship [is] the reason, it's hard to tell, I think it might be a lot to do with again, sort of word of mouth, so if someone from your community comes along, then, you know, you're more inclined to come as well." (*Representative, Integration Network 1)*

The representative here suggested that it was their "community" which carried the message of the Integration Network's availability. Although no participants mentioned it in interviews, from the participant observation I noted that often the Scottish Refugee Council, other asylum related charities or asylum case lawyers referred people to the Integration Networks, therefore they were not as reliant on word of mouth as the other types of organisations.

Recruitment was not a process that applied to the commercial organisations in the same way as the others, but it was still reported that they mainly engaged with the African diaspora and African customers through word of mouth.

The religious groups also cited word of mouth as their main method of recruitment. Religious Organisation 1's representative said that they had also distributed leaflets and were given referrals from other religious groups and churches, but he was unable to suggest how successful this was in comparison to word of mouth. All the users of Religious Organisation 1 cited word of mouth, with similar accounts to this:

> "I remember a certain Nigerian, who's also an African in a shop, he's a kind of guard in a shop. And he asked me whether I found a church, a black church. I'm sure that all Africans here they always want to assist other because they know that they can always be an identity crisis… So he directed me to this fellowship and I… went there, the next [week].That's how I found it. Just by word of mouth." (*Cedric, M, Student, Cameroon*).

There was a distinct geographical element; most of the word of mouth spread of information and facilitation of recruitment took place at particular sites. In some instances these sites were the organisations themselves, in other instances they were organised events, such as community events developed by the organisations. Other commercial venues beyond the two recruited into this study were also cited as important places for Africans to gather.

5.3 Types of migrants at various organisations

I wanted to understand if there were types of migrants that attended particular organisations to assess their potential reach. There were similar patterns across all the organisations, with all types of migrants reported to be in attendance. The only exceptions were the Integration Networks which were specifically directed at refugee populations in Glasgow. The proportionate numbers from each migrant category attending organisations depended on the nature of the local area demographics. For example Advocacy Group 6, based in a large town with a relatively large university, was reported to have mostly student users.

In contrast, two of the women's groups in the sample had similar remits and were both in similar areas of Glasgow, but had distinct attendees:

> "Representative: Most of the members are retired NHS workers…
> Researcher: Do you have representation of students and asylum seekers and refugees?
> Representative: Students, very few in our group, very few. Asylum seekers refugees… there were a very few." *(Representative, Advocacy Group 2, Women's Association)*

> "Because we work mainly with African women, so they left Africa for various reasons and then they come here. Most of them have sought asylum... No students really, no students, no... Word of mouth is more about other refugees or asylum seekers, no students. But I kind of saw maybe once... so if you see a number of like about 20 people, I think we have just two that are professionals, people that are really settled here. The rest of them is just really asylum seekers and refugees." (*Representative, Advocacy Group 1, Women's Association*).

Their differing sets of users suggests that assumptions cannot be made about who might be attending an organisation of a particular type without taking into account the local context and connections that organisations have with particular social networks and other organisations. The reasons for these different sets of users might be that Advocacy Group 1 takes referrals from the Scottish Refugee Council, whereas Advocacy Group 2 is based more on a network on individual acquaintances. As suggested in the last chapter, refugee participants tended to have more distinct social networks with other refugees, and therefore if no one from Advocacy Group 2 had connections with this group it would be unlikely that they would be recruited. This also demonstrates the potential influence that boundaries between social networks can have on the audience that a community organisation might be able to reach.

Given this evidence, caution should be applied in making assumptions on how broadly an individual organisation can be said to reach a diversity of diaspora members.

5.4 Levels of Activity

It is important to gain insight into organisations' levels of activity. By this I am referring to how active they are in the community, how often they meet and how often they hold events. Organisational activity levels could determine the extent to which they are useful facilitators for health engagement initiatives. Levels of activity reflected numbers of people engaging with organisations and also to what extent organisations had capacity for activity. Levels of activity

varied widely by organisation type, and were dependent on the organisations context.

The organisations that were the least active in the sample were the Country Associations. One issue identified by participants was the lack of consistency in Country Associations, which caused problems for their continuation.

> "Actually the problem we... you know, you meet like every week or every month, you know. Once we met, you know, when maybe we're having a meeting and maybe it's going to be about three months, six months, it depend on what happens... So when there is something happening, people, they got, you know, a text message, or a letter, that we have to have a meeting on that day or that month. So that's why people, when they got that message, they have to meet and talk, what is going on, then that is it. So that's why sometimes, you know, if something you have to plan for, kind of that." (*Kheyre, M, Somalia, Refugee)*.

The idea that these associations only met "when something happens" was reported by the majority in discussions of Country Associations.

The Advocacy Groups I engaged with had similar issues to that of Country Associations, with limited sustainability. The majority of groups I tried to contact through details on the internet or through other research participants or informants were no longer active. This was broadly reflected by reports from organisation representatives and users.

All of the Advocacy Groups in this sample had offices, apart from one of the women's groups, but only two had regular user meetings, on a monthly or weekly basis, and these were the women's groups. Therefore having the formality of an office did not necessarily indicate higher levels of regular timetabled activity. There was a tendency to only have meetings with users when there was an event of significance.

> "Researcher: And do you have kind of regular meetings and things, where everybody gets together?

> Representative: It depends, now, because what sort of activities we're doing – if we are doing activities
> Researcher: You don't have like a regular... so you just don't sort of meet on a regular basis?
> Representative: No." (*Representative, Advocacy Group 3, African wide)*

Integration Networks benefitted from having a specific remit, permanent accommodation and sustained funding, all of which were reported to support regular activity. Both that I visited had permanent offices and an abundance of regular weekly sessions (usually two a day), such as drop-ins, English language classes and other services dealing with issues around health, housing and employment. The networks were reported to be in a strong position to engage on a regular basis with users. Dedicated offices made a considerable difference, as they were able to offer a space for people in the local community to use, even without attending classes or specific activities.

Commercial entities were busy, according to their representatives, because they filled a gap in the market for African specific businesses. One business, the African restaurant, was very well established to the extent that its representative reported it to be an important hub of African social networks for the city of Glasgow, and this was confirmed by other participants. The other, an African Salon, was not as established but was reportedly still a busy social hub. It could be safely assumed that primarily African serving commercial entities would have regular contact with Africans as customers otherwise they wouldn't be viable.

The levels of activity of religious groups were connected to the levels of activity of the churches or mosques they were affiliated with. The two religious groups affiliated directly with churches both met on a weekly basis. They both had relatively secure accommodation in churches where they hired out rooms. However, as I attended several months of services at Religious group 1 during participant observation, and a few at religious group 2, I noted that their representatives exaggerated the numbers that attended. There were claims of regular congregations between 20 and 30, but the most I ever saw at either site was around 15. There were also interesting patterns in participants' attendance

in religious group 1, with people coming and going, and only approximately 10 core members attending every week.

5.4.1 Issues caused by lack of consistency

There was clear contrast between those organisations that did meet regularly and those that did not in terms of the social networks that were established, and the concurrent social support that they were able to provide. According to some organisation representatives, a lack of meetings meant that connections between group members did not have space to develop. Due to the limited funding that most of the organisations in my sample had access to, they were also dependent on voluntary contributions. Not being able to engage members regularly meant that it was very difficult to build momentum for local projects they were attempting to start. Another representative suggested that people would only attend the Advocacy Groups when they had a specific problem they wanted help with.

> "Yeah like, organise, that's like my, my threat [to the organisation]. Like, most people come here... they come just when they've got problems. And I think, that's the most big problem with the organisation, and stuff like that..." (*Representative, Advocacy Group 5, Ethnic Minority Wide*)

Lack of consistency was also identified by several participants as related to engagement fatigue and disenfranchisement. Here I asked one of the representatives if they would consider doing health work in the future:

> Representative: For a community organisation to go into very specific issues and such then, you know, there's a limit as to what capacity ...because ad-hocking it here and there, it doesn't really... if anything, I think it actually does more harm, you know, resources, structure in place, to have that continuity.
> Researcher: Do you think that people sort of get attached and then nothing really happens?

> Representative: That's when, now you have this kind of... disenfranchisement. "Oh, I don't care about" or "they're just coming in a different name, they're going to be around a day or so and then..." *(Representative, Advocacy Group 3, African wide)*

Fatigue and cynicism about efforts to engage with communities, develop more substantial community networks, hold events or advocate for communities was reported to increase the more inconsistent the attempts were. If some effort was made but it was perceived to be badly carried out or to be unsustainable, it would have a negative effect on similar efforts in the future.

> "That's what a lot of the diaspora are doing. So they're back, so they get involved in something and if it doesn't work out, they get burned or they don't like it or they fall out, then they just go back and say, "You know what, I'll just carry on with my life and just focus on my life. Why did I come here? And my family are far away and it's just me and my family." So yeah." (*Representative, Advocacy Group 5, African wide*)

Inconsistency was identified as making users feel disenfranchised from overall efforts to engage. Particularly illuminating is this representative's suggestion that temporary efforts result in people becoming more individualised and perhaps damages the will to engage in collective efforts. Both these reports stem from representatives from African wide Advocacy Groups, which might be due to the difficulties in trying to mobilise people based on a pan-African identity as discussed in the last chapter.

5.5 Functions of Organisations

In the following sections I have split the organisations' functions into three broad categories: social network formation and facilitation; forums for advice provision; and signposting and referral to other organisations. I will also describe the extent to which organisations directly engaged with health service providers. A major issue that arose was the lack of communication between organisations and their competition with each other.

5.5.1 Social Network Formation and Facilitation

All of the organisations' representatives apart from one (from Commercial Organisation 2, the salon) explicitly stated that building social networks was an organisational priority.

> R2: It's talking to, but it just understanding. It's, because I think it's just like... It's knowing that it's somebody from their own land and they can understand, and they can relate to it, and they can... I don't know. It's a cultural thing I think. They don't think they were being judged or being seen as you know [different]... Just that cultural aspect of "yes, I'm here, and I'm, these are my challenge I'm facing, but I'm going to strive, but let me tell you how I feel right now." And they just open up. (*Representative, Advocacy Group 5, African*)

Organisation users suggested that people in the organisation "understood" them in a way that perhaps people not familiar with their cultural nuances would not. This lead to users forming connections with each other and the organisations, and was a common theme in discussions of the organisations' facilitation of social networks. This could reflect the common perception in the sample that many Africans in Scotland face challenges of cultural misunderstanding and unfamiliarity. The majority of organisation representatives said their organisations provided an environment where African users were *not* seen as different, and a safe space in which people who might feel otherwise marginalised could feel part of a supported network.

Whilst all the organisation representatives claimed that social networks were facilitated within their groups, there was no evidence to monitor this. Some participants suggested a measure of the extent of social network development was whether or not connections made in the setting of the organisation continued outside it.

> "Loads of people like, that's just the hub for everyone to go to... so I think loads of people meet there and if you meet them outside you'll see people and talk to them..." (*Susan, F, Kenya, Student*).

Several participants across all types of organisations suggested they had developed close friendships through the organisations. There were exceptions:

> "No actually in most cases most of the people I tend to see I've normally meet them there [at the organisation]. And actually when we're out of the place we don't really go to like actually we don't go into each other's houses like we go here we go there. We would normally meet there." (*Christopher, M, Malawi, Student)*.

This description reflects much more site constrained networking. It is difficult to determine why this might be the case for some organisations and not for others, and there did not seem to be any particular pattern to occurrences of social networks being sustained outside the sites of organisations. Whilst all of the representatives reported social networking facilitation as an important function, and most of the organisation users were positive about the impact this had, it became clear that the extent of social network formation was highly variable. The extent to which participants were dependent on the various organisations for their social networking was variable. It was clear that those who were in a more vulnerable position, especially refugees, and those students and economic migrants who had recently arrived in Scotland, were more dependent on the organisations. Those who had been in Scotland for longer appeared to have wider social networks to draw upon and were therefore not as dependent on organisations for social networking.

5.5.2 Forums for, and providers of, advice

The most widely reported function of the organisations was as sources of advice and signposting. All representatives stated that their organisations provided this to varying extents. There were two forms of advice: on an individual one to one basis, which was more common; and in group sessions around particular topics.

Mostly advice giving was reactive, with individual issues being dealt with as they arose.

> "We have a free way of engagement. So we have individuals where people walk through the door or pick up the phone and phone us and say "I have

> this problem, what can I do about it?" (*Representative, Advocacy Group 4, African).*

Representatives suggested that their organisations would be the first port of call for many individuals in the diaspora. It was suggested that an African affiliated organisation would have better understandings of the experiences of African migrants. This support was thought to be pivotal to some individuals in the diaspora:

> "They have to go home now, and they could say, "I'm going out of this office back into this world where I'm on my own again until I come back to the [organisation] and then the barrier gets down and I can just be myself. And the confidence that they gain for some people is incredible to see after a few weeks, how they just like "thank you so much, that really helped, just coming to chat." *(Representative, Advocacy Group 5, African)*

For some organisations advice might not be the specific reason for engagement but was a by-product of relationships already built in other ways.

> Researcher: Is it more about advice giving?
> Representative:I mean the advice giving just happens organically I guess... I mean you know, the kind of focus has always been, come along, meet other folk, chat and do some activities and get a meal." (*Representative, Integration Network 1*)

This was reported to be a natural by-product of the development of informal networks of support and relationships of trust between attendees and others at the organisations. Organisation representatives were keen to promote these networks of support and increase the capacity of their organisations to do this.

As well as giving advice, people at organisations referred people on to other services where appropriate. This ranged from sharing informal experience in the Country Associations, to more formalised direct referrals to other services from the Integration Networks and some of the Advocacy Groups where service

provision staff were contacted directly on behalf of those being referred. It was suggested that members of the diaspora were more comfortable approaching the African affiliated organisations than other Scottish organisations. This was due to relationships of trust they had with organisations and assumptions that as African organisations, they understood the needs of Africans substantially better than Scottish organisations:

> "I mean, we have to signpost and this is the thing, you had to signpost but sometimes even though you're signposting people will still come and talk anyway. Even though you're signposting so you've... it was quite... you heard a lot of stuff. You heard a lot of stuff. I mean, because they are more comfortable talking to me than they were talking even maybe to the counsellor. So this is something again that the [organisation], it's almost like you need diaspora people to be counsellors... If people in the diaspora were employed to be, you know, counsellors or whatever, it would probably help more." (*Representative, Advocacy Group 3, African*).

As this representative suggests, the African affiliation seems to override the appropriateness of the organisation for the particular issue at hand.

Organisations also ran specific group workshops, for example a Country Association's work around youth education:

> "There is a useful project we are running right now, which is making use for young generations, meeting chatting to them, explaining the difficulties they have education wise, to give them the level of education. Because a lot of people in our community, especially the middle-aged, they don't have the level of the education, and they are still adopting the old system some of them had back at home. Some of the people may still feel shy to go to college. They can go to college and learn. So that's what we are preparing for the younger generation." (*Representative, Country Association 1*)

Others would have guest speakers to talk about specific issues, particularly in the Religious Organisations and the Integration Networks, perhaps because they were able to guarantee that a sufficient number of people would attend talks:

> "We have some educational and enlightenment programmes. So that even though they are not exposed to them in the way they are working, they can learn from the time in the fellowship... so there are some times when we have speakers." (*Representative, Religious Organisation 1*)

However, health related advice was more commonly reported to be provided on a one-to-one basis. Some of the organisation representatives suggested that health was a more personal topic, and this affected the way health issues were dealt with in these organisations.

> Researcher: I mean, do people seek health advice or anything?
> Representative: No. I mean that people can talk personally to each other, but apart from that there is nothing really. They can ask for some help, and someone else in the group may refer them to the health centre or something. But the other... what the [organisation] can do is more of an educational, informative, what is happening, what is available... health issues... we have the confidence of the person... it is not an open forum. (*Representative, Religious Organisation 1*)

This was a typical response from organisation representatives concerning health issues. Whilst many representatives said their organisations would be appropriate arenas for discussing health issues, they often emphasised this dimension of privacy. However, this was not the case for all organisations. Some of the Advocacy Groups and the Integration Networks were better equipped to be able to tackle health issues. This may have been due to the fact that they had dedicated staff who could be trained for this. However, public health discussions were still very abstract in nature, and there were no reports of public sessions around particularly sensitive topics, for example sexual health.

5.5.3 Direct engagement in partnership with health services

There was some evidence of partnership work with health service providers, with representatives of both the Integration Networks, one of the religious groups and two of the Advocacy Groups stating they had worked with NHS staff. However, partnerships varied and none of the representatives reported a sustained, long term and regular partnership with any health service providers. Whilst this perhaps reflects the limited resources of the organisations, it could also be indicative of a lack of local NHS capacity to engage with third sector organisations.

> "[We were involved with] a kind of minority ethnic inclusion group from the NHS. You know, so they were like, "if people have health problems they can you know have access to the NHS through them." So you know I kind, I was able to link to that... I can't remember what it's called though." (*Representative, Religious Organisation 2*)

This account was typical, in that direct interaction with the NHS did not seem regular enough to be a substantial part of the activities of the organisation. The only organisations that had regular activities of this type were those that had a more permanent base, and that had regular meetings, or a drop-in centre. The most active in this regard were the Integration Networks which clearly had more resources than other organisations and were able to run health-related sessions with outside speakers. This could also reflect the aims of the different organisations and the extent to which health issues were decided to be in their remits.

> "So I'm running a men's health group [at the Integration Network] so we're on different programme sessions yes, every Friday. Sometime I contact the NHS, it depend on the subject to know, for example diabetes. Sometime the NHS workers come to us to talk about various problems." (*Representative, Integration Network 2*)

Representatives from groups that did not have regular health related sessions expressed substantial interest in doing so. For example, the representative from Advocacy Group 2, one of the women's associations, suggested, "we wanted to

talk about, we wanted to bring in like a midwife to talk about pregnancy or talk about how you look after your child." Other representatives also talked about wanting to increase engagement with external health promotion professionals.

> Representative: Like even collaboration with say, OK, let's organise a programme to talk to people about infertility, talk to them about high blood pressure. You know, then people will be like, "oh, that's why I'm here, you know to talk about high blood pressure, that's why I'm here." You know, when I was in Africa, I would go to different churches and I would talk to them about infertility, the whole place would be packed. They want to hear you know, about the medical condition, because some people have these medical conditions even though they don't know what to do, they are scared to go to the healthcare system. But if you have that kind of relationship, you know with the NHS organising programmes, and collaboration with the churches... then I think that could help.
>
> Researcher: Do you think that's something most churches would welcome? That kind of interaction?
>
> Representative: Yeah I think so. But it would depend on you know, the church, and the theology, and all that. (*Representative, Religious Organisation 2*)

One of the reasons that people were "scared to go to the healthcare system" could be that they perceived it to be very different from those in Africa. Participants reported that for some individuals, particularly when recently arrived in the UK, this unknown factor was enough to stop people using services altogether. Another reason was that potential service users might be worried about substantial healthcare costs as per the models of care in their countries of origin. As such, the organisations had an important role in dispelling the initial myths that would act as a barrier to service use.

All organisation representatives thought that their users would be keen to receive future health related initiatives from their organisations. This would be contingent on a variety of issues however, not least the capacity of the

organisations to be able to host activities, and the extent to which the local health services might be able to provide someone to meet their specific needs. It would appear that the Integration Networks and some of the more established Advocacy Groups are well placed to develop these partnerships but that other organisations would probably require substantial support from local service providers.

5.5.4 Lack of Intercommunication and Territoriality

One of the most significant barriers to engagement with the diaspora reported by the organisations representatives was a lack of cooperation between organisations.

> "It's not, it's not, it's probably not generalisation because I could say that while I was, when I was Chairing the [Advocacy Group 5, African advocacy], yes it was challenging and I can honestly say we are all now, we are our own worst enemies because it was difficult, you know, [our Advocacy Group] is an umbrella and I was trying to convince Country Association s, some of them, I said to them, come on board, you know, our own constitution states who we are, we're an umbrella organisation, we are not trying to take on your role. You, I mean if you're from Zambia or from Tanzania or from Mozambique or wherever you understand your country better than I will. But the difference, the different, and I can understand you wanting to connect with your fellow countrymen, that's okay. But when we're talking about the overall coming together for, you know, speaking in one voice you have to come in, you can't just all be able to do this outside." (*Representative, Advocacy Group 5, African Advocacy)*

Other representatives (one from a Country Association, two from Religious Organisations and two from other Advocacy Groups) suggested similar scenarios where various organisations were territorial in their approach and cited poor, or non-existent, communication between community groups. This perhaps reflected the lack of overarching unity within the diaspora in general.

This kind of territoriality was also mentioned to be an issue by a representative from a religious group.

> "Representative: We've attempted to associate... the feeling I get is most of the other churches don't want to associate with... Yeah because you know there's even some churches you know, I don't want to mention names, you know that are some churches, and they have different branches, and you know, some of the branch members would say that, "oh a member of that branch..." you know, will not want to associate with another branch.
> Researcher: Even within the same church?
> Representative: Yes even within the one church, you know, so it's all a case of you know, so those are some of the challenges." (*Representative, Religious Organisation 2)*.

Lack of cooperation between organisations manifested negatively in various ways. The most substantial negative for organisation representatives was not being able to pool their resources (both in terms of people and funding) to develop more substantial initiatives to promote the position Africans in Scotland.

5.6 Summary

This chapter explored the nature and functionality of African affiliated organisations. There are a wide range of organisations claiming to represent Africans in Scotland. The data suggests that there are high levels of diversity amongst organisations even of the same type and local contexts. Their diversity is driven by a number of aspects, including the individuals who are attending and running the organisations, the stage of development and formalisation of the organisation and the local demographic landscape. Their abilities to reach the diaspora and take develop programmes of activity were dependent on the extent of their regular funding, how regularly active they were, consistency of attendance and whether or not they had permanent accommodation and staff.

In terms of impact of African migrants access to healthcare, most organisations provided only informal one to one advice on health issues and their capacity to work with health service providers was limited. Some organisations, if they had the capacity to do so and a suitable remit (some advocacy groups, religious groups and all the integration networks) had attempted public health engagement type initiatives, some in collaboration with the NHS. However, these were reported to be relatively rare, and there were no examples of sustained activity of this type in the sample. Capacity to develop these types of health programmes was determined again, by regularity of activity and attendance levels, funding and permanent staff and accommodation. Whilst the representatives were keen to work with service providers, it is clear that their organisations abilities to do so vary. As such, the nuances of organisations should be understood in detail before they are collaborated with especially their sustainability, available resources and reach in the diaspora.

6 Chapter Six - Engagement with health services and Understandings of health

6.1 Introduction

Approaches to and experiences of general health service provide a useful contextual framework in which to understand the nature of, and barriers to, HIV related engagement behaviours. Some of the issues that participants had, and also aspects of healthcare use that they were positive about, can provide a foundation of learning for how to encourage HIV related service use. This chapter focuses on participants' experiences of general health services. Experiences and understandings of HIV specific service use will be covered in Chapters Seven and Eight.

The majority of people in Scotland report positive use of health services (Scottish Government, 2015b). However, only 72% said they felt positive about being able to access a General Practitioner (GP) when they needed to (Scottish Government, 2015b). The majority in the Scottish Health Survey were positive about actual treatment received at GP practices but one third wanted more influence on decision making processes concerning their healthcare (Scottish Government, 2015b). The majority of my participants were satisfied with their experiences with healthcare in Scotland. There were exceptions to this, however, and these will be examined in detail.

A number of participants (12 of 27) did not report use of healthcare services in Scotland beyond GP registration. While this was sometimes contradicted during participant observation by accounts of extensive service use, most participants reported that they would go to the GP, and were unwilling or unable to provide further detail when I asked them about the nature of their interactions. Mostly they gave statements analogous to "everything was fine". Positive experiences were often framed as "nothing went wrong" making it difficult to explore these instances further. In this chapter I will focus on participants who were able to describe first-hand, and often problematic, experiences in more detail.

6.2 Participant understanding of health service use

When I asked participants where they would go if they were ill, the large majority reported they would go to the GP (24 of the 27). Those that did not were two refugees and one very recently arrived student in Scotland who had not yet registered with a GP and was dependent on his university health clinic. On the other hand, some of the organisation representatives reported that the need to register with a GP was not something African migrants were familiar with, especially those who had recently arrived in the country:

> "Even to know where to go and get stuff from for what, for doctors. For example, most countries, surgery is just something different. And then if you say, like, you're going to a doctor's, it's something different. And they don't know where they need to register to... to go for healthcare even, like – like, I come from Africa, you don't need to register. You just need to go to any healthcare doctor you want. And then pay for your money and come out. So we decided... we did like a survey, to see what [Africans] are suffering from here. So the main thing, the first thing they say, like, they are suffering to know where to go and register for doctors, to know where the hospitals are." (*Representative, Advocacy Group 4, Ethnic Minority Advocacy)*

This advocacy group was based in a town outside Glasgow, and its representative stated there were far fewer visible services than in Glasgow. However, lack of knowledge among newly arrived migrants was reported to be common in Edinburgh and Glasgow as well.

> "I knew because I had my brothers and sisters that had been in the country for ten years or so, so with that experience I knew exactly what to do, you know. But for somebody who just arrived here and knowing the system back in Africa where it is very different… some of the problems are knowing where to go." (*Representative, Advocacy Group 1, Women's Association)*

This lack of knowledge was explained exclusively by the contrast between the UK and African healthcare systems. It was identified to be a particular issue for

those who came from countries such as Eritrea or Somalia where there is little in the way of a formal healthcare system. This lack of previous experience with systematic healthcare provision meant that these participants were particularly lacking in knowledge resources to guide adaptation to the UK healthcare system. It could also be the case that rather than a lack of knowledge about where to attend or the processes involved, this may reflect a lack of confidence as a barrier to services use.

6.2.1 Asylum Seeker and Refugee eligibility for care

An issue specific to refugees concerned lack of knowledge about the legal entitlement to care.

> "I know that healthcare is very very difficult access here especially when they are at that stage because a lot of doctors think that because they are asylum seekers, they've got no entitlement to healthcare, so they can't register and things like that. So those are difficult." (*Representative, Advocacy Group 2, Woman's Association*)

Although none of the refugees reported direct experiences of being denied access to healthcare, the above perception was common among all my participants, refugee or otherwise. Some thought that there was a risk that if you were perceived to be a refugee you might be refused care or even deported.

> "Some people have been telling that "sometimes if you are sick and you don't have a paper [visa documentation] and even if you are admitted to hospital they can take you away. I used to think that the same thing would happen to me… If you don't have permission to live here and you are sick, if the doctor sees or the nurses or whoever… they can take you from here and they can deport you. I've been hearing rumours…" (*Alain, M, Refugee, DR Congo*)

Again, the rumour that this might be happening was potent enough to reportedly cause people to not attend health services. This had a broader effect because participants (students, for example) had what they considered to be precarious visa statuses here in the UK. It also contributed to an overall perception that

health services could be a site of hostility towards Africans. This was regardless of the fact that no one in the sample knew directly of any incidents where this had happened.

6.3 Influences on health services use

In this section I will discuss two influences on health service use that were reported by participants to be of particular importance in the diaspora. The first is “folk” understandings of health, and the second is the influence of religious understandings.

6.3.1 “Folk” understandings of health

“Folk” understandings of health (that is non-professional healing specialists in the countries of origin, which are largely distinct from mainstream biomedical approaches of Scottish healthcare) were discussed by a small minority of participants (5 of 27). This approach was reported to be a potent influence on the diaspora, especially on those who had come from countries in which there was a lack of a formal healthcare system, for example Somalia, Eritrea, and Sierra Leone.

> “Filsan: Somalia... we have no hospital, and I don’t know it... yes.
> Researcher: Ok, so in Somalia, was it just chemists? A pharmacy? Did you go to the doctors?
> Filsan: Somalia I come from an island. I went to no hospital... There is no hospital, no police, no everything. If you have, maybe you have a headache maybe, or you have got a stomach pain – stomach pain you take water, and two different leaf with some salt, then you mix... maybe you eat garlic, it’s ok, maybe headache, you feel sick, and you take some leafs, then you... make a cold maybe.” (*Filsan, F, Refugee, Somalia)*

For these participants, prescriptions, appointments and other taken for granted aspects of the Scottish Healthcare system were completely new. In addition to this many of the assumptions that are inherent in the Scottish system, for example the trust that the majority of individuals have in their doctors (Scottish Government, 2015b), might not be applicable. There were issues concerning the

effect that “folk” influences had on the understandings of the treatment that people were receiving.

> “So if let’s say this, we came from a different system, you know, where it was, you know, if you feel sick, you know, you have to get a... the medicine... the medicine that we use is from the trees, you know? Either the leaf, you can boil it and you drink the, you know, the water. Or boiled roots, know? Or the fruit of the trees, you know, can be a tablet. It depends what the problem you have. So... but, you know, and when we eat it, then we become better. So, but we came in... you know, in, developed country that, you know, this tablet treat you know this kind of disease, this kind of disease. Then, for me, I don't have that knowledge and, you know, I'm not educated with kind of, you know, medicine or some kind of that. Then you give me the wrong tablet so it means I don't know if you... what do you mean? You want to damage my body or whatever? Tell me. I said “oh, how if I don't know even to read the instruction.” So it meant that if I don't know how to read the instruction, I have to eat that. If I'm going to eat... instead of to treat the problem, I'm going to cause another problem.” (*Kheyre, M, Refugee, Somalia*)

Kheyre illustrated that particular assumed knowledge around norms of interaction could be particularly challenging for individuals who are not familiar with a formal healthcare system. For example he found it difficult to reconcile “folk” knowledge with a pharmaceutical approach and felt helpless when he was given a pill by a doctor. This was typical of the way that participants who referred to a folk model of health felt about the system in the UK. Whilst it was also apparent participants were able to adapt to the UK system, they seemed to have to make leaps of faith that made them uncomfortable, concerning the care that they were getting. This was particularly the case if, as Kheyre above suggests, their ability to communicate in English was low, generating more instances of potential misunderstanding. In the absence of familiarity with pharmaceutical treatments, Kheyre had to trust the healthcare worker. Whilst this is something all healthcare users must do, Kheyre, and a few others in the sample, had arguably less background knowledge and experience on which to base that trust, which caused them to feel more unsure of their courses of

treatment. This was also a factor of the context in which these participants existed, and it was a particular group in the sample which experienced this anxiety around healthcare. They tended to be those from aforementioned countries with a lack of formal healthcare systems, those who were lacking in language skills and those who were in an already marginalised position, i.e. refugees.

6.3.2 Religious influences on understandings of health and service use

Religious understandings of health were those that were promoted by religious institutions and as in the "folk" understandings were reported to be distinct from the mainstream biomedical approach. Some participants said they sought complementary healing through prayer. However, one of the representatives (a minister from a religious group 2) reported that there were some institutions in Scotland that promoted a more evangelical approach to health.

> "Some churches may feel, look at NHS as a kind of... rival or something, you know... or competitor or something like that. Yeah. The belief system, healing, yeah yeah, but it is a very very strong one, yes, you know if you have faith you can be healed, you don't need to go to hospital, you don't need to you know, go to the doctor and all that." (*Representative, Religious Organisation 2*)

The representative went on to suggest that whilst rare, there were enough of these institutions in Scotland to cause him concern. Several participants (particularly those recruited from the religious organisations) identified people (friends of friends etc.) who took this approach. However, there were no suggestions that healing through prayer was a competitor to "professional" medical approaches for any participants. It should also be noted that participants suggested that the majority of religious figure heads and those subscribing to religious beliefs in the diaspora were likely to hold values that were not mutually exclusive with mainstream healthcare service use.

Advice seeking and support from religious institutions and leaders was common across all migrant categories.

> "There are some people in the church that has problems, and even though they may be taking medication from the medical field was not really so effective, but when they hear words of encouragement, you know, under the power of the Holy Spirit, you know, many of them are able to feel better, you know?" (*Representative, Religious Organisation 1)*

It could be the case that religious leaders are approached not because of peoples' beliefs in religious healing but because they are trusted figures in their lives. For religious organisation representatives, a perspective of spiritual understanding, such as support from God, was a central characteristic of their advice giving, but it cannot be assumed that people who approached them were seeking this specific form of religious based advice.

It is also important to note that neither folk nor religious sources were reported to be the sole influences on participants' understandings of health, but they were described to be particularly strong in the African diaspora in comparison to the rest of the population in Scotland.

6.4 Experiences of health services in Scotland

As noted at the start of the chapter, most participants had positive experiences of health services. Just six participants had mainly negative experiences and all related their overall negative experiences to perceived discriminatory treatment due to their African origin and seemed disenfranchised as a result. . Other participants had minor negative experiences which did not affect their overall positive perception of health services, or had heard of such negative experiences through their social networks. It was the latter that participants tended to discuss with me.

6.4.1 Positive experiences of health services

The regularity and dependability of the health service were seen to be its main positive features. For example, Souleymane, a refugee from Guinea, had complex, long-term health issues and was very satisfied with his treatment.

> "Yes every time they give me, when they check me from. Every time I come with medical case a report they give me, every time I need new one, prescription, a report they give me. I pick up this type medicine." (*Souleymane, F, Refugee, Guinea*)

Souleymane had been in Scotland for six years and although educated, his English was weak, and he had been destitute (homeless and without any income or support from any agencies) for some time. However, he reported that he had never had any problems with the NHS management of his health conditions, and he had engaged with the health services here shortly after his arrival. Whilst his was just one account, he was one of the most vulnerable individuals in the sample, who on paper might be predicted to have issues with service use. The dependability of the services was something he valued very highly, as did others in a vulnerable position.

All of the participants were aware of the right of access to healthcare in Scotland.

> "In terms of health, from our own experience, we have not seen a general disparity... Like we are free to register in the health centre. Going on own personal experience, we are treated. You can go to the doctor with no problems... I feel the health service, the doctors are receptive to everybody, whether you're black or you're white, you enjoy the free health that is available to everybody. Yes..." (*Representative, Religious Organisation 1*)

No one in this sample had been denied access to health care, or even heard of people being denied access. Free access for everyone was seen to be in marked contrast with health services in participants' countries of origins, and a significant advantage of healthcare in Scotland. Like regularity and dependability, free access was one of the most appreciated benefits of the Scottish system.

6.4.2 Negative experiences

Those who had negative experiences came from all groups in the sample, were of all ages, migratory categories, and educational and economic background. Some had recently arrived, but others had been in the UK for over 10 years. This section will look at some of the barriers that particular participants met that were acknowledged to have an adverse effect on their future willingness to engage with the health services. The perceptions described below mostly relate to how participants thought they were perceived and treated by healthcare workers. Some participants complained about the lack of weekend hours or the shortness of GP appointments. However, these are probably issues that patients of all backgrounds experience. Here, I highlight issues that participants suggested were particular to African migrants.

Some participants perceived there to be a lack of understanding of African specific health issues among health practitioners in the UK. Emmanuel thought that Scottish doctors were not as well equipped to deal with African specific issues as English doctors who had more interaction with African patients.

> "When I went to see my friend in... down in England, he said, "it's because they [Scottish Doctors] do not understand." The doctors up north do not understand, as the doctors down south. Why? Because [they] have limited interactions with Africans here, and they also don't study that." (*Emmanuel, M, Economic Migrant, Nigeria*)

Some who decried lack of knowledge by healthcare workers had this perspective, and for them it was a natural state of affairs. Others however, felt that doctors should know more about Africans, and suggested that a lack of knowledge was connected to negative perspectives of Africans by healthcare staff. Even some of the participants who had been satisfied with their healthcare experience suggested that there was a lack of understanding of African health among staff here. As well as references to a lack of understanding about the general "health" of Africans, there were specific examples reported by participants, including: inabilities of health workers to find veins in dark skin; lack of knowledge concerning malaria; and lack of understanding of sickle cell anaemia. Whilst knowledge of these issues were not deemed critical by

participants, they were used as indicators of a wider lack of knowledge. For those who had experienced any of this, it appeared to have a substantial effect on their overall perceptions of the healthcare services, eroding the confidence that participants had about the health service being able to meet their needs.

A few participants also talked about health workers being unaware of, or lacking sympathy for, participants' cultural values and contexts.

> "I have seen a doctor, he is saying to a female patient, you are not cooperating. He asked her some very sensitive personal information, she not want to answer that. He says are you circumcised when you are young? A young girl does not want to talk about these things. So they have to understand the issues of our culture. We want to integrate, but at the same time there are some sensitive issues which we are different for." (*Representative, Integration Network 1*)

Whilst such sensitivity around sexual health or other personal issues is not solely an issue for African migrants, several participants suggest that it was *more* of an issue for them, as they held strong beliefs on what it would and would not be appropriate to talk about. This was particularly the case when dealing with healthcare workers of the opposite sex. One of the main examples of cultural insensitivity was healthcare workers not making allowances for the time it might take for Africans to adjust to Scottish culture, i.e. become more closely aligned with the norms of patient-doctor relationships that Scottish people might have. Some participants felt they were expected to "get over" their cultural norms concerning healthcare, or they would be deemed, as above, to be "not cooperative". Cultural norms were described as who it might be appropriate to talk to, what topics were more sensitive than others, what level of detail patients were willing to give about conditions, norms around physical touching between patient and doctors during examinations and many other examples. The few participants who mentioned this cultural insensitivity suggested it would dissuade them from future service use.

Most of the issues around cultural insensitivity were reported by refugee participants. This is perhaps because they came predominantly from countries where there was less health infrastructure (e.g. Somalia, Sierra Leone, Eritrea).

They also thought that their experiences as refugees were sometimes not sufficiently taken into account by healthcare staff.

> "The issue... was the lack of understanding of the difficulties and the needs of people who is coming from sub-Saharan Africa. I remember one situation in the hospital. There was a doctor, he says to the patient, "did you come for the weather?" and the lady says, what did he say, and it's always difficult to translate. I translate to the lady and she says this is not the question I expect from the doctor, this is the question I expect from the immigration officer. So there is a big problem... we wish sometimes that the doctors have more training, to deal with people that come from violence, from difficulties, to be more understanding of the needs. From rape, people who saw death at their home. The way they speak to the patients, how do you deal with the woman who come from the civil war, her family has been killed, she has been raped. You must have some respect some careful words." (*Representative, Country Association 1*).

Participants' dealings with the Home Office had an effect on their interactions with official figures of other sorts, including doctors. This is apparent from the example above where the patient felt the doctor was interrogating her in a similar manner to an immigration official. Refugee participants reported feeling as though they were always being tested by officials, including doctors, and that they felt insecure, due to the fear and stress created by dealings with the Home Office. In combination with the extreme physical and psychological trauma that many had endured, and potential lack of empathy concerning these circumstances, interactions with health care providers appeared fraught with risk of further distress.

For some participants, perceptions that Scottish doctors lacked understanding of African medical and cultural issues manifested as distrust of those doctors and their motivations. This in turn was a substantial barrier to service use.

> "Because I had a problem with my stomach all the time, and then when I phoned back I [contacted] about three others [doctors], when my stomach was killing me, phoned back home [Africa] and the doctor told me actually, he'd send me some tablets from there. But here if you go

> here, they can't [help you], they say, maybe you're stressed, maybe this a,b,c,d. So they don't help you so much. (*Representative, Advocacy Group 5, Ethnic Minority Advocacy*)

This particular issue is indicative of differing expectations of treatment, with this representative clearly wanting medication and not being offered it. But it is also illustrative of a broader mistrust of Scottish doctors, as this experience became formative of his perspective that Scottish doctors were not willing to help. This participant mistrusted the doctor's advice to the extent that he contacted a doctor in his country of origin. Another participant checked whether a particular medication was suitable with an African friend who was studying nursing. The friend advised him not to take it and he subsequently lied to the GP saying he had taken the tablet but it had not been effective. His GP then gave him different medication. Several participants reported they would be more likely to trust an African doctor than a white one:

> "If I get told by an African doctor, yes maybe I will have reception... So if he told me, if he says anything… easily I'll believe him, because… he is African." (*Emmanuel, M, Economic migrant, Nigeria*).

Kodzo, an African GP, had specific explanations of this mistrust.

> "Researcher: You talked a bit about mistrust, do you have any opinions where that mistrust might be generated from?
> Kodzo: Oh I can pinpoint specifically... oh I don't know where it stems from, but here is a general mistrust of the... I would say white people. Generally there is because they always feel a bit marginalised, look down upon. They're not too sure whether what they are saying is for their best interest or they just want to take advantage of them. So they don't tend to want to entrust their health to someone they don't really trust.
> Researcher: Is that something that's quite, that's quite widespread do you think, amongst that group?
> Kodzo: Yeah yeah, I think so, because as a GP, some, a lot of those people are your friends, so you'll get phone calls and they will tell you about their medication problem and you will tell them, "oh go and see your GP", they say, "oh can't you help me?" and I'll say, "well OK, go and see

> your GP and tell them this is what you think is wrong with you". And then they will, you know, so they would rather seek advice from a fellow African. So then go they go round asking medical advice, and someone say "oh I know an African GP Kodzo" so then, they give them a call first." (*Kodzo, M, Economic Migrant, Ghana*)

This revealing exchange from Kodzo might just be one individual's experience, but as a GP he was in a unique position to comment. This distrust is most likely connected to the perception that Africans are not well understood by Scottish doctors. As Kodzo highlighted, this, in combination with the fact that Africans in Scotland can feel marginalised and "looked down upon" by the majority society, could combine to develop this mistrust.

Mental health vulnerability among the refugee participants was highlighted as a particular area where understandings were perceived to be lacking.

> "Especially we asylum, you know, we've got a lot of things in our head, you know? Stress, you know, fear, worried, you know? Then we did try to get better then we've got side-effects, we're getting crazy, you know? Getting crazy, that's right, we're getting mad you know..." (*Kheyre, M, Refugee, Somalia*)

All ten refugee participants thought they had mental health issues. This was disclosed either during the interviews or the participant observation, and none had been referred to mental health services, despite some specifically seeking these. It might be the case that the general population also does not have sufficient levels of access to mental health services, but it is illustrative of a disproportionate inequality that all ten of the refugee participants, all of whom said that they requested services, did not receive referral.

Stress was highlighted as being a particular issue.

> "After I came here this country, too much is stress, stress. And I think stress from Home Office is too much with the interview refuse. I called more than three times, I got called in for Home Office, it was too much. Yes, too much. If I want to sleep, -no sleep. If I want to eat – I can't,

> because too much is stress. Yes. I remember in my country, I have children there, I don't know much of them's alive or not. It too much stress." (*Filsan, F, Refugee, Somalia*)

It was also clear that many participants in this group would rather not engage with doctors because they felt that their mental health concerns were dismissed.

> "To, for GP, to ask for GP is a problem, because when you need to go to GP before you need to ask appointment. If you have appointment, they give you appointment for health. You can't ask a lot of things, "I come to ask this," no. If they ask you, "you don't have problem for health?" "I don't have." So if you say you don't have, finish." (*Aaban, M, Refugee, Rwanda)*

This might be illustrative of Aaban's lack of understanding of how to communicate a mental health issue, as he did not equate stress with being a health problem, so perhaps only saw physical ailments as being related to his concept of "health". However, Aaban reported that if he did not present with a physical condition he was repeatedly sent away from the appointment without referral for further health care, for example mental health support. Aaban did report that he had said to the doctor he had been suffering from mental health issues. Further discussion with Aaban after the interview revealed that he may have had considerable mental health issues that were affecting his quality of life.

Other refugee participants felt that even their physical health concerns were unfairly dismissed. For example, several had chronic, recurring, tension and stress related headaches, and felt they had been given little attention beyond prescriptions of rotating over-the-counter pain killers.

> I've got headache, I went to the GP more than four times... and GP he give me same medicine four times... paracetamol and ibuprofen... and I ask him, "this medicine, this is no help". Still he give me paracetamol and ibuprofen." (*Filsan, F, Refugee, Somalia*)

These participants felt that GPs were not "understanding why I'm suffering... to check properly like [people from] other countries" (*Alain, M, Refugee, DRC*). This perception was suggested to be a consequence of their African background or because they were refugees. This perpetuated what was already felt to be a hostile environment (due to their perception of negative media portrayals of refugees, other experiences of prejudice, and/or hostile treatment by the Home Office). The participants who were willing to discuss these experiences (4 of 10) suggested they had lost hope that their doctors could, or more importantly, wanted to help them.

1.1.1 Perceived discrimination in the healthcare setting

Six participants (from all three migrant groups and a range of educational backgrounds) reported being explicitly discriminated against in healthcare settings because of their African background. All qualified this as unusual. Discussions around discrimination were complex, and often participants questioned their own accounts of whether or not they were discriminated against. However, they were reported to have a strong negative effect on their willingness to use health services.

In one incident, a participant was treated badly by reception staff at a GP clinic whilst seeking healthcare for her visiting mother. The incident culminated with one of the reception staff hanging up on her when she challenged their dismissive attitude.

> "But for you to see the doctors you have to pass through these first gatekeepers and when you get them wrong, when they are nasty people, when they are not so well informed . They were very rude. In fact, when I was speaking to the GP, I said, "is it because of my skin colour?" That this receptionist would not hang the phone [up] on a Scottish person or a white person on the phone. So that [hanging up] means, you can die. So the lady said "no, no, no, she doesn't think so, that they have people who are not all white, staff who are working there."... I am not happy with that." (*Joy, F, Economic Migrant, Nigeria*).

Joy was like all of those who had experienced discrimination. Their perceptions of the health service were dominated by these negative experiences, even though they readily admitted that these incidents were unusual.

Another participant, Stella (*F, Economic Migrant, Nigeria*), felt that she was severely patronised when she went to have a blood test because of her African background.

> "She talked to me as if I was a child. I cried... but I wasn't – I was angry, because when the nurse came, she told me I was late again. I said, yeah, I'm not stupid, I know I'm late, and I'm sorry I'm late, but this is the second time I've tried to fix this appointment. [She said] "no no no no, you are late." I said, "OK". And then the nurse comes again and as she's taking me in she begins to talk to me again. I said, "madam, I know I'm late-" and then she interrupts me. So I didn't say anything at all." (*Stella, F, Economic Migrant, Nigeria*)

This particular experience reduced her confidence, and she suggested that subsequently she would "pray to never have cause to use the services [again]". This was despite the fact that Stella was actually working within the health sector herself.

The lasting effect of isolated negative incidents was evident. Stella was able to recall the incident above in great detail even though it had happened several years ago, reflecting its considerable impact. However, there was some ambiguity of perceptions of discrimination:

> "In term of African... if somebody for example face negative issues... some time become more reluct-, they come more reserve to take part in services. [with GPs] you can see that time of connection then just they have time to listen to you, to hear your story, what your pain are, what you are suffering from. [But] sometimes you can hear, you just say, two minutes. You sometime want to express yourself but just pushing me to go fast, say, "oh nothing can do, feel it or..." That's because I'm African, that you do that... question mark, you know. Sometime they are, people

> say that, we don't understand why people sometime hate African, yeah. Why?" (*Representative, Integration Network 2)*

This example of people feeling they were not given enough time within the GP appointment to fully explain their issues, or that the GP did not appear interested in what they had to say, is a complaint that arises regardless of people's background (Scottish Government, 2015b). As with this case, participants' perceived discrimination in healthcare did not take the form of overt racial epithets, but subtle perceived differences in treatment. However, it is important to emphasise that regardless of the presence of intention to discriminate by healthcare workers, as long as the treatment is perceived as discriminatory, it could have a negative effect on potential willingness to use services. This had a considerable effect for some participants

I subsequently asked if participants had been willing to challenge what they perceived to be discrimination and only one had complained. The rest felt similarly to Souleymane:

> "No, I no want give people hard time because it can make people hate you. So, because you know, ask him, "now, matter why you doing this, why do this?" sometime people no listen to me." (*Souleymane, M, Refugee, Guinea*)

The perception that discriminatory treatment could not be challenged was important because it normalised discrimination. This furthered entrenched a lack of confidence in using services by those who felt they had been discriminated against.

Refugees tended to report distinct experiences of discrimination. In the context of a perceived anti-immigration culture and negative media about "health tourism", half of the refugee participants complained that they had been publically identified as being asylum seekers or refugees by healthcare staff.

> "The other problem as well, when you got to the reception, in front of people she's asking are you asylum seeker or... so the people who are there who don't know this process, it was like an insult, it was like an

> insult. If they were nice as opposed to no, just take them as human. "Can I help you?" that's it. Not only ask, "are you an asylum seeker"." (*Alain, M, Refugee, DRC*).

Public questions about visa status in conjunction with perceptions of xenophobia and an overall environment of anti-immigrant and in particular anti-asylum seeker sentiment meant that participants experiencing this kind of treatment felt they were being accused of taking advantage of services. This identification was embarrassing and off putting, despite their knowledge of entitlement to care.

On the other hand, several accounts suggested that service providers did not possess this knowledge:

> "I know that healthcare is very, very difficult access here especially when they are at that stage because a lot of doctors think that because they are asylum seekers, they've got no entitlement to healthcare, so they can't register and things like that. So those are difficult." (*Representative, Advocacy Group 2 , woman's group*)

This was volunteered by the participant, rather than at my suggestion that this was the case. The rumour that you might be refused access appeared sufficient to cause people to not attend health services for fear of having to deal with such a confrontation.

Attending services was also tempered for refugees by the perceived risks to their already tenuous visa status:

> "Some people have been telling me that, "oh sometimes if you are sick and you don't have paper, even if you are admitted in hospital they can come and take you away," things like that... they can get you from there and be deported... I've been hearing rumours that there's a certain woman... who was admitted in hospital and deported, and as soon as she reached the country she died." (*Yaema, F, Refugee, Sierra Leone*)

The power of the rumour here was apparent. Even though, as I observed, staff in the asylum seeker drop in centre reassured participants that they would not be refused healthcare or detained if they had an asylum claim or were refugees, some participants still claimed that it was possible.

6.5 Summary

Participant understandings of health and healthcare were said to be distinct in certain ways to the rest of the population. This was said to be an issue when it was not sufficiently taken into account by service providers. Although most participants had generally positive experiences with the healthcare system in Scotland, reports of negative experiences had significant effects on the perceptions of service providers by all the participants. Negative experiences all related to an insufficient understanding of the participants' values, cultures and backgrounds. For a few this was seen to be a lack of effort on the part of service providers due to discriminatory views held by staff. The perceived shortcomings of services in terms of knowledge of Africans and sensitivities to the way Africans approach health and health services had a considerable impact on the will participants had to use services. At best they found it irritating but at worst it eroded the trust that they had in the abilities and willingness of service providers to help them. Of particular note are the experiences of the refugee cohort in this study, as they were both the least well-resourced to engage with services and had seemingly met with the most hostile response from service providers. Apart from this there were no obvious patterns by age, gender, time in the country or other demographic variable. The data in this chapter will inform discussion later in the thesis about what can be learned concerning designing interventions and initiatives that Africans feel have their best interests at heart, display empathy and understanding and of what they expect and require feeling comfortable in service use.

7 Chapter Seven - Awareness and Understandings of HIV and HIV related stigma

7.1 Introduction

This chapter will explore participants' awareness and understandings of HIV, the sources of information for these perspectives and levels of discussion about HIV in the diaspora. I will then look at participants' understandings and experiences of HIV stigma, as this was one of the central barriers to HIV discussion and related service use. These findings contribute to answering research question four ("To what extent and in what way do African migrants discuss sexual health, HIV, HIV testing and health service use within their social networks?").

7.2 Definitions

I will use the terms "understandings" and "biomedical knowledge" with regards to HIV in distinct ways. "Understanding" refers to individual perspectives and conceptualisations around HIV, i.e. lay knowledge. I will not assess this as being "correct" or "incorrect", as I want to describe participants' perceptions rather than judge them against a standard of biomedical knowledge. "Biomedical knowledge" describes the extent to which people knew about the bio-medical aspects of HIV, including vectors of infection, mortality, treatment and other related technical and professionally sanctioned knowledge.

7.3 Awareness of HIV in the sample

All participants demonstrated substantial awareness of HIV, except for one who claimed to be unaware of it (*Aaban, M, Refugee, Rwanda*). He had very poor English skills which could have been a contributing factor: he became visibly stressed in the interview when struggling to communicate in English. When asked about his HIV biomedical knowledge he replied "HIV?, what is HIV?" and I attempted to prompt further but he only responded with "I don't understand." He may have been more familiar with the acronym SIDA as used in French (Rwanda being a former French colony), but unfortunately this was not explored

in the interview. Apart from this exception, the rest of the sample could be described by Victor's statement:

> "Everybody is aware... like I said, even in places where everybody I think in a certain, in a given population, or even, like, more, over ninety percent of people are aware of HIV. But it's not left to you. Because [there are many] advertises of contraceptions or things." (*Victor, M, Student, Nigeria*)

Like Victor, participants tended to cite health promotion in Africa rather than in the UK as their main source of HIV awareness, understanding and biomedical knowledge. Sources of information about HIV will be discussed in the next section of this chapter.

Participant levels of knowledge on the biomedical details around HIV and transmission were high. All participants with whom it was discussed were aware of modes of transmission and that HIV was no longer necessarily a deadly disease. They were aware of the availability and efficacy of anti-retroviral treatments in the UK but none discussed specific treatments. Knowledge about treatment was also robust within the sample. Many participants made the distinction between HIV in the past as a terminal disease and the current availability of treatment that made it a manageable condition:

> "I actually know like two... two people now from my country [now living in the UK] that actually have HIV, and I always talk to her, "that is not the end of your life... at least here they have medication." Back home you are nothing, but here they can help you, they can give you medication until they see how you are progressing." (*Yaema, F, Refugee, Sierra Leone*)

If I had managed to build sufficient rapport with participants, we were able to discuss personal sexual health. These participants were all aware of the established knowledge of how to protect yourself from infection, safe sex and other aspects. For some participants it was clear that they were not comfortable talking about personal sexual health, and therefore it was difficult to ascertain their levels of knowledge. It could also be argued that those that

were less willing to have a conversation about HIV might be those who would not have good knowledge concerning the disease and its transmission. However the majority were comfortable discussing it in the abstract sense and demonstrated competency of the biomedical nuances of transmission, lack of mortality and the options available for treatment.

7.4 Sources of Information and Exposure to HIV related Health Promotion

Participants were asked for their main sources of their HIV knowledge. The large majority of the participants (29) said that health promotion in their countries of origin was a key source. Of the participants that discussed this in detail, all recalled that efforts had a high public profile and were very widespread:

> "I think everyone understands that point. There are discussions back home! The biggest discussions happen in Africa. It is, you can hear it in any African city. Where there is more billboard, more leaflets, more information, probably than anywhere else in the world. The things are happening back in Africa. So people are very aware. If you want to live a long life then you have to change your ways of living. People understand." (*Representative, M, Country Association 1*)

Other participants mentioned the work of NGOs, charities and governments contributing towards overall levels of biomedical knowledge and awareness in African countries. HIV was framed as a high national level priority in various countries, and health promotion was ever-present. Interestingly the representative above also suggests that "the things are happening back in Africa" suggesting that health promotion might be more appropriate there than here. The extent to which health promotion is not necessarily needed as much in Scotland in comparison to Africa was a continual theme of these discussions, and reasons that participants might have this perspective are connected to their assessment of Scotland as an environment lacking HIV infection risk, covered in chapter 8 findings.

Although these are perhaps insufficient reports on which to generalise about HIV health promotion across Africa, they do provide a stark contrast with

participants' perceptions and experiences of HIV related health promotion in Scotland. For a large majority of the sample, both organisation users and organisation representatives, there was no awareness of any HIV health promotion initiatives targeted towards Africans, and little awareness of more broadly population targeted HIV health promotion .

> "Well personally from you know, maybe it's because of my age, or maybe it's because of the places that I go, maybe it's because of the people that I know. But I've not really sort of felt first hand, and sort of, you know, promotions, or any efforts to promote health [around HIV] in my community at all." (*Representative, M, Commercial Entity 1, Restaurant*)

The majority of participants who I asked about this, regardless of age or migrant type or background, claimed they had just not been exposed to it due to their circumstances. In addition to this HIV for these participants was not relevant to their daily lives, so they would not note its presence. HIV related health promotion had little salience for them due to their low levels of self-assessed risk of infection as will be discussed in greater detail in the next chapter. As Yaema (*Refugee, F, Sierra Leone*) emphasised when describing health promotion efforts around HIV: "People will say, I don't want to listen to [it], I don't have time for that."

Another aspect of the contrast between health promotion in Africa and that carried out here was that in Africa it was reported to be done in very public ways, with TV commercials, billboards, leaflets and continual high profile public discussion. This was accepted by participants as normal and a requirement to try to deal with the issue of HIV. In the UK participants did not perceive any health promotion, and also did not think it was necessary in the same public way as it was carried out in Africa. The lack of visible health promotion around HIV was not problematised by participants. It seemed as if many had not thought about the contrast until we discussed it in interviews.

7.4.1 Discussion of HIV in the diaspora

Another potential source of information about HIV could have been discussion within the diaspora in Scotland, but similarly to HIV health promotion,

participants stated that there was no discussion of HIV. Fifteen organisation users and six representatives spoke explicitly about the lack of discussion amongst African communities in Scotland.

> "Researcher: Is it something that's discussed?
> Cynthia: Hmm. I don't think people like discussing about AIDS, I don't know...
> Researcher: People don't like to talk about it?
> Cynthia: No
> Researcher: Why do you think that might be?
> Cynthia: I don't know. I don't think people like talking about it... hmm, no, I don't know." (*Cynthia, F, Student, Zimbabwe*)

This was a typical exchange, highlighting that participants reported a complete lack of discussion, rather than limited discussion. This could be due to participants' concept of "discussion", i.e. public group based conversation. It had been said earlier by organisations that sexual health issues were "private", i.e. were not appropriate to be talked about. Perhaps this topic was not sanctioned as appropriate by norms of social etiquette. However when I asked further whether or not it was discussed in private, there was still a reported lack of conversation at any level.

Participants did not consider a total lack of discussion of HIV in the diaspora as abnormal. Often when I tried to elicit an explanation the lack of discussion about HIV would be treated as a truth which did not require further explanation.

> "It's just not talked about." (*Kodzo, M, Economic Migrant, Ghana*)

This made it challenging to have fuller exchanges concerning HIV discussion in the diaspora during interviews. However, a minority, for whom there was no demographic pattern, were able to examine potential reasons for the lack of discussion about HIV in more detail. There were two main explanations given. The first was referred to by Cynthia, that people did not like to talk about it due to stigma. The other was the lack of relevance of HIV discussions to peoples' lives. These two potential explanations will now be explored in detail.

Several people alluded to stigma around HIV:

> Don't know, you know [long pause] HIV's a touchy subject. People get scared, they don't want to talk about it. So that's it. (*Representative, M, Commercial organisation 2, Salon*)

Particularly poignant was the phrase "so that's it". This was a sentiment I encountered with several participants, a lack of will to entertain exploration of the roots or nuances of stigma around HIV. In this narrative, stigma was a social fact, and there was no benefit in scrutinising why it existed, or what were the driving causes of stigmatisation. An alternative explanation might be that stigma around HIV was so powerful that it silenced these discussions on the nature of stigma.

However, most participants were able to discuss stigma in more detail. When I asked what was at the root of people's fear of discussion, participants who had an answer referred to two issues, illustrated by Deborah:

> Deborah: Yeah, I feel like African people definitely do not like to talk about HIV/AIDS. They hide it. They're scared to talk about it.
> Researcher: Why do you think people don't like to talk about it?
> Deborah: I don't know, I think it's just. I think they know people are going to treat them differently... I think… because it's such taboo… people don't say is because they're so embarrassed. (*Deborah, F, Student, DRC*)

Stigma according to this narrative caused people to avoid discussion of HIV because they expected to be socially marginalised. Discussions around HIV were "taboo", they were not socially sanctioned as appropriate, therefore people engaging in them would find themselves alienated. For some, the embarrassment factor was connected to the unacceptability of discussing any matters of sexuality or sexual health:

> "Yeah they're [Africans] very reserved. It's not in their nature to sort of talk about certain things very openly. You know, I think in Europe people are quite open about you know, sexual things, and they will talk about, and they would discuss the intricate details. But, Africans are not the

> same. We're very, very reserved in nature. To get to the point where people are talking about HIV/ AIDS is not something that happens..." (*Representative, M, Commercial organisation 1, Restaurant)*

Discussions of HIV are overshadowed by the connection to sexual activity, which in this case is the cause of reservation. From this representative's perspective this makes HIV a topic that would not be deemed appropriate for general discussion in the diaspora.

Another reason given why discussion of HIV was stigmatised was the potential of upsetting people due to the disease's connections with mortality, as identified by Linda:

> There are some people that would not want to [talk about HIV]… especially when you've had victims of HIV, you don't want to talk about it because it's depressing. (*Linda, F, Student, Nigeria*)

Death as a taboo was as substantial as sexuality as a reason to not discuss HIV but had less connection to embarrassment and more to not wanting to be morbid in conversation, i.e. to talk about something that was "depressing". Both of these "marks" of stigmatisation, sexuality and mortality, contributed to a social context in Scotland described by the participants as non-conducive to discussion of HIV without social penalties and marginalisation.

Beyond stigma, the other main explanation for a lack of HIV discussion was that participants did not feel HIV was relevant to their lives, i.e. they were not at risk and therefore it was not something which needed to be discussed.

> Yeah, I mean, it's not necessarily because it's taboo... I just... I think that... I just assume that because... that for most people it's just not something I think about sincerely, just like it isn't for me. I mean, I never give it a thought... in my day to day life, in my day to day interactions with other Africans you know, it's just not something I think about at all. Maybe it's the kind of thing you assume is a million miles away until it comes, you know, close. (*Theresa, F, Economic Migrant, Nigeria)*

Theresa cites physical distance, which could represent the perspective that the issue is far away from Scotland, in Africa. This was a common approach in the sample, with the environment of Scotland contrasted with that of Africa. Participants distanced themselves from those perceived to be affected by HIV. The ways in which participants considered their personal risk of HIV and the levels of risk in Scotland will be discussed in detail in the next chapter.

The absence of discussion was reported across the whole sample, regardless of country of origin, migrant type or any other demographic category.

Two individuals clarified that whilst HIV does not tend to be discussed, there are potential exceptions at various points in the life course. One was identified as being "when somebody's close to getting married… and they want to know the status of their potential partner" (*Isaac, M, Student, Uganda*). Usually in these cases it was reported that there would either be pressure to test from religious leaders or family members, and this was seen as contextually acceptable. The other point of acceptable open discussion was screening during pregnancy. In the latter case, Kodzo, a GP, identified the following pattern of behaviour:

> So they are screened for all those things and HIV and then they will come out and say, "phew, they screened me for HIV and it was negative" and then we'll laugh about it but then that's about it. Then that's it dead. So, and the conversation stopped. (*Kodzo, M, Economic Migrant, Ghana)*

HIV tests and conversations around HIV were more contextually acceptable at these points because at these junctures HIV status is perceived to have more relevance to peoples' lived experiences. In addition, in the second case of pregnancy screening, this procedure is routine for all pregnant women and therefore is more discussable, as someone else is taking the decision to make it relevant. None of the participants claimed that it was inappropriate to discuss HIV in *all* contexts. It was therefore not a complete taboo, but required a particular circumstance to counter the strong associated stigma. The circumstance perhaps made the discussion more about the life event than the individuals involved, which could be a reason that stigmas connected with sexuality and mortality were easier to navigate, and therefore did not shut down conversation.

The next section will look at participants' understandings and experiences of stigma in detail.

7.5 Stigma

An important focus of this research was HIV-related stigma as a barrier to African migrant engagement with HIV related initiatives. Twenty nine participants, both representatives of organisations and organisation users, discussed stigma in different forms, although some did not explicitly use the term itself. HIV related stigma was still reported to be a considerable issue in the diaspora. A representative from a Scotland-wide African advocacy group, with extensive experience working with African communities in Scotland, did not think socio-cultural norms of stigma had changed, and that stigma was still prevalent amongst Africans in Scotland.

> Stigma still remains pretty much the same. I mean, nobody really wants to talk about HIV or… as far as… yeah so stigma is still pretty much the same as it was before... there's been no change over the years." (*Representative, F, Advocacy group 6, African advocacy*).

In this section I will explore stigma in greater detail. First I will examine reports of how participants felt they were associated with HIV for being African. This was covered in some detail in the last chapter in the context of health engagement, but here it will be discussed in more general terms. Then I will examine stigma generated from within the diaspora, enacted by Africans on other Africans. I will then discuss the phenomena of stigma existing amongst participants and their social networks despite the sample having good levels of knowledge about HIV.

I will use some of the concepts discussed in the literature review to describe stigma experienced and understood by participants. "Enacted" stigma (Goffman, 2009) is the result of actual action of stigmatisation between two parties. "Felt" stigma (Goffman, 2009) concerns stigma experienced without necessarily having been stigmatised, but based on the likelihood of experiencing stigma, which can define a person's perspectives and actions.

7.5.1 The stigmatising association between Africans and HIV

The most commonly referred to and "felt" HIV stigma experienced by participants was the assumption made by non-Africans that the majority of Africans have HIV.

> Researcher: Do you understand anything by stigma?
> Cynthia: Yeah... A stigma just saying like most people who come, men, especially with men like most men from Africa have AIDS, right, that's a stigma, like. So everyone would say that, "OK, most men from Africa have AIDS."(*Cynthia, F, Student, Zimbabwe*)

This stigmatisation was also connected to another assumption of "Africa being the source of HIV" (*Susan, F, Student, Kenya*). With the exception of being prompted to test for HIV (explored in the previous chapter), none of the sample had directly experienced enacted stigmatisation by someone explicitly connecting their African origin with a likelihood they had HIV. Instead, it was assumed that people in the UK thought there was an inherent connection between HIV and Africans. As with experiences of discrimination discussed in chapter 6 findings, it did not require direct experience of this treatment by a non-African for participants to be certain that this assumption existed and was widespread.

One reason given for this assumption existing in the UK was mass media and its representations of the epidemic and Africans in general.

> "Because most of the media, and publications tend to focus always on African, it's an African, you know, sickness, or Africa[n] disease. And, by doing that it opens a lot of prejudice you know. You know... You know when they show images on TV, they show mostly Africans. They don't show a white man on the TV there who is suffering from AIDS. So..." (*Susan, F, Student, Kenya*)

Participants did not identify explicit declarations of connections between HIV and Africans in the media, but saw implicit cues through which the general

population formed ideas about HIV being inherently connected to Africans. For some participants even media reports of other disease outbreaks or famines contributed to the stigmatising connection with HIV, as it perpetuated the image of a virulent, infectious and infirm Africa. The idea that HIV was an African issue was seen as highly derogatory, and was another barrier participants found to engaging with issues of HIV. Participants' actions and perspectives were affected by this felt stigma in that they anticipated a hostile environment and actors within that environment who would make connections between them as Africans and HIV, regardless of their individual circumstances, characteristics and backgrounds. HIV became a topic with which they anticipated negative connotations, and they were therefore pre-emptively defensive about it. This affected the way they perceived any potential conversation about Africans and HIV.

7.5.2 Anticipated stigma from within the diaspora

Most discussion of stigma in the interviews centred on that originating from within the diaspora. This, in contrast to the stigma from outside the diaspora, was focused on the stigmatisation of individuals rather than generalisations about all Africans. No one reported experiencing enacted stigma themselves, and only two participants reported stigmatising others. There were more reports of anticipating enacted and felt stigma in various circumstances, due to the assumption that people would be stigmatised if they were connected with HIV, either through diagnosis or rumour. In this section I will report what participants suggested were the nuances of this stigma. HIV stigma was reported to be complex and connected to several fears which will be explored in detail. These included the fear of death, fear of transmission and fear of social isolation due to known status as HIV positive.

Despite nearly all participants reporting an understanding that HIV is rarely fatal in Scotland with sufficient access to widely available HIV treatment, the connection between HIV and mortality was still very deeply ingrained:

> "Because people have seen other people suffer from the disease. They've seen other people lose their lives. They've seen entire families being wiped out because of the disease. So for this reason they deem it very

> dangerous and they wouldn't want to lose their family members because of HIV. So their best, you know, prevention, is to just keep away you know, from these kind of people." (*Isaac, M, Student, Uganda*)

The process of stigmatisation around mortality was complex. Experiences and awareness of death due to HIV tended to be reported as experienced in countries of origin rather than in Scotland, but these experiences, direct or otherwise, were powerful enough to shape behaviours in Scotland, a setting where participants knew medication to prevent death from HIV/AIDS is widely available. Despite this some participants reported knowing individuals who would still take the measure of isolating others connected with HIV from their social networks as a method of protecting themselves. Often individuals connected to HIV were labelled euphemistically as "these kind of people" or something equivalent, rather than as HIV positive, demonstrating how strong stigma is in preventing open discussion of the issue of HIV. Others in the sample suggested there was still a lack of knowledge concerning the treatability of HIV, and this was a strong barrier to being tested at all, since individuals would rather not know if they had the disease and therefore not have to deal with the perceived or expected stigmatisation, but also the expected physical suffering that would follow.

> If they suspect they have HIV… they're gonna keep that to themselves because they don't want to be stigmatised. They don't want the other members of the community to know that they have it… [because they're] not knowing that is something they can live with, something they can be given medicine for. That information is not there. (*Representative, M Advocacy group 4, ethnic minority advocacy*)

This representative contradicts the reports from nearly all participants who all said they were aware that HIV was not necessarily fatal. This is indicative of the complexities around HIV stigma, with knowledge and understanding sometimes conflicting. By the above account, experiences, or expectations, of other people's suffering and mortality due to HIV could be a more compelling determinant of action than the knowledge that HIV can be treated.

Oudry, a refugee from the Congo, explained how a positive diagnosis and the associated perception of mortality would also have a powerful effect on family members in countries of origin. This highlighted another layer of complexity for stigma connected to mortality for people with global networks.

> You are here in Europe and then your father or your mother here in Africa… So the people that stay here in Africa and then you are here, they receive the bad news: you are killed them... so your son or your brother in Europe is sick… (*Oudry, M, Refugee, DRC*)

By "you are killed them" Oudry means one could cause terrible emotional distress, as clarified further on in our interview. Oudry went on to explain that due to beliefs that HIV was a terminal illness in the Congo, in addition to the difficulty of communicating with people in his home country, the stigma around disclosure and discussion of HIV was still very strong here in Scotland. Conceivably, therefore, an individual might not want to know if they had HIV due to the anticipation of the devastating impact they it would have on their families, exacerbated by the geographical distance between them.

Connected to the fear of mortality was the anticipation that others would fear being contaminated and thus enact stigma towards those identified as HIV positive or perhaps seen engaging with HIV related services.

> I think it's there because people don't want to die. No one wants to die, and people are afraid of people who have AIDS because they think if they're, if they stay too much with them, that then the inevitable that somehow they'll be contaminated with it. So maybe if they learnt a bit more about living with someone with AIDS they would go away you know, with something that is dealt with, you know. (*Representative, M, Commercial Establishment 2, restaurant*)

A key aspect here is the idea of "inevitability", i.e. that it is inescapable that if you "stay too much" with someone who is HIV positive you will become infected. It is notable that this representative thought that sufficient education might address this. However, the stigma here is in direct contradiction with reported levels of biomedical knowledge around transmission. This means that knowledge

of the pathways of transmission does not necessarily translate directly into an understanding of the likelihood of transmission, pathways and likelihood being two distinct concepts. Therefore people could be knowledgeable whilst still having unrealistic fears about the threat of being infected.

A more extreme example shows that some stigmatising attitudes persist in direct contradiction of knowledge of routes of transmission. Kodzo, the GP, recollected how he did not disclose to his "highly educated" wife that a family friend was HIV positive, for fear that she would stigmatise her.

> "So my wife never knew and then she [the HIV positive woman] continued to be a family friend and things. I would have unrelated conversations with my wife and I'd bring in HIV… just to see how she would react and she would say "I don't understand how people can go and to have HIV and if I knew someone I wouldn't even want to touch them."… She behaves like that… even she who is an educated woman who has completed university and things and knows all the facts about HIV, still refuses…" (*Kodzo, M, Economic Migrant, Ghana*).

Kodzo refers to a "refusal", insinuating a conscious decision to continue to hold stigmatising attitudes about HIV. He reported his wife would not even "want to touch them", although she knew she would not be at risk of infection through skin contact. One organisation representative identified this type of attitude to be due to "cultural values", (*Representative, M, Religious Organisation 3*) which could indicate the deeply ingrained nature of the stigma. The contradiction between correct knowledge of HIV infection and transmission and continuing stigmatising attitudes was multi-faceted. The implications that this has for future efforts to engage African migrants with HIV related initiatives will be covered in the discussion chapter.

A strong aspect of HIV stigma which participants identified might be particularly pertinent for African migrants was the fear of being ostracised from social networks and broader society if diagnosed with HIV. This was acknowledged to be a powerful felt stigma, anticipated regardless of lack of direct experience of it or of reports that it had happened to others in direct contact with

participants' social networks. The rumour that it was the case was strong enough to have an impact on participant understandings and perspectives.

> "Victor: Yeah there's stigma
> Researcher: What does stigma mean to you?
> Victor: Yeah, being limited from society, and people see you as an outcast, sort of. And that's, that's the stigma that goes with it. But some do say, "okay, [those with] HIV, people should treat them as human beings, treat them friendly", but I don't really see how possible that could be because… you would say, if you are not positive you don't want to be… but then that is not to say that if you realise that somebody's HIV [positive], that you, you run away from such a person… that is not…" (*Victor, M, Student, Nigeria*)

Victor, and many others, strongly felt that people who were diagnosed with HIV would be "outcasts". The concept of ostracisation or social isolation was identified by participants as a barrier to engagement in the same way as other anticipated reactions from social networks to diagnoses.

This type of stigma was also identified to have a double impact for people in the African diaspora by several organisation users and representatives, particularly for those that were new in the country or had social networks that were deeply entrenched in the diaspora:

> Yeah I mean, those that have HIV, there is the fear of rejection by the, by the local community, but the African community because if they are rejected that means they're not really accepted anywhere. Do you get? So if you're ethnic community rejects you then basically you don't have anything, because already coming out of your homeland to another country, you've left family and friends, so the only link to your family and friends are those in your ethnic group. (*Kodzo, M, Economic Migrant, Ghana*)

Kodzo argued many African migrants are already isolated and marginalised in Scottish society, and are reliant on the diaspora for social connections and

associated support. Therefore fear of potential isolation from the diaspora could have a powerful effect as individuals might feel they are already in a precarious social position.

7.6 Conclusion

Levels of awareness and knowledge around HIV were reported to be high amongst the African diaspora. Participants claimed that overall people were well informed about HIV. This information did not seem to come from sources in Scotland or the UK more broadly, but from experiences of health promotion in countries of origin. Participants suggested that they were unaware of initiatives in Scotland concerning HIV, and that there were no discussions about HIV within their social networks. One of the central reasons given for this was that HIV is still highly stigmatised in the diaspora. Participants described their understandings of why stigma still had considerable impact, including connections to mortality, the taboo of sexual behaviour and the anticipation of being ostracised from social networks. How these findings might inform a future initiative to engage Africans with HIV related services will be covered in detail in the discussion chapter.

8 Chapter Eight - Perceptions of vulnerability to HIV Infection and responses to potential targeting of Africans for HIV related initiatives

This chapter examines the extent to which participants agreed with the epidemiological evidence that Africans in Scotland were at higher risk of HIV infection than the general population. The extent to which potential service users feel they are at risk of infection is an important determinant of whether or not they regard HIV related health promotion as relevant and whether they will consider engaging in services. This chapter will look at how participants understood risk and vulnerability to HIV and their reasoning for accepting or rejecting the epidemiological evidence about higher risk. I will then describe what participants reported as being factors that would increase risk of HIV infection. Finally I will look at participants' reactions to, and perspectives on, targeting African migrants for HIV related initiatives in Scotland.

8.1 Understandings of Risk and Vulnerability

One of the main topics of HIV related discussion in the interviews was the extent to which participants agreed that Africans in Scotland were at higher risk of contracting HIV or having an undiagnosed infection, and what they understood to be pre-cursors of being at higher risk. I did not pre-emptively structure these portions of the interview, due to the extremely sensitive nature of the topic (as discussed in chapter 3: Methods). Instead I focussed on what participants considered to be key risk factors, which will be examined below.

Some participants had multiple positions on whether or not Africans were at higher risk, and for some their perspectives developed throughout the course of the interview. This perhaps indicated that they had not thought about the issue in depth prior to the interview. I tended to ask the question in terms of "at high risk" rather than "at higher risk than others". This was because I was interested in their perceptions of risk, and did not want to lead their understandings of this topic.

Respondents did not necessarily distinguish between population risk (applied to the African migrant population) and risk to them as individuals. In most cases it was apparent which kind of risk was being discussed due to the language being used and whether or not we referred to specific risk factors for individuals. With these qualifications in mind, I will now give a general overview of participant perspectives on risk.

8.1.1 Overviews of Ideas of Risk in the sample

Participants were divided between three broad viewpoints, those that accepted that Africans were at higher risk of HIV infection, those that were neutral and those that explicitly denied higher risk. The first group were in the minority (eight organisation users and only one representative). The users consisted of economic migrants, students and refugees, and there were no discernible patterns by country of origin, level of education or any other demographic variable. Three organisation users and one representative made neutral statements such as “I don’t know”, or “I suppose that could be the case”. Fifteen organisation users (over half of the total organisation users) and one organisation representative explicitly denied heightened risk for Africans in Scotland. I will now examine how participants who accepted risk and denied risk supported their positions.

8.1.2 Acceptance of Risk

There was a variety of explanations from the group of participants who accepted that Africans were at high risk. Their position tended to stem from an acceptance that risk of infection in Africa was high, rather than relating to risks in the UK. These participants reasoned that risk transferred from Africa to the UK because people might not know they were infected. Yaema (*F, Refugee, Sierra Leone)*, who had escaped civil war in Sierra Leone, thought that Africans in Scotland could be at high risk because they had come from situations where rape was frequent. This was a reason given by another participant who had been subjected to gang rape in Somalia. A third participant suggested that in some countries, poverty would mean that sexual health would not be as much of a priority as food and shelter. The concept of sexual health being of lower priority

due to limited resources was a recurring explanation. Resource scarcity was also deployed as an explanation in a different way:

> "In resource poor centres, people might cut corners, if they weren't informed." (*Stella, F, Economic Migrant, Nigeria*).

Rather than relating to resources to deploy sexual health safety measures this related to a lack of knowledge concerning sexual health, but has the same connotations that sexual health would not be as much of a priority in these conditions as other basic needs.

Another reason provided for acceptance of high risk was "African culture" in conjunction with the perceived high risk social environment in countries of origin. For some participants this described the perceived reluctance of Africans to disclose HIV, or engage with services, which when linked with high prevalence meant high levels of risk.

> "I would understand if they say "particularly vulnerable" because most Africans are very confidential [about sexual health] and they wouldn't want to know their status and they wouldn't disclose it to anyone. And, coming from Africa, there's a greater risk... because it's very big in Africa, there's a lot of people with HIV. And the health service over there.... doesn't really prevent it... you know, healthcare to prevent transmission of, you know, HIV. It's just also the healthcare services in Africa aren't as trusted as the one in the UK as well, sort of thing. (*Isaac, M, Student, Uganda*)."

From Isaac's perspective, inherent in "African culture" are characteristics of privacy around matters of sexuality, leading to a lack of open conversation about risk and HIV status. This in combination with the lack of substantial healthcare services to prevent transmission and the high levels of prevalence in Africa created an environment of high risk.

8.1.3 Denial of Risk

The majority of the sample denied that Africans are at high risk of HIV infection and most were outspoken in this assertion. This was the point in the interviews when respondents were most likely to become angry or emotional, showing that for many this was an aggravating and emotive issue. Many seemed to think that the claim that Africans are highly vulnerable to HIV was a discriminatory reflection on them personally as well as defamatory to Africans in general. Participants articulated passionately their distaste with this claim, and below are the main reasons given for this amongst those who denied risk: Africa is a diverse continent; the negation of risk due to the time spent in Scotland and mistrust of statistical evidence.

For several in the sample assuming "Africans" all to be at high risk was unacceptable since Africa is a heterogeneous continent, socially, environmentally and in terms of HIV prevalence.

> "It's the impression that the prevalence is very high in Africa, so they just presume that you, you're likely to be a carrier... My general opinion is that they're [the risk evaluation] not true, again they have drawn based on experiences in a few African countries and sort, sort of assumed that the whole of Africa have the same level of prevalence which is not true." (*Benjamin, M, Economic Migrant, Nigeria*)

Central to this type of denial was the assertion that generalising that all Africans are at high risk ignores country based prevalence. In addition to this, many participants did not see how a continental level assessment of risk related to them as individuals and their lived experiences. This was regardless of their countries of origin's prevalence. For participants, their life experience was more important in understating their levels of risk. Therefore many were unwilling to engage with this narrative of risk, and rather than causing concern or heightening awareness, this generalisation at a continental level was a substantial barrier to engaging with the idea of elevated levels of risk. This disengagement due to generalisation should be understood within a wider context in which participants reported that they are discriminated against and

generalised about on a regular basis, meaning it perhaps had more of a negative effect for this group of people in particular.

Another participant, Theresa, suggested that the category of African is perhaps too broad but she takes a different perspective from that focussing on country levels of prevalence.

> "Theresa: I do think of other Africans, other African ethnicities as being at a high risk, you know, like Kenyans and Ugandans, but I just don't think in terms of Nigerians.
> Researcher: Is that... that's interesting. So, well, is that just... because of the situations in those countries then or?
> Theresa: Yeah, to be honest, I always think... I know Nigerians are highly educated, but I don't think of... I don't think of other African ethnicities as being highly educated as Nigerians are, which is probably totally wrong, it's just one of those assumptions." (*Theresa, F, Economic Migrant, Nigeria*)

Theresa's suggestion that education may be a risk determinant shows that the understanding of "Africans" being too broad a category is not necessarily based on HIV prevalence alone, but is multi-faceted and complex, taking into account social factors such as education and socio-economic class. Those that deployed this explanation took the position that the diversity in infection risk between African countries was connected to a raft of social, political and socio-economic factors. These were understood to be connected to prevalence of HIV and perhaps the abilities of countries to deal with the epidemic, which in turn reflected the levels of personal risk of people from those countries who were now in Scotland. The idea that one level of risk of infection could apply to all Africans was again seen as a discriminatory generalisation from this perspective, and the authorities who had made that generalisation were characterised as not taking this multitude of diversities into account.
Many participants who had been in the country for an extended amount of time (several years or more) took exception to the idea that they were in the same category of risk as a recently arrived African immigrant.

> "Like I think if you really explain to somebody and then like in my case we've been in the UK for about six years, so we haven't been exposed to the risks even..." (*Christopher, M, Economic Migrant, Malawi*)

Risk for participants who took this perspective was based on the assumption that the risky environment is contained geographically and does not persist over time when one is removed from the risk environment. The timescale of risk negation after leaving the risk environment differed for different participants. Another participant, Tamilore (*Economic Migrant, F Nigeria*), singled out recently arrived individuals as "first timers":

> "So I don't see those people [who have been in the UK for years] doing that. But I think people coming to study, you know, first timers, that will be a good way of seeing probably the prevalence of first timers. But those that are settled and working here, I don't really see that. But if they say "this is high risk," they are not going to get that response." (*Tamilore, F, Economic Migrant, Nigeria*)

Tamilore specifically referred to attempted interventions. Participants taking the environmental risk understanding position suggested that it would be exceptionally difficult to persuade someone that they were still at risk despite the lack of environmental risk factors. They reported that Africans who had been here a long time would assume that statements about "Africans" and risk of HIV only applied to recently arrived individuals and not them, and would therefore not engage with HIV related initiatives.

Many of the participants who denied that Africans were a risk group problematised the epidemiological data I presented, sometimes stating disbelief:

> "I don't believe in these statistics, I think they're bogus." (*Cynthia, F, Student, Zimbabwe*)

This stance arose from the perception that those who had produced this evidence had a particular motivation connected to the continuing discrimination that participants experienced in Scottish society. From this perspective, statistics were not trustworthy as the authorities producing them had an anti-

African or anti-migrant stance, and the statistics were just another part of this process. Participants cited the anti-migrant sentiment they saw in national political discourse and in the mass media and did not necessarily separate these from the authorities producing statistical evidence of higher levels of risk.

> "Researcher: Epidemiologically Africans have been identified as being particularly of a... elevated risk
> Kodzo: I think it's just nonsense that they're saying that, because they're trying to say that all the HIV in Scotland was brought in by foreigners, that's what they're saying... Some of the infection is coming through from the African community... [But] a lot of the [infection] is coming in from other European countries and men going out to Thailand and all those kind of things are bringing in all these things into the system. So, but then the easy escape route where they have taken is that it's the Africans." (*Kodzo, M, Economic Migrant, Ghana*)

Kodzo (a GP) claimed to be well informed on the epidemiological information available. Like other participants he refuted the statistics on the basis that there was a tendency for authorities to identify Africans as the source of HIV. This was part of a greater narrative of portraying Africans in a certain way so as to keep them marginalised in society. An indicator that there is perhaps a moral dimension to the argument against the legitimacy of statistical evidence is that Kodzo refers to European countries and "men going out to Thailand" which could refer to infection through intravenous drugs and use of sex workers, two activities perceived as immoral. Factual evidence was interpreted emotionally by these participants, and the objectives behind these statistics were questioned. The doubt created by the questioning of agendas coupled with the perceived discriminatory environment that the UK represented was enough for these participants to dismiss evidence that Africans were at higher risk. This shows that for some people, access to the data concerning levels of presentation with HIV of Africans in Scotland would not be enough to convince them of heightened risk of infection.

There were others who did not deny the statistics themselves, but questioned the utility of identifying Africans as an at high risk group, specifically in terms of trying to engage with them.

> "You know, but the bottom line is that if there's a perception that you know Africans are being taken as scapegoats and they are at risk... So it automatically makes people want to disengage." (*Representative, M, Religious Organisation 2*)

The use of "automatically" could signify that this is not necessarily about disagreement with the idea that Africans are at high risk, but that inherent in this message is a dimension of blame which is counteractive to engagement. Participants suggested that as soon as there was an element of blame or morality involved, people would switch off from the message that these initiatives were about their health, and perceive them instead as being about identifying them as causes of the epidemic and vectors of disease.

8.1.4 Understandings of what increases individual risk

Discussions of what would cause individuals to be "at risk" occurred during discussions of whether or not Africans were "at risk". There were two dominant narratives produced by the participants and both were related to behavioural factors: the connections between risk and promiscuity and risk and morality. Morality was a broader concept which encompassed promiscuity, but also included other concepts such as religiosity and more general ideas about leading a "good life". However, as will be discussed, it could be suggested that "morality" or "the good life" may have been euphemisms to avoid discussing promiscuity and its overt sexual connections.

For the majority of participants an important risk factor of infection was sexual behaviour. Victor, below, criticises the assumption that Africans have higher levels of risk of infection, because by his understanding, risk of HIV is based predominantly on behavioural determinants. He claims that there is no distinction in sexual attitudes or "behavioural patterns" between Africans and other people in Scotland. He therefore calls into question the legitimacy of the statement that Africans are "prone to HIV".

> "If you talk about HIV, even in Scotland for example, I don't... if HIV is readily transmitted through sexual interactions, and I don't really see any difference between... behavioural, sexual behavioural patterns in Africans, [and] what's going on here. From the way I see it, if one says, "this continent for example is prone to HIV and things like that" and you're comparing it, that continent there, we should see a marked difference in sexual behavioural patterns." (*Victor, M, Student, Nigeria*)

Victor does not understand why Africans are being singled out for attention. For him sexual behaviour is the determinant of risk, and by this logic, he cannot understand the justification for saying that Africans are at higher levels of risk, so rejects this statement.

More participants cited promiscuity specifically than general sexual behaviour. Promiscuity was defined by participants as having multiple sexual partners and being non-monogamous within relationships. One of the most commonly cited reasons to deny personally being at risk was the idea that only individuals who were promiscuous would be at risk of infection. This understanding led to some participants interpreting that their sexual behaviour as individuals was being questioned when they were identified as part of a group of African migrants who were at higher risk of HIV infection. The jump between group patterns of prevalence and commentary on individual behaviour patterns was easily made by participants who argued against Africans being at higher risk of infection. One prominent argument concerning promiscuity was that the host population of Scotland were more active sexually than the African diaspora:

> "Sorry to say this, but actual Africans are not that promiscuous as the Caucasians in as far as concerning behaviour. But like in terms of who promiscuity, we're not as promiscuous as our counterparts here… It's like HIV, kind of linked with promiscuity. But like here the lifestyle that I've seen here where people can just sleep with anybody or whatever… In Malawi I know we're not that promiscuous. And then actually it's good that people look at HIV linked to promiscuity, some of the people are not willing to come forth if they are infected and when they get HIV that means they are promiscuous." (*Christopher, M, Economic Migrant, Malawi*)

According to this line of reasoning, if HIV risk is based on promiscuity, then Scottish people would be at equal or more risk than African migrants. This is dependent on a raft of assumptions about levels of promiscuity of Africans and Scottish populations, and the homogeneity of these characteristics across these populations. However, participants who followed this narrative, like others who were against the idea of Africans being at higher risk, were critical about the flaws in the logic on the part of the authorities that they identified as leading to their being designated at higher risk. For these participants this was a legitimate counter-argument to which they believed was being deployed by authorities.

Some participants (7) discussed "morality" as a determinant of risk of HIV infection. Arguably this is a proxy for promiscuity. These participants believed that leading a "moral lifestyle" would protect themselves against risk of HIV. Within this reasoning religious commitment was seen as inherently moral and therefore protective, as demonstrated here by Emmanuel:

> Researcher: Do you think that HIV is an issue for the African diaspora here?
> Emmanuel: ... I wouldn't think so, so much. Why? Ah yes, apart from people who get from blood transfusion... most of the people I know here are either Christians, or Muslims... I know that there are Africans that could be at risk. I can give you example of African who could easily be at risk are the Africans who either go to church, or because it's part of their life to go to church, but they are not committed in any form or another to church. (*Emmanuel, M, Economic Migrant, Nigeria*)

Emmanuel's stance is particularly notable as he suggests that only attending church is not enough, one has to be committed to the Christian lifestyle in order to avoid the risk related to immorality. Emmanuel and others in the sample who took this approach to risk (Christian and Muslim) connected risk with a non-religious lifestyle. Souleymane (*M, Refugee, Guinea*) refers to HIV as a "sickness from Satan". When asked later if he thought health promotion around HIV was a good thing, Souleymane said it would be, but that, "Me not going to attend, why for? Not my way. Me, I'm a man of God". These participants were confidently able to say that they were not at risk because they lived a moral religious life. Practically speaking, if morality is indeed a proxy for promiscuity, then being

moral is equivalent to not engaging in sexual activity with multiple partners. However, the way it was framed by these participants was not explicitly connected with sexuality but instead the vague characteristic of morality. Whilst it could be argued that it would be better to be direct and discuss promiscuity, if participants thought that their commitment to a religious lifestyle was protective, even if they are just referring by proxy to monogamy, then there is value in engaging with this dialogue. If this is how individuals choose to portray their understanding of determinants of risk of infection then it should be taken into account in engagement.

8.2 Targeting services and initiatives at Africans

Over the last two chapters I have discussed participants' understandings of stigma and risk. Intertwined in these understandings are the often emotional responses to Africans being identified as being at higher risk of HIV infection than the rest of the heterosexual Scottish population. After covering stigma and risk in interviews I went on to explore what participants thought about targeting of African migrants for HIV specific initiatives as a higher risk group.

Targeting was raised in the interviews when I felt a sufficient rapport had been built to discuss HIV in detail without making participants uncomfortable. This was the case in 14 interviews. It often came at the end of the interview after discussing individuals' experiences with HIV related services.

Targeting HIV services specifically to the African diaspora was in the main negatively perceived by the sample; only three thought it would be a good thing.

> "If you make that the main target or the main testing HIV no one will come. Do you get? The people that will come… if you send it out to a thousand you would probably only get five responses or ten responses kind of thing. No one will come." (*Kodzo, M, Economic Migrant, Ghana*).

Targeting was understood to be the development of programmes to encourage HIV testing that were aimed specifically at African migrants. This encapsulated health promotion materials such as leaflets and advertisements, engagement with African communities by health workers and testing prompts by GPs. All

participants understood that targeting was about an opt-in test rather than forced testing, and when participants veered onto the topic of enforced testing, I reminded them that this was not the kind of targeting I was discussing.

The most common reason given for negative perceptions of targeting was that it would perpetuate the stigmatising position that HIV is an African issue, and Africans in the UK are vectors of HIV.

> "It's like Africans are the suspect and definitely the general population will think "hundred people came in to Scotland, they were all checked, forty of them have got [HIV]" I know statistics. The media will pick it up and people look at you on the street and think, "oh dear, how am I sure [you don't have HIV]?" You know. You go into a GP's surgery, they need to take blood from you, they think, "this one is not tested, you know we better be careful with the [because of infection]" you know. Then it will create more tension. It will." (*Tamilore, F, Economic Migrant, Nigeria*)

Participants held the position that Africans existed in a hostile environment in Scotland, and proposed that HIV specific African targeted initiatives could perpetuate further discrimination. For participants, this was especially the case concerning HIV testing.

> "[Africans] thoughts [concerning targeted HIV initiatives] might be, "wow, look at what they are doing now. Why us?" because it will mean, why are we different?" (*Emmanuel, M, Economic Migrant, Nigeria*)

Emmanuel's reference to "what they are doing *now*" reinforces that reactions to targeting should be understood in the context of a perception by participants of a history of mistreatment of Africans. In this context Emmanuel suggested that Africans might be particularly sensitive to the potentially negative ramifications of targeting the diaspora for HIV. HIV targeting could compound existing discrimination, and this might even be the case at an official or state level:

> "You are trying to put me to categorise, to say that these people like this. The next thing will be that all Africans who come to this society to live in one place. So that if they are suffering from a particular thing, they

> should just suffer divided amongst themselves and die quickly. Maybe those who are sick they will send them back to their country, and deprive them of what they should enjoy." (*Cedric, M, Student, Cameroon*)

Cedric here inferred a malevolent intent behind the targeting from officials and was concerned about the possibility that separating Africans by targeting could potentially increase divisions between the African diaspora and the rest of society.

The previous sections concerning experiences with being prompted to test for HIV, on understandings of stigma and risk have given detail about why Africans would feel that being targeted for HIV testing would be inappropriate and reflects badly on Africans. In the following section I will report on responses to what preferable alternatives might be.

8.2.1 Blanket testing of the population

Several participants suggested that if everyone was tested for HIV, it would contribute to dispelling the stigmatising connection between Africans and HIV. This would be particularly the case if it was automatic, rather than opt-in:

> If there's a system in place that sort of requires that there's an automatic testing of every individual, then that is a different case, you don't feel you've been picked out, then you'll just be part of the system right? So, for instance, every Scot is tested right, if it happens then it's just easy for African, wherever they come from, to, not to feel, be picked at, right, so we just flow into these system. (*Representative, Advocacy Group 4, Ethnic Minority Advocacy*)

Four participants identified this particular tactic. These participants suggested if testing was carried out in this manner it would be more acceptable for Africans in particular, as they would not feel like they had been separated from the rest of Scottish society. Automatic testing in this context was seen as preferable to opt-in testing directed specifically at Africans. This was not a hugely popular proposition however, as it did not deal with the inherent risk of stigma in engaging with HIV related services.

8.2.2 Targeting those who were recently arrived

Four participants said that testing people who have just travelled from Africa to the UK could also depersonalise testing, and therefore avoid perceptions that assumptions were being made about the lifestyle of individuals, which would in turn dispel stigma and perhaps remove some of the barriers to engaging with interventions. This aligned with the environmental understanding of risk that proposed that Africa was the risky environment, and that risk diminished after time outside that environment.

> We know people here will go on holidays some of the people they don't go for holidays some of them they go and sleep with people there. Then they're coming back and they bring diseases here. Actually, like most of the people who are found with HIV here most of them might have, most of them actually get it when they go on holidays abroad. But when that emphasis is not really… that actually HIV's not just in the Africans, it is also possibly like a Caucasian person who'd be found with HIV… Okay, and then like it's like those hotspots, those are places where people get HIV… So if you, public health intervention should really target everybody. Say, "fine guys, everybody". I mean nobody's going to feel embarrassed we've been targeted. And then you say, "Okay all Africans will be included. (*Christopher, M, Malawi, Economic Migrant*)

While it was proposed that this might reduce stigma, participants did not discuss how those at risk would be identified. Neither did they suggest how to convince individuals who had recently travelled, but had not engaged in perceived risk behaviours, to test. However, this approach was still perceived to be more logical and therefore acceptable to participants than targeting Africans purely on the basis of being African.

A few participants thought that all new migrants should be given an HIV test as standard.

> "Get this test so it is sorted right at the point of entry, within weeks, as part of their registration or whatever. I would prefer that way because I don't see how you are going to target Africans, you know, that are

> already here without causing a big opera… Once they settle then they become, it's like, "I'm alright". So… I don't know." (*Tamilore, F, Economic Migrant, Nigeria*)

This would make testing routine and therefore again not provide space in which stigma could be generated around individuals' lifestyles or what they perceived to be risk factors. There is not enough data from new migrants in the sample to ascertain whether or not this would be acceptable for this particular group, but all the participants who had had routine HIV tests on entering other countries (such as Canada) did not seem to feel they had been unfairly targeted.

8.2.3 Targeting people from other areas with high levels of HIV prevalence rather than just Africans

Several participants proposed that it would be better to promote HIV testing for those from countries with particularly high prevalence. This could circumvent the stigmatising suggestion that all Africans were at higher risk, regardless of prevalence in their country of origin.

> "If- there need to be- if, I don't know the… where the most, where it's concentrated. So I would think not just Africans, any country that has that sort of population then there should be like a general rule when giving visas to say, "this is one requirement," because, yeah like a test maybe." (*Tamilore, F, Economic Migrant, Nigeria*)

The logic behind this geographical targeting was that it would be easier to accept than targeting of people from the whole continent. In addition stigmas around lifestyle and morality would not be generated. This approach was also proposed to be preferable if it also targeted non-African countries, with Thailand given as an example by several participants.

8.2.4 Widening the health focus

Several participants said that an approach to testing where the HIV test was just one part of a larger health promotion programme would be better received than an HIV specific focussed programme:

> "You know, so in like Africa people are calling for a more integrated approach, you know. So maybe they can mix it up with other infectious diseases, so nobody knows whether he's coming for HIV, or coming for Malaria, or coming for infections, or TB, or you know, or whatever. But once you separate it, you know, then everybody knows the diagnosis. So in the African population I think that can be one of the disincentives, you know." (*Representative, Religious Organisation 2*)

This representative specifically refers to a testing "diagnosis" but there were similar opinions amongst the other participants concerning HIV related health promotion. By using an integrated health approach, the risk of HIV stigma was thought to be considerably lessened because people would not feel they were singled out as vulnerable to HIV. Perhaps more importantly, they would not be visibly connected to an HIV service, and therefore it would negate risks of being seen to be attending an HIV service and the anticipated stigmatisation that this brings.

8.2.5 The importance of a substantial explanation for testing

All of the alternatives above affect the explanation or justification for targeting of African individuals, adding certain caveats that mean that prompts to test or targeting are done on the basis of more substantial reasons than just being from the continent of Africa. The five participants who were prompted to test all felt that if they had been given more of an explanation of why they had been prompted, it would have been more acceptable.

> Benjamin: If… someone had just come here to study, just for a year or two years, the question the person will is ask is "why [would I test]?" if they were studying much longer, the questions is why again. There has to be something that would actually motivate somebody to do a test. If you're in good health, the question is, "would you really just go for a test". There has to be some incentive… there has to be a rationale of it.
> Researcher: A rationale beyond just the idea of high prevalence in Africa?
> Benjamin: Yes, I think there would have to be something more.
> (*Benjamin, M, Economic Migrant, Nigeria*)

As I have reported in this chapter, Benjamin and others complained that the "at high risk" category for Africans did not reflect their own lived experiences. Understandings of individual vulnerabilities to HIV did not align with the assertion that they were in a higher risk category simply by merit of being first generation African migrants. Therefore they felt no need to access testing or to pay attention to related health promotion.

> "Researcher: Do you think there's any way to encourage Africans who are here already then to go be tested?
> Doris: No I don't think so because what would make me, for example go for a test? I'm in good health you know, I have one partner… so there needs to be criteria. There needs to be criteria to say, "this person has chronic illness and they seem to have several partners." You know, there should be some criteria that would make a GP be able to say, "this is part of our assessment," (*Doris, F, Economic Migrant, Nigeria*)

Without a substantive explanation participants were left to develop their own ideas about why they would be asked to test. Again, these explanations tended to be connected to questions around lifestyle, promiscuity and morality, given that participants tended to understand levels of personal risk within that framework.

> "So why are they just pinning me down that like they should test me and not the Caucasians? Well people here who go to town just to sleep with women to go and sleep with men and men go and sleep with those other people in Spain, whatever." (C*hristopher, M, Economic Migrant, Malawi*)

Participants suggested if there were more rationale behind why they were being targeted was explained in a more nuanced and sophisticated way then the space in which they assume aspersions were being made about their individual lifestyles would be minimised.

8.3 Conclusion

This chapter covered participants' understandings of risk of infection. These were based on two main narratives, that of environmental risk and personal behavioural risk. Environmental risk concerned a range of social, socio-economic, education related, and prevalence related issues. The key aspect of environmental risk was whether or not it persisted over the journey to Scotland. For most participants environmental risk declined over time, and Scotland was not seen as a risky environment. Personal behavioural risk concerned ideas about personal sexual behaviour, promiscuity, and for some, morality. Participants reported that they did not take part in behaviour they considered risky and therefore did not feel the at high risk category applied to them. This created tension when they were targeted for testing or HIV related initiatives more broadly. Targeting of HIV services towards Africans was in the majority seen as negative. Participants gave a series of alternatives to targeting, all of which sought to diminish the inherent connection they thought was being made between Africans and HIV, regardless of the personal circumstances and environmental issues which they thought made people vulnerable to HIV. All of these alternatives concerned in one way or another developing a more nuanced explanation of why Africans were being singled out.

The next chapter will cover the implications for all of the results on future efforts to engage Africans in Scotland with HIV testing services.

9 Chapter 9 - Discussion

9.1 Introduction

In the previous five chapters I have outlined the findings of the qualitative research I conducted. In this chapter I will discuss the key findings and how they relate to the literature presented in the initial review.

Firstly I will briefly summarise the findings, then discuss six specific areas which I think confirm and extend existing research and have the greatest potential to contribute to current approaches. These areas of focus are: appealing to appropriate identities to encourage African migrant service use; barriers caused by insufficient consideration of the context of African migrants in Scotland; developing links with community based organisations; the profound influence of stigma; communicating risk of infection, and finally, targeting.

This chapter will consider implications of my research findings and make recommendations for future engagement and intervention design.

9.2 Summary of findings

9.2.1 Identity and social networks in the diaspora

Identity was reported by participants to be fluid and dynamic. Their identities contributed a diverse range of meaning and influence to their social networks and vice versa. There were several identities and related social networks that had importance for participants, the main ones being: African; nationality based; and religion based.

Most participants believed that an “African” identity existed and was a useful concept in terms of promoting solidarity in Scotland amongst Africans, and that Africans had some commonalities that contrasted with native Scottish people. However, many also thought the identity was highly problematic. Problematic aspects stemmed from the high levels of diversity in Africa concerning cultural values, understandings and language. This tended to result in practical barriers when attempting to unify African communities in Scotland under a single

identity. Mostly, however, issues with the “African” identity arose when it was ascribed to Africans by non-Africans. Not only was this perceived by participants to obscure the diversities and nuances among African people, but it was also connected with a series of negative assumptions that participants felt the rest of the population in Scotland might make about them. These included assumptions about a lack of education, high levels of poverty and a lack of development. The social networks of participants were reported to be mostly African filled. This was explained by the presence of mutual understandings and experiences because of a common African background.

Alternative identities and related networks to those based on the “African” category were reported to be identity as a foreigner, nationality based identities, identity as “black”, religion based identities and migrant status based identity. Of these, nationality based identities and religion based identities, and their associated networks, were reported to be most relevant to participant experiences. Nationality based identities were said to be stronger and more distinct in character than the “African” identity. Social networks based on nationality were present in Scotland, but required a certain threshold of numbers before they were able to form. Religion based identities were said to be widespread in the diaspora. Social networks formed around sites of worship such as churches and mosques. However, there was a range of religiosity present in the sample, and participants reported that they had varying levels of ties to religious networks.

Migrant status related identities had the greatest influence on the refugee cohort of the sample because they lacked social and financial resources to network beyond the sites connected to their migrant status. They also reported that the Home Office placed considerable constraints on their daily lives, meaning their status as refugee or asylum seeker was the greatest determinant of their identity and social networks.

9.2.2 The nature and function of African affiliated organisations

The data suggest that the range of African affiliated organisations included in my research have high levels of diversity even between similar organisations within similar contexts. This diversity manifested in who attended them, their reach in

the diaspora, the resources they had available, their remits/objectives and the extent to which they were able to sustain regular levels of activity. Organisations which had greater reach and influence on Africans in Scotland tended to be those that had sustained funding and operated from permanent accommodation. Lacking these characteristics was reported to be a considerable barrier to functionality. Lack of consistency of activity by organisations had negative effects on their abilities to engage with the diaspora as this caused fatigue with engagement efforts over time.

The main functions of all the organisations involved in this research (apart from the commercial organisations, whose function was to sell a product) were social network formation and facilitation, advice giving and signposting to other organisations and public services.

There was some evidence of partnership work with health services, but this was minimal, evident in only a minority of organisations, and there were no sustained examples. Some organisations reported that they were a source of information about health services and provided some support in health service engagement, but again these were among the minority.

9.2.3 Engagement with health services, HIV related services and understandings of health

Participants displayed a range of understandings of health and healthcare systems. The large majority had only used GP services in Scotland and reported that this would be their first point of engagement if they had health issues.

Two influences on approaches to health service use were identified by participants that might distinguish them from Scottish approaches: “folk” and “religion based” understandings. These were said to exert greater influence on people who either had recently arrived in Scotland or were from countries that had a lack of formal healthcare system.

Most participants had both positive and negative experiences of health service use in Scotland, but the large majority were happy with their experiences. Regularity and the dependability of the health services in Scotland were

strengths highlighted by participants. Free access was also a favourable contrast to health services in countries of origin.

Negative experiences covered a broad range of issues, but most concerned a perceived lack of understanding of African migrants and potential experiences of discrimination in the healthcare setting. Some participants perceived that African physiology and cultural characteristics were not well understood by Scottish doctors, and that this was sometimes handled insensitively, particularly the cultural issues. This sometimes led participants to lack trust in healthcare workers. Lack of understanding was particularly prominent in refugee participants' unmet needs concerning mental health issues.

Discrimination in the healthcare setting was reported by a small minority of participants. These participants' perceptions were dominated by their negative experiences and eroded their will to further use health services. Rumours and stories about negative experiences of health service use by Africans, such as discriminatory treatment, had an influence on participants regardless of whether or not they had experienced negative treatment themselves, and eroded their trust in the Scottish healthcare system to be able to meet their needs.

Three participants reported testing regularly for HIV on a voluntary basis. Only five had been prompted by GPs to test for HIV here and they had all found this prompt to be inappropriate. All five participants reasoned that they were not at risk of HIV for the reasons covered in the subsequent chapter on Risk, summarised below.

9.2.4 Awareness and understanding of HIV and HIV related stigma

The sample had very high awareness of HIV, modes of transmission and the nature and availability of treatment of HIV. For the large majority of the sample this knowledge came from health promotion in their countries of origin. In contrast, participants reported an almost complete lack of HIV related health promotion in Scotland that they were aware of. In addition to this, participants reported a total lack of discussion of HIV reported in the diaspora, which they did not consider abnormal. Two main reasons were given for a lack of discussion: stigma and a lack of perceived risk of infection in Scotland. Stigma around HIV

meant that people expected to be socially marginalised if they brought it up in conversation. Stigma was also connected to the risk of upsetting other people if they or their relatives had had negative experiences with HIV or AIDS. Concerning risk, participants did not feel that they were at risk of HIV and therefore the issue was not a concern that needed to be discussed. Exceptions to the lack of discussion were identified to be particular life points: immediately before marriage and screening during pregnancy.

HIV related stigma was reported to still be a considerable issue in the African diaspora in Scotland. Stigma took different forms, with non-Africans marking people in the diaspora and Africans stigmatising others in the diaspora. External stigma was enacted on Africans by non-Africans through association of Africans with HIV, both as sources of HIV and vectors of the disease. The mass media was identified by participants as a reason this stigma perpetuated, with Africans reportedly portrayed as diseased and virulent. This stigma was connected to the perception by participants of Scotland as a hostile environment for Africans due to discrimination and anti-immigrant sentiment.

Stigma from within the diaspora concerned stigmatisation of individuals connected to HIV rather than Africans in general. It was also mostly anticipated stigma rather than enacted stigma. Several reasons for HIV stigma's continuation within the diaspora were given: fear of HIV's potential deadliness, fear of infection from individuals with HIV and fear of ostracisation within already marginalised social networks.

9.2.5 Understandings of risk of infection with HIV and responses to potential targeting of Africans for HIV related initiatives.

Only a minority of participants thought that Africans in Scotland were at higher risk of HIV infection than the majority population. Most believed that they were not at higher levels of risk for a variety of reasons. Participants tended to have environmental understandings of risk. The risk environment Africa represented was left behind with migration to Scotland, and for these participants, Scotland was a low risk environment. Another reason why participants did not necessarily feel at risk as individuals was that Africa was described as a highly diverse continent in terms of its environmental risk factors. These included: differing

levels of HIV prevalence; differing health care systems that could be said to insulate against risk; and different attitudes to HIV risk awareness and protection against infection. If they had come from a country where these factors were not an issue, then they did not consider themselves to be at higher risk. Another reason given for lack of risk of Africans in Scotland was that risk diminished over time, so people who had been in Scotland for a long time claimed insulation from environmental risk issues. Some participants denied higher risk on the basis that they believed the statistical evidence for this to be dubious. These participants distrusted official sources of evidence and suggested that an agenda might be in place to move blame for HIV infections onto African migrants.

Participants had two particular explanations for what might put them as individuals at higher risk of infection: promiscuity and immorality. Promiscuity, i.e. history of multiple sexual partners or sex outside the marital relationship, was seen as a key risk factor for HIV infection. Participants who did not consider themselves promiscuous therefore easily distanced themselves from risk. Morality was also appealed to as a precursor of HIV risk, with those living an immoral life said to be at higher risk. Living a moral life was characterised by observation of religious standards. It was unclear to what extent this was just a euphemistic way of discussing promiscuity.

The majority of participants said that targeting Africans for HIV initiatives was inappropriate, due to the previously explained understandings of risk and stigmatisation connected with HIV. According to participants, targeting would further stigmatise African migrants as the vectors of HIV infection and further marginalise them from society. Alternatives to targeting Africans suggested by participants were: blanket testing of the entire population; targeting those who had recently arrived in the UK; targeting people from countries with high prevalence (including those out with Africa) and targeting Africans with general health initiatives in which HIV would be one of many health issues addressed. These alternatives were connected to the reports that participants would have been happier to be prompted for testing if more explanation had been given as to why they were being targeted beyond just being from Africa.

9.3 Appealing to appropriate identities for encouraging African migrant service use

I have chosen to focus on identity as part of this discussion since participants questioned the current approaches to using "African" as a way to appeal to African migrants. The "African" identity is the framework in which current guidance for encouraging HIV testing with African migrants has developed (National AIDS Trust, 2014; National Institute for Health and Care Excellence, 2011). The vast majority of current efforts to increase uptake of HIV related services by people from high prevalence countries in Africa appeal to "Africans".

It was clear that the African migrant diaspora was highly heterogeneous across many dimensions. The action plan "The Knowledge, the Will, the Power" (Dodds et al., 2008) emphasises that behaviours and responses of African people to intervention efforts will be shaped by "location, age, gender, religious belief, migration history, cultural values, information and changing social and material circumstances." (Dodds et al., 2008). The particular manifestation of these factors that I focussed on in this research was participants' self-ascribed identities. Identity negotiations, moving between identities and different sets of norms and values, are especially profound for individuals in minority social settings (Kuusisto, 2010). Negotiations are particularly important because the majority's values and expectations are perceived as fundamentally different to those experienced at "home" (Kuusisto, 2010). Initiatives designed for and targeted towards African migrants need a nuanced understanding of the types of identities they might adopt in order to appeal to those identities in a relevant way. My research has revealed some potentially helpful principles for engaging African migrants' identities so as to improve the chances of relevancy.

9.3.1 The problems with the utilisation of "African" identity

For participants, "African" seemed to have multifaceted, complex and different levels of meaning, many of which were negative. Therefore the assumption that "African" will have salience for all African migrants in Scotland should be challenged.

For some there was merit in the “African” identity, beneficial in community organising and bringing individuals together to develop support networks. It was a self-generated identity associated with pride, and the characteristics of it were developed by Africans themselves. This is distinct from the way in which the identity is imposed on Africans by non-Africans, especially by the health services. This imposition, according to participants, carried with it numerous assumptions dominated by negative stereotypes. These identified Africans as suffering from: low levels of education; poverty; illness and lack of social and economic resources. It has been documented that when ethnic groups feel marginalised on the basis of a racial identity, especially if this identity is highly visible in society (i.e. because of skin colour), their minority status serves to intensify threats to identity, feelings of social isolation, and concerns about exclusion and discrimination (Mollica et al., 2003). Therefore concerns about the stereotyping of Africans made by health services could be exacerbated by the use of “African” as an identity. This might be particularly the case concerning HIV, as the “African” identity as deployed by non-Africans had extra negative assumptions in Scotland concerning Africans as the sources and vectors of disease.

Another issue was that “African” as a generalisation overwhelmed individual participants’ characteristics when applied to them by non-Africans. They did not like being considered primarily as “African” rather than according to their individual merits. Again, this links to the assumed stereotypes that participants thought were being connected to them via this identity. Stryker (Stryker & Serpe, 1982) refers to “race” as a master status in that it can override other characteristics of a person in the construction of their identity.

Dodds (Dodds et al., 2008) is critical of the pattern of “black African” being the standard terminology deployed in HIV prevention efforts, as she argues that the validity and utility of the term are unclear. Indeed these findings suggest that “African” is heavily bound in Africans’ assumptions of stereotyping. In addition, Aspinall and Chinouya (John Aspinall & Chinouya, 2008) suggest the identity of “African” in healthcare engagement and research obscures more deterministic variables like language, nationality and religious differences. Furthermore, using “African” can cause discrete national groups, ethnic groups and those divided by geo-political boundaries to go unnoticed even though they may have divergent

values regarding health and healthcare use. Therefore not only does deploying the term potentially cause negative reactions amongst Africans, creating barriers to engagement, it also carries the risk of obscuring variables that might determine variation in health service and HIV related service use (John Aspinall & Chinouya).

Given all of these issues, it is clear that "African" needs to be deployed in a very sensitive manner, and perhaps only when there are Africans visible in the development and implementation of initiatives. This would help negate the perspective of negative assumptions connected with the imposition of the African identity by non-Africans.

African identity could also be deployed more sensitively through language use that avoided potential connections with the negative stereotypes that the target audience of Africans might assume are being made. An awareness of this potential reaction might also be used to inform approaches to community engagement in a sensitive and nuanced way, taking care to develop thorough understanding of African communities rather than just using continent of origin as an identifying marker.

In relation to this, participants reported alternative identities which could be used to appeal to the diaspora. I will discuss the key examples below.

9.3.2 Nationality based identity

Nationality based identities were shown to be important for participants, but did not have the same risk of negative connotation as was the case with "African" identity. National identities were not associated with potential for discrimination, and did not necessarily carry the same associations with poverty and disease. However, there were conditions to nationality based identities being used which should be taken into account. Mehra (1998) suggests that for minority identities, there needs to be a minimum threshold of shared identity and social interaction for a particular identity to become relevant, and this only applied to a few nationalities in Scotland. Identity here was negotiated based on the presence of communities. Pragmatically it would not make sense to develop appeals to service use on the basis of nationalities if this threshold had not been

met. For others, their national identity was something they wished to avoid. This was the case primarily for asylum seekers and refugees who had experienced and escaped terrible traumatic events and circumstances in countries like Rwanda and Eritrea, and did not necessarily want to be associated or interact with other people from those countries.

National identity was far less problematic than African identity for participants and it perhaps provides a less risky approach to appeals to service use. However it needs to be deployed with sufficient awareness of the nationality in question, rather than repeating national stereotypes.

9.3.3 Religion based identities

Religion *was* reported to be of central importance to social identity and networks for many in the diaspora. However there was also a wide variety of religiosity displayed in the sample. The most important finding concerning religious identities was that no assumption of universality can be made about its relevance for participants. Affiliation to a church or mosque did not necessarily mean that religious identities were a dominant part of peoples' overall identities. Assumptions should not be made that appeals to religious identities or religion based social networks will have relevance for all Africans in the diaspora. Perhaps more important than religious dimensions of identity, in terms of appeals to engagement, are religious sites of networking. Even when individuals had lower levels of religiosity, they still tended to engage with religious networks and networking sites. Religious networks were easily accessible, convenient and provided substantial social support. Therefore the utility of the religion based identity for engagement might be appealing on the basis of site of engagement. Churches and mosques remain important, as central nexuses of social networks, and are therefore potentially important sites of intervention, engagement, health promotion and recruitment. Religious organisational use will be discussed later in the chapter. This approach has its own limitations. Some participants were sceptical about the extent to which a "private" health concern might be able to be discussed in a religious environment, and HIV or sexual health related discussions might meet considerable barriers from potential gatekeepers. In addition to this, religion based understandings about "morality" as a precursor to HIV risk might minimise

opportunity for objective and non-judgmental discussion around HIV, particularly concerning stigma. However, religious sites continue to present a considerable opportunity for engaging with the diaspora.

9.3.4 The use of migrant based identity for refugees

The identities of refugee and asylum seekers in the sample were dominated by migrant status dictated by the asylum process and subsequent attempts to gain work, housing and welfare as refugees. They were the only group that described little control over their own identities. The implications for engagement are that particular effort might be needed to produce services that resonate with their refugee identities. However, any use of the refugee identity to encourage service use must be extremely sensitive, as refugee participants were highly aware of the negative characterisation of refugees in British society, and were therefore hesitant to be identified as such, even though they found it very difficult to engage any alternative identities.

9.3.5 Identities - conclusion

There are clear risks and rewards in deploying different types of identities to try and engage Africans in services. Whilst the African identity is the most strategically straightforward, and requires the least precursor knowledge about the target audience, it is for these exact reasons that it faces the greatest risk of alienating those it is trying to engage. Alternative identities require a greater understanding of the nuances of the targeted group. Recommendations that emerge from these findings are that identities should be better understood and it should not be assumed that “African” is positive to African migrants, especially when it is being deployed by non-Africans, or services that are viewed to be non-African.

9.4 Insufficient consideration of the context of African migrants as a barrier to engagement

The previous section noted that a lack of contextual and nuanced understanding of the way that identities were used by African migrants led to situations where participants felt that unfair assumptions were being made about them. This same lack of contextual understanding also applied to perceptions of service

providers. It has been noted in other research in Scotland that the barriers to more efficient and appropriate engagement with African migrants stem from a lack of consideration of their lived realities (Burns et al., 2007). Service provision could benefit from gathering more sophisticated understanding of the influences on service use decision making and African migrants' perceptions about services. In this section I will discuss two main areas of contextual detail that emerged in this research within which greater knowledge could result in more appropriate engagement. These are the existing environment of marginalisation and prejudice, and African migrants' sources of information about health and HIV.

9.4.1 The existing environment of marginalisation and prejudice

Most participants perceived the UK as a hostile environment for African migrants, and for some this caused hesitation when using health services, and when thinking about engaging with HIV services. Several participants had experienced what they thought was prejudicial treatment when using services, which had an extremely negative effect on their will to use services in future. The National AIDS Trust (National AIDS Trust, 2014) suggests that a pivotal reason much of the existing information and support around HIV testing and care is ignored by Africans in the UK is due to their perceptions of the hostile environment. This is driven by a hostile immigration system, politics and mass media which appear "consistently hostile to their arrival and presence in the UK" (National AIDS Trust, 2014).

The way African migrants in this research viewed health services and efforts to engage with their communities was through the prism of their perceptions of the hostile environment Scotland represents. Therefore it is essential to develop service provision and research priorities that take into account the effect that discrimination experienced, perceived or predicted might have on service use.

Research on immigrant health has typically concentrated on issues of culture, and research on influences of discrimination and its consequences on health and service use is relatively new (Viruell-Fuentes et al., 2012). Beyond recommending further research on the effects of a hostile societal context, some specific recommendations for health engagement can be made. Acevedo-

Garcia et al (Acevedo-Garcia et al., 2012) suggest that for successful migrant health engagement, a starting point must be a framework of understanding that emphasises structural barriers. Structural processes of discrimination formed the prism through which my participants viewed services. This related to immigration policy, social and socio-economic context, experiences of institutional racism in the job market, and experiences or reports of discrimination in health service use.

In order to counter these structural inequalities, Quesada et al. Quesada et al. (2011) propose a move away from focus on the details of individual migrants and instead towards structural understandings of determinants of their health engagement, in particular vulnerabilities that are engendered by the societal context. This could be a useful way of overcoming individualised models, in which "cultural" issues are given explanatory priority, placing the onus of change on individuals rather than on collective and societal processes (Acevedo-Garcia & Almeida, 2012). Page-Reeves et al. (2013) use a "structural violence" concept which emphasises issues such as fear of perceived official bodies and structurally facilitated and encouraged discrimination as determinants of the way migrants engage with services. Referring to these forces as "violence" helps to emphasise the considerable negative effects they can cause.

I would argue that an engagement framework that takes processes of structural violence into account would improve chances of both minimising perpetuation of structural discrimination and also resonating with the experiences of African target audiences. Such a framework could determine the nature of the language used to appeal for engagement, the way community gatekeepers might be recruited, the priorities of the intervention and other aspects in a direct and prominent manner, with specific reference to the local situation in Scotland.

With more visible statements on mechanisms which lead to anti-migrant sentiment and the impacts of the political context on discrimination, service providers might be perceived as more sensitive and empathetic by potential migrant service users. This type of structural intervention would require a considerable cultural shift in approach to research and service provision that might be difficult to operationalise.

However, the design of individual efforts to engage could have more visible statements acknowledging the levels of structural discrimination that African migrants face. This would challenge perceptions by potentially targeted communities that specific efforts to engage are coming from the same sources as the structural discrimination they perceive in Scotland. This could in turn encourage engagement. Service users would be more likely to connect with a service that displays empathy to their position, and this would also encourage trust development between users and providers. Whilst this approach may have been taken by some organisations in the UK, it does not appear to be well documented in the academic literature, and is certainly an area for further investigation.

Concerning the issue of structural violence and experiences of discrimination by my participants, this research reflects the possibility, given the lack of direct experience by participants, that these are not as extensive as they are perceived to be by African migrants in Scotland. It is very difficult to measure discrimination as identified by those discriminated against (Athwal et al., 2010). However, I have used the definition used in the pivotal 1999 MacPherson report (Athwal et al., 2010) in which a discriminatory incident is one which is perceived to be discriminatory by the victim or any other person. In this research participants felt the Scottish environment was discriminatory and that they were victims of structural discrimination, therefore it is vital to take this into account when trying to encourage service use.

9.5 Understanding sources of, and the nature of, information about health and HIV that are used by African migrants in Scotland

African migrants' patterns of health service use are shaped by their sources of information about these institutions. These could be termed culture driven perceptions of migrants, which in the previous section I have argued against. However, cultural expectations have been shown to affect peoples' service engagement behaviour (Dixon-Woods et al., 2005). Dixon-Woods identified organisational cultural dissonance where the cultural norms of healthcare organisations do not align with those of their users (Dixon-Woods et al., 2005). These data on participants' sources of information about, and understandings of,

the health services could improve services and help them reach the highest number of potential users in the diaspora. In addition, using already existing conduits of information might lead health services to be more trusted.

Study participants had high levels of knowledge about HIV and understandings of various routes of engagement with the health services in Scotland. It was also clear that social networks were a trusted source of most of their information around health. For some, this source was more valued and more trusted than health professionals themselves. These community based sources held as much influence over some individuals' health related decision making as professional medical influences, in some cases more so. This was linked to participant perceptions of the Scottish environment as hostile, which extended to include some perceptions that professional medical staff were not as trustworthy as other African contacts.

Dixon-Woods et al. (2005) in their systematic review on vulnerable groups and access to healthcare suggests that "lay referral systems" have a considerable influence on help-seeking behaviour for those in a "vulnerable" position in society. Burns et al (2007) in their study of why Africans present late to HIV related services in the UK suggest that they tended to rely on their informal networks and word of mouth for health engagement information, particularly around HIV. They suggest this is primarily because of culturally inappropriate and inadequately targeted health care initiatives.

Dixon-Woods et al (2005) argue against the idea that lay systems which encourage over or under-use of the health system are "wrong". Instead there needs to be recognition of the value of these systems as formative and determinant of people's decision making processes and actions. Trying to force "professional" types of understanding into a system dominated by lay referrals will be unlikely to have the desired effect. This was evident in my research, with resistance displayed to professional narratives about health, and narratives of distrust of doctors and healthcare staff apparent in the sample. Instead Dixon-Woods et al. (Dixon-Woods et al., 2005) advocate that accurate information is easily available in formats that are relevant to the lay referral system for the target audience, such as radio stations and community networks.

A more thorough understanding of sources of information and lay referral systems within the diaspora could provide details about where to focus health promotion or intervention efforts, and what kind of approach and language would be most appropriate. If approaches are framed around lay referral systems and how to complement these, rather than contradicting them, a more suitable, nuanced and better received health engagement message might be possible.

9.5.1 The power of rumour

One particularly notable aspect of the influence of social networks on individual decision making processes around health service engagement that emerged during this research was the power of rumour. Of particular influence were reports of negative experiences with the health services that passed through social networks. Whilst very few participants had directly experienced negative treatment, many more knew of someone that had. Negative stories persisted in social networks longer than narratives of positive or "normal" healthcare use. Many of these rumours concerned incidents of racism or broader discrimination. It could be that in comparison to these rumours, information from professional sources countering rumours takes a lower priority in informing healthcare decisions, particular if the rumours concern the untrustworthy or antagonistic nature of the professional sources. Research on Africans' health services use in London has revealed the considerable negative effect that previous experiences of anti-migrant or anti-African discrimination has on the will to engage with further service use (Anderson & Doyal, 2004; Dodds et al., 2004)

One potential way to counteract rumours is to question why they exist. There were particular rumours for example concerning negation of visas due to illness, aggressive quarantine of malaria patients, and prejudicial attitudes of healthcare staff, especially receptionists, that seemed to be recurring. It is difficult to suggest how these rumours might be countered, but being aware of them prior to trying to engage with African migrants would help service providers to be ready to attempt to refute them. If a particular rumour was problematic then trusted sources within the diaspora could potentially be recruited to try and counter the rumour.

9.6 Developing links with community based organisations to encourage service use

One objective of this research was to ascertain to what extent African affiliated organisations affect African migrants' access to health services. As seen in the results chapters, their influence was not substantial. However, my research did reveal some detail about the extent to which African affiliated organisations might be useful in promoting health service use in the wider diaspora.

A potential solution to the difficulty of recruiting Africans to HIV related interventions for Africans (National AIDS Trust, 2014) would be enlisting the help of trusted individuals and organisations to help facilitate. Whilst all the organisation representatives were keen to facilitate healthcare service use, and many were also keen to develop sexual health and HIV related initiatives, it was clear that there was very little of this happening in a sustained and systematic manner. This relates to issues I found that might act as barriers to successful facilitation and collaboration with community based organisations in the future. In the following section I will discuss these barriers and potential solutions.

9.6.1 Problems with community organisations

Many of the organisation representatives I spoke to discussed difficulties in reaching large numbers of Africans in the community. They attributed this to lack of resources to undertake activities and a lack of community cohesion, which adversely affected attempts to come together around a particular identity.

Campbell & McLean (Campbell & McLean, 2002) found in their study of African Caribbean community engagement in England that whilst the African Caribbean identity played a central role in peoples' interpersonal relationships, it did not extend to the community level in terms of advocacy, activism and organisation. Their participants identified reasons for this as a combination of apathy, individualism and lack of confidence. This certainly seemed to also be the case with reports of community organisation in my study.

Another substantial problem for the organisations in my research was that the only ones that had any consistency of activity and sustainability were those that

either had confirmed funding (integration networks, commercial venues) or religious organisations. Representatives recounted that their unfunded organisations suffered from considerable changes in activity levels, which badly affected the will of their communities to subscribe to them or support them as volunteers and users. Lack of sustainability also severely limited what organisations were able to accomplish within communities, and caused “fatigue” amongst community members. This fatigue manifested as scepticism about organisations by community members and a consequent lack of reach. The National AIDS Trust report (Hjerm & Bohman, 2014) warns that consistency in the African voluntary sector in the UK is a priority issue, citing the lack of maturity of most organisations. The authors recommend that civic infrastructure be developed in order to maximise impact and reach African communities. This is perhaps beyond the scope of health interventions around HIV. However it is important to highlight that supporting the sustainability of these organisations, perhaps through core funding, could help to achieve community health related goals. Alternatively an intervention might be developed to enhance a community organisation with the specific objective of increasing HIV related service engagement, but it would have to also improve the longevity of the organisation to be worthwhile.

Another aspect of organisations I encountered was a lack of inter-organisational cooperation and communication. This led to a highly fragmented African community organisation sector competing for resources. Cornish and Ghosh (Cornish & Ghosh, 2007), in their assessment of successes of community led HIV prevention initiatives in India, comment that power dynamics within target communities are rarely taken into account by intervention designers. They blame idealistic views of community participation which rarely reflect hierarchical and exclusionary realities, especially within already marginalised communities. My research suggest that a considerable understanding of local power relations and politics between organisations is a requirement to collaborate successfully with the right organisations, i.e. those that have substantial reach within the diaspora and will be able to contribute significantly to an intervention.

Repeatedly, research into community organisation collaboration has found that groups that wield the greatest power tend to dominate the course of

interventions (Shiffman, 2002; Stern & Green, 2005). In my research an analogous situation might be collaboration with local elites. Rather than communities engaging for collective benefit, those who are already relatively powerful take advantage of opportunities offered (Beall, 1997) or can even obstruct others in order to maintain dominance (Cornish & Ghosh, 2007). This certainly reflects what I found in my research, with a very select few elites and organisations within the diaspora being the only ones repeatedly approached by councils and other official entities for engagement purposes, alienating other communities and organisations. For future efforts, identifying local internal community power structures would be vital in avoiding potential pit falls such as these. This type of information could increase the chances that health initiatives collaborate and engage with a cross section of the diaspora rather than a specific subgroup that holds a position of power.

All of these barriers to successful collaboration with community based organisations have the same solution, which is to have considerable knowledge of local groups and their contexts before approaching them to take part. My findings on the characteristics of these organisations confirm Campbell & McLean' (Campbell & McLean, 2002) caution: blanket attempts to engage with community groups that do not take into account local nuances, political landscapes and the characteristics of particular communities will be unlikely to be successful in utilising local community organisations.

9.6.2 Specific benefits of collaborating with community groups

Despite the issues identified above, there are potentially substantial benefits to developing collaborative efforts with African affiliated organisations to encourage HIV related healthcare engagement. Community organisations have been shown to be a considerable resource in various ways in efforts to engage with African groups (Hickson et al., 2009). They can improve reach, increase acceptability and contribute to the development of practices that can increase chances of sustainability of interventions (Hickson et al., 2009). In my research many of the organisations were claimed to have important social functions in local communities, and it appeared as though local Africans trusted the organisations as sources of advice and support. This was also found to be the case in consultations for the NAT (National AIDS Trust, 2014) report, which

suggested that small third sector and volunteer organisations were often alternative communities people turned to in order to avoid mainstream services due to distrust, expected discrimination and stigma.

As previously discussed, the context in which African migrants live has a considerable effect on how they will react to attempts to engage with African communities. This is true on a national scale in terms of perceived anti-migrant and anti-African sentiment, but it is also true on a local scale. The local realities within which African communities exist could change the way potential service users feel about interventions. Direct sources of information on local contexts are local community based organisations. The Sigma African HIV Prevention Handbook (Dodds et al., 2008) suggests local knowledge held by community groups is a "key tool in shaping the context of local HIV prevention interventions." (Dodds et al., 2008, 32). Community organisation involvement may also help to ensure that those targeted influence the development of the interventions which therefore encourages ownership and salience.

Beyond these aspects of general collaboration, two specific types of organisations displayed particular potential during my research: asylum seeker drop-in services and religious organisations.

It was clear that for asylum seekers and refugees, drop-in services and related charities formed central links in their social networks in an exclusive way that was not the case in terms of organisations for other migrant types. This was particularly the case for recently arrived asylum seekers or refugees. Therefore they represent a unique opportunity to reach these particular individuals who otherwise would be extremely marginalised and difficult to engage with services.

Religious organisations were also of particular note in that whilst not ubiquitous, they formed a considerable part of African migrant social networks and site of networking. In addition to this religious leaders were perceived by my participants to be highly trusted community members who could act as powerful collaborative advocates for HIV related initiatives. Religious organisations can have considerable influence over members' behaviours at multiple levels when collaborating with health based interventions (Campbell et al., 2007). This was

also found to be the case in data reviewed on African communities in England by the National Aids Trust (National AIDS Trust, 2014), where pastors and imams were singled out as being sources of trusted support. NAT (National AIDS Trust, 2014) cite organisations such as the African Advocacy Foundation and the African HIV Policy network as conducting HIV intervention programmes with the help of religious leaders and sites of worship. The African HIV Policy Network (Dodds et al., 2008) suggest that because faith based approaches to care often emphasise mutual care and responsibility, they have much in common with health promotion aims. African pastors in England have also been found to be agreeable to efforts to support those with HIV and be involved in prevention measures (Dodds et al., 2008). There are no reasons to suggest this is not the case in Scotland as well, however perhaps more research should be conducted to confirm this is the case, as recommended by the NAT (National AIDS Trust, 2014) report.

Assumptions about the usefulness of religious groups should be qualified, however, as there is the risk that religious gatekeepers hold conservative views concerning homosexuality and extramarital sex, which could prevent frank and open discussion of issues of sexual health. This was also found to be the case by (Dodds et al., 2008) where religious leaders in studies reviewed proclaimed willingness to help develop HIV related efforts, but found them conflicting with conservative beliefs around sexual health. Campbell et al. (2007) suggest that substantial collaboration with these groups at the stages of design and delivery can help to identify and avoid these potential issues.

9.7 The profound influence of stigma

In exploring the barriers to discussion of HIV, convincing African migrants that HIV is relevant to their lives and engagement with HIV related services, the issue of stigma arose repeatedly in this study. This aligns with a large body of research that has consistently found stigma to be the central barrier to HIV prevention and treatment programme use (Chesney & Smith, 1999; Kalichman et al., 2009; Mahajan et al., 2008). There is considerable evidence that pre-emptive fear of stigma is enough to prevent Africans in the UK from using testing services (Dodds, 2006). Stigma has also been found to be a problem specifically in Scotland, and in particular in African communities (International Planned

Parenthood Federation, 2010) Furthermore, for African migrants, stigma presents a particular threat to what is their most valuable means of support in the UK, their personal networks of family and other African migrants (Dodds et al., 2004).

All of these factors create a highly complex picture of HIV stigma for African migrants in the UK. My research illuminates some nuances concerning stigma which will be discussed below. If future prevention and treatment efforts are to hope to engage African migrants, then stigma amongst Africans in Scotland will need to be better understood and addressed.

9.7.1 The disconnect between stigma and HIV knowledge

One recurring theme in my research was that it was not necessarily the case that people who reported a high level of biomedical HIV knowledge about transmission, the nature of treatment and were aware that HIV is not necessarily fatal, would not stigmatise others. Participants with whom stigma alleviation was discussed all suggested that education would be a major influence and perhaps the best solution to dealing with HIV related stigma, and those who had the facts around HIV would no longer stigmatise. However, this does not fit with the evidence from other participants that people who were well informed could still stigmatise.

Indeed, the NAT (National AIDS Trust, 2014) report highlights that there is insufficient evidence to suggest a causal link between being well informed about HIV and having fewer negative judgements towards people with HIV. It is also the case that the effectiveness of interventions designed to reduce HIV related stigma that focus specifically on knowledge is unclear (Mahajan et al., 2008), and knowledge communication programmes, particularly in the mass media, have shown limited positive impact (Bertrand et al., 2006). An alternative to education to combat stigma suggested in the NAT (National AIDS Trust, 2014) report is to strive for a greater understanding of how HIV stigma operates in African communities in the UK, and how knowledge, education and stigma are linked for these communities. Once these mechanisms are better understood, specifically in relation to these communities, it may be clearer what a constructive path to stigma alleviation, and therefore facilitation of service use,

looks like. My findings on some of the details of stigma contribute some way to this, but further research is required to understand the specific processes by which stigma is generated and perpetuated in Scotland.

Another criticism of previous efforts to alleviate stigma is that most have tended towards biomedical understandings and individualistic approaches, rather than focusing on the structural determinants of processes of stigma (Scambler, 2009). In my research, structural determinants of stigmatisation of Africans as HIV carriers were identified as the mass media, and wider phenomena of racism and anti-immigrant discrimination. Scambler (2009) also suggests that contemporary HIV/AIDS stigma efforts are top down, and aspire to change individuals' behaviour in particular ways, with a tendency to not take into account social contexts and structures. Perhaps a better approach than challenging individual levels of knowledge and related assumptions would involve better understanding of what the structural influences are within communities that lead to stigmatising processes and instead challenge those with the cooperation of community members.

9.7.2 Decreasing the potential for health service related perpetuation of stigmatising Africans as carriers of HIV

One of the central barriers to using HIV related services identified by participants was that they were afraid they might be identified and stigmatised by other members of their community. Indeed, felt stigma arising from expectations of experiencing enacted stigma can arguably be as much of a barrier to service use as enacted stigma itself (Deacon, 2006).

But there was another layer of complexity to this, in that participants thought that health services in general stigmatised them as having HIV just because they were Africans. All of the participants who had been prompted to test had been prompted by a GP at a general health clinic. All of them had been to various extents surprised by this prompt, with some participants feeling insulted by it to the extent that it dissuaded them from further service use.

This takes place in a societal context perceived by my participants to associate Africans with HIV in general, which aligns with other research on the topic

(Burns et al., 2007; National AIDS Trust, 2014). This could in turn exacerbate fears of stigma within the diaspora as individuals look to separate themselves from the most stigmatised, i.e. African migrants with HIV. It should also be acknowledged that levels of HIV related stigma in many participants' countries of origin are likely to be high (De Cock et al., 2002; Dlamini et al., 2009), which is almost certainly another influence on African stigmatisation of Africans and means these issues are probably deeply entrenched.

All of these influences increase likelihood that Africans will expect or indeed experience HIV related stigmatisation in service use. It is arguable that HIV stigma related to Africans in the UK is extremely complex (National AIDS Trust, 2014), and would require long term research to untangle and properly understand. My results indicate that initiatives intended to engage Africans around HIV issues have to be hypersensitive to any potential stigmatising processes. This should be above and beyond what might be the case with other groups, based on nationality or ethnicity, which are not so severely stigmatised in wider society, or have so many complexities concerning stigma in their communities and social networks. The African migrant response of denial and resistance to the idea of increased HIV vulnerability are diametrically opposite to that of another highly stigmatised minority group, men who have sex with men, who campaigned for greater recognition of their vulnerability to HIV, and for increases in beneficial public health responses. Offering an explanation for this does not fall within the scope of this research, but contrasting the difference in experience between these two groups might reveal further details about the processes by which HIV stigma has become so apparently entrenched amongst African communities in Scotland.

This entrenchment has connotations in practice which could be applied in many areas of engagement including: the framing of language to be neutral; the training of staff to be hyper aware of stigmatising processes; nuance in the way people are targeted; awareness of the visibility of people using HIV services and the problems that can stem from this; and to issues around confidentiality. My research suggests how absolutely vital these types of efforts might be to persuade Africans that they will not be stigmatised, and that the services themselves will not further cause stigmatisation.

Burns and Fenton (Burns et al., 2007) highlight areas of good practice regarding engaging African migrants with HIV services in the UK. They suggest that one of the reasons for stigma associated with service use is that HIV testing in the UK tends to reside solely in the professional sector, creating barriers to engagement and space within which stigma can grow. Community-based voluntary counselling and testing services have had some success in African countries (The Voluntary & Testing Efficacy Study, 2000). However there have been issues with this approach and there have been efforts to follow it which have not been successful (Prost et al., 2007). Shifting action from the professional to the community sector is no guarantee of lessening stigma. As Prost et al. (Prost et al., 2007) suggest, feasibility is dependent on the local context, the desire for these kinds of services, and the extent to which communities see a need for them. In addition there is not a detailed evidence base for community based prevention and testing for African communities in the UK, or an understanding of how to integrate community based efforts with wider mechanisms of mainstream HIV prevention structures (Thornton et al., 2012). Whilst my research does not specifically inform intervention design in this area, it does broaden the knowledge of the stigma that might be present in the diaspora. It also emphasises that stigma takes places in a structural context which needs to be taken into account before it can be addressed.

9.8 Communicating risk of HIV infection in order to encourage service use

The second topic, after stigma, that was most recurrent in discussions of why participants did not engage with HIV related efforts, was understandings of HIV infection risk. The large majority of participants in my research thought they were not at risk of HIV, and therefore did not consider HIV related services to be relevant to them. The underestimation of risk is consistent with other studies on perceptions of risk of infection by African migrants in the UK and across Western Europe (Burns & Fenton, 2006; Burns et al., 2008; Erwin et al., 2002; Fakoya et al., 2008; Sadler et al., 2007). The idea that they would be at risk simply because they were African migrants was ridiculous for some and offensive to others. However, epidemiological data shows that African have a substantially higher prevalence of HIV than the majority heterosexual population (National AIDS Trust, 2014).

Risk was understood by participants in two main ways, in terms of social environmental context and in terms of individual lifestyle. Social environmental context was understood in terms of whether people had come from a high risk area (e.g. Zimbabwe) and the elapsed time since arriving from that environment. Environments were described as high risk on the basis of local social, political and economic contexts as well as prevalence of HIV. Political upheaval, war, lack of medical resources or a formalised medical system and high levels of rape were identified as risk factors. For some of those that understood risk in this way, it persisted across continents, but lessened over time. For others, removing oneself from that environment immediately lessened your risk. The lifestyle understanding of risk was not mutually exclusive with the social environmental explanation, and many participants used both. The lifestyle explanation was behavioural in nature. Participants appealed to ideas of living a "moral" lifestyle to protect from HIV risk, but this was arguably a proxy for promiscuity. Risky lifestyle practices were not related to structural issues, but resided in the behaviour of individuals.

As (Sadler et al., 2007) suggest, people without HIV who do not know their HIV status need to perceive themselves as being at risk in order to take action, such as testing, to avoid HIV. In this section I will discuss some of the results concerning perceptions of risk and how they might be changed, or whether they need to be changed at all.

9.8.1 Strategies for risk communication

One strategy for risk communication is to define risk groups in a different way. The National AIDS Trust (National AIDS Trust, 2014) report "HIV and black African Communities in the UK" proposes that discussion around risk needs a substantial shift in focus away from ethnic variables. Instead they suggest a focus on behavioural aspects of risk, for example sex in high prevalence countries in the recent past. This would of course include most African countries, but also – essentially - others such as Thailand, and concern travellers as well as migrants (National AIDS Trust, 2014). This would fit with the risk understanding of the participants in my study, as it takes into account behavioural as well as environmental factors. However, it would not necessarily capture all African migrants. The NAT (National AIDS Trust, 2014) go further and suggest that HIV

prevention efforts focus too much on African risk as the primary risk of infection in heterosexual populations. They suggest that this paradigm needs to shift, and that risk identification needs to be much more specifically defined. This could take into account number of concurrent partners, new partner, unprotected sex, anal sex, casual sex and sex in countries of high prevalence.

Perhaps with a revised understanding of risk which is more in line with how African migrants themselves might decode risk of HIV infection, a more persuasive argument for testing and use of prevention services might be possible. It would also have the benefit of lessening the stigmatising and off putting proposal that all African migrants are at higher risk of HIV infection.

Another strategy to change the self-assessed levels of HIV risk is to address the context in which the message of higher risk is being communicated. Communication of risk lies in a context of potential distrust of those selling the message that Africans are at higher risk of HIV. Participants said that there was a general distrust of GPs, the health system and authorities in general amongst some in the African diaspora, and this meant that they did not trust appeals for testing and statements that they as African migrants were at higher risk of HIV. This distrust was a considerable barrier to service use. A large meta-analysis of healthcare use studies found that establishing good doctor-patient relationships is key for encouraging patient engagement (Parsons et al., 2010). Trust has consistently been found to be a strong requirement for good relationships (Campbell et al., 2007; Ford et al., 2003; Talen et al., 2008). In addition to this, an NHS Quality ambition in Scotland is to develop “mutually beneficial partnerships between patients… and those delivering healthcare services which respect individual needs and values and which demonstrate compassion continuity, clear communication and shared decision making.” (Parsons et al., 2010).

Examples of factors that lead to an improvement of trust have been identified as healthcare workers having substantial knowledge of the patient and tailoring their approaches to patients’ needs (Bastiaens et al., 2007; Talen et al., 2008). Some of my study participants expressed the view that Scottish health workers did not understand Africans and their health needs. Whilst concepts of cultural competency can result in the obscuration of structural influences of inequalities

in health engagement (Acevedo-Garcia & Almeida, 2012), in terms of building a relationship of trust there may be merit to a certain amount of cultural training (Brach & Fraserirector, 2000). Perhaps this could be focussed on GPs working in areas with high numbers of African migrants.

Another specific requirement for trust relationships identified by the King's Fund (Parsons et al., 2010) meta-analysis is empathy. Empathy covers many concepts, but of particular relevance to encouraging African service engagement are: ability to discuss personal matters with the GP; the feeling of being treated with dignity and respect; the feeling of being taken seriously by the GP; and feeling that the GP is interested in the person rather than the illness or condition. Of particular interest is the last requirement. If patients perceive that healthcare workers are focussing on HIV rather than on them as individuals in their prompts to test, it would result in a breaking of empathy and therefore trust. The concept of knowing details about the individual also fits well with the narrative of risk that is proposed by the NAT (National AIDS Trust, 2014) and participants in my research.

The actual content of the message about risk and the explanation behind it were also identified as being extremely important by participants. Those who were prompted to test for HIV were offended by this. This is because they assumed that the thought process in prompting them was a judgement on their sexual behaviour. Most, and others in the sample given the hypothetical scenario, suggested that if they had had a more substantial explanation of why they were being prompted to test, they might have been less offended. It should be noted that they would not have necessarily taken an HIV test, but their relationship with the health service staff would not have suffered as much. Participants left with insufficient explanation tended to fall back to narratives of negative perceptions they had about the health services and authorities in general in Scotland being antagonistic towards Africans.

Explanation of the process that leads to a judgement to prompt to test could be connected to the need for service users to be part of decision making processes. This was found to be an elementary dimension of patient satisfaction in the King's Fund survey (Parsons et al., 2010). The King's Fund central recommendation to improving interaction with GPs suggested that GPs must be

more explicit about when a choice is required and what the options are, and give patients time to make decisions and offer feedback about them. This was not reported to be the case by any participants in my research; most were simply told, you need to or you should have an HIV test. If service users had more autonomy in their negotiation of testing it might improve their perceptions of the services. This in turn might result in higher numbers deciding to test. In examining the acceptability of opt out testing in primary care sites in England, Glew et al. (National AIDS Trust, 2014) found that an explanation for the reasons to prompt testing were crucial for acceptance. Without this explanation, Glew et al. (Glew et al., 2014) propose that "The offer of an HIV test may be received as a judgement of an individual's sexuality, ethnicity or behaviour." (Glew et al., 2014, 63)

9.8.2 Good practice: the SHIP programme

The Sexual Health in Practice programme developed by the Medical Foundation for HIV and Sexual Health is a health worker training programme that emphasises breaking down stigma in sexual health by providing communication tools and access to resources (Pillay et al., 2012). It has been assessed and found to empower health workers to significantly increase general practice testing rates at various sites in London (Pillay et al., 2012). Importantly SHIP teaches a systematic approach to test prompting which aims to remove barriers to HIV testing. The programme emphasises good clinical knowledge, effective communication skills and risk assessment and sexual health history taking skills (Pillay et al., 2012). Using the SHIP approach could address many of the issues that my participants had with test prompting, by giving more explanation and more in depth interaction with better developed communication skills.

Whilst programmes like SHIP have been found to increase testing rates, and should be widely rolled out, there are broader issues with the general targeting of African migrants as a high risk group which will be discussed in the following section.

9.9 Targeting

For most participants, targeting Africans for HIV related interventions on the basis of them being African migrants was wholly unacceptable. Even among the small minority who said it was a positive approach, there was scepticism about whether it would be effective. The majority also suggested that targeting Africans would actually generate further barriers to engagement by increasing potential for anticipated stigma and potential increase in distrust for the health service.

These perspectives align well with the literature on targeting. As previously discussed, the African diaspora in Scotland and more widely in the UK is highly diverse. Sigma's African HIV prevention handbook (Dodds et al., 2008) emphasises repeatedly that not all Africans in the UK are equivalent in their HIV prevention needs. In addition to this, not all interventions are acceptable or even useful for all Africans. Therefore, Sigma recommends, each intervention should target particular groups of African people for whom it was designed. Dodds (2008) states "No intervention can be appropriate for all Africans living in England and no intervention should have "Africans" as its target group" (4).

The National AIDS Trust (National AIDS Trust, 2014) report found considerable "resistance to racial profiling" (11) in prevention efforts and a need to define more carefully who is at risk of HIV so as to increase relevance and salience of intervention efforts. Their informants suggested a consistent dislike by many Africans for HIV prevention activity "singling out" African men and women. They suggest there needs to be an alternative developed to the ethnicity based focus which "alienates the intended audience" (National AIDS Trust, 2014, 12) of African migrants. Their policy recommendations focus on greater visibility of media directed at the entire population concerning HIV, especially in high prevalence areas, rather than just at Africans. This would naturally take in areas with high numbers of African migrants, such as London. However, this would leave Africans outside these areas vulnerable, so this is a pragmatic solution in the face of limited resources.

Concerning a higher level of policy making, there are critiques concerning service providers' focus on infectious disease for migrant healthcare

engagement, when there is a lack of evidence that migrants are more at risk of infectious disease than chronic disease (Castañeda, 2010). Castaneda argues that morality based concerns about migrants as the vectors of disease have influenced academic and public health priorities in this area, particularly concerning sexual health. If the approaches advocated above are taken as a foundation on which to build a programme of targeting Africans for HIV related interventions, it might contribute to an increased sensitivity around this issue, and help to put into place measures that could lessen stigmatisation of Africans as carriers of HIV, as discussed in the stigma section above.

What has been found in this research aligns well with Mary Dixon-Wood et al's (Dixon-Woods et al., 2005) work on "invitations" for screening. She suggests that invitations, or in this case targeting, "seek to impose qualifications of candidacy on people, but people negotiate and make their own judgements about the extent to which they match those qualifications and their preference about accepting invitations" (Dixon-Woods et al., 2005). In this research it is the *imposition* of these qualifications that have often acted as a. The idea that someone else decided the extent to which individuals should be tested for HIV without the participants' themselves having any influence on this decision is problematic.

Mary Dixon-Woods (2005) suggests that services often rely on the idea of an "ideal user" when they are being designed. This is one who is able to use the set of competencies and resources that fit the way the service is organised and delivered. In relation to potential future targeting of African migrants, an ideal user would be an African first generation migrant who accepts of the epidemiological assertion that they are at a higher level of risk, who is resource and knowledge proficient enough to engage with services and who is not dissuaded by barriers such as stigma. The implicit assumptions that have been made about this ideal user are the ones which also result in the apparent distrust and resistance to targeting.

An alternative to targeting, encouraging UK population wide HIV testing regardless of epidemiological prioritisation, would be perhaps economically unviable for service providers trying to focus limited resources. However, if targeting is ineffective for Africans, there is an argument that it is also an

inefficient use of resources. The question remains whether or not targeting Africans for HIV is useful. My research suggests that it potentially can be, but has to be done in a way that is extremely sensitive to the issues I have raised here.

Current UK National Guidelines for HIV Testing by BHIVA, BASHH and BIS (British HIV Association, 2015) suggest that all newly registered people at GP practices in high prevalence areas should be offered an opt out HIV test. NAT (National AIDS Trust, 2014) contend that the majority of African migrants live in these areas. One issue is whether or not African populations in Scotland live in the high prevalence areas, and this data would need to be verified before confidently making this statement for Scotland. Opt out testing practices have achieved 96% acceptance rates in ante-natal settings, so perhaps this kind of cultural change might be acceptable over time in primary care settings (Glew et al., 2014). Viable opportunities for opt out testing could include GP registration or acute medical admission to hospital (Glew et al., 2014). This approach is endorsed by the British HIV Association, and NICE Guidelines (Glew et al., 2014). Guidelines also recommend that HIV testing should be routinely offered to people from known high prevalence countries (more than 1%) which includes all sub-Saharan African countries. Glew et al. (2014) piloted opt out testing at several English primary care sites and reported that all pilots were successful in increasing testing rates. This was offering testing to all patients, rather than those from higher risk groups, i.e. MSM and Africans, so it is difficult to say whether the barriers that arose for Africans would be negated by this approach.

10 Chapter 10 - Conclusion

In this final chapter I will reiterate the original research questions, outline the main conclusions that can be drawn from my research, and present some policy implications and recommendations. I will then discuss the strengths and weaknesses of my study before finally addressing recommendations for future research.

10.1 Aims of the study

To recap, the overarching aim of the study was to contribute to the understanding of the diversity of the population of sub-Saharan African migrants in Scotland, explore understandings of HIV and perceptions of HIV risk and develop knowledge on how to encourage the use of HIV testing and prevention related services within this group.

10.2 Main Conclusions

10.3 What are the levels of heterogeneity amongst the African migrant population in Scotland, and what dimensions of heterogeneity could affect future efforts to engage them with HIV related services?

The sample showed very wide levels of heterogeneity in all the dimensions explored. Of particular relevance to engagement with HIV related services was the diversity of identity and related social networking reported within the diaspora.

- The “African” identity is acceptable to Africans when it is self-imposed, but when imposed by non-Africans it was perceived to be bound with a series of stereotyping negative assumptions. This perception was informed by wider views that the UK represents a discriminatory environment for African migrants, especially given the public anti-migrant rhetoric of recent years.

- Participants perceived that non-Africans in Scotland linked them with HIV as the vectors and sources of the disease in the country. This meant that use of the “African” identity to appeal to individuals to engage with HIV related services was burdened with multiple perceptions of stereotyping, leading participants to be suspicious of the motives of service providers and decreasing will to engage with these services.

- Appeals to other forms of identity had potential to make HIV related services seem relevant whilst lessening the negative stereotypes connected with the African identity. In particular, nationality based identities and religious affiliated identities were reported to be used by participants and members of the wider diaspora.

- Nationality based identities resonated with participants and diminished potential for generalisations at a continental level which were rejected by the majority. One drawback was that appeals to nationality based identities might only be practical with a minimum number of individuals from a particular country.

- Religious affiliation was said to be common in the diaspora, and most participants had a religious identity. However, not all participants found this identity relevant. Perhaps more relevant were religious sites of social networking as potential locations for recruitment to future services, since these were important social network nexuses in the diaspora.

- Refugees had unique identities dominated by their migration status. As such they would need to be considered specifically in appeals to HIV related service engagement.

- Many participants reported having social networks containing mostly Africans. Religious social networks were common within the diaspora. Nationality based networks were common where the particular nationality had above a certain threshold of numbers of individuals to generate the network.

10.4 What organisations claim to represent Africans in Scotland and in what way do they affect African migrants' access to health services?

There were a diverse number of African related organisations represented in this research, including: advocacy groups; integration networks; a country association; religion affiliated groups and commercial entities. These are typical of the types of organisations across Scotland that claim to represent Africans.

- Organisations were highly diverse, even when of the same type and in similar local contexts. Diversity was driven by a number of factors, primarily: extent of funding; access to permanent accommodation; and whether or not they had staff and organisational objectives. Organisational objectives were often ambiguous, so were not necessarily the main drivers of organisation function.

- Organisations had varying amounts and frequency of interaction with African migrants. Organisations that tended to be more active in the diaspora were integration networks, some advocacy groups with sufficient resources, and religiously affiliated groups. Levels of activity were primarily driven by accommodation, funding and availability of staff and volunteers.

- Impact on African migrants' access to health services varied greatly between organisations, however all organisations provided an environment where conversations about advice on health and access to healthcare took place. This tended to be done informally, on a one-to-one basis, and were reactive in nature. Some organisations had more formalised health related programmes, such as talks from outside speakers or discussion groups, but these tended to be the ones with funding, accommodation and staff (the integration networks, some advocacy groups and some religious groups). These were only rarely carried out in collaboration with the NHS. There were no examples of sustained activity in collaboration with health services to promote access.

- Organisation representatives were enthusiastic about their organisations collaborating with health services to encourage service use and for HIV related initiatives. However conditions would need to be met for this to be successful. Organisations would need sufficient resources and capacity and also have their members approve of individual initiatives. For example, some organisation leaders, primarily those of religious related organisations and country associations, expressed concerns about the suitability of sexual health related initiatives in these environments.

- Organisations should be assessed in highly nuanced detail to make sure they are suitable as collaborators.

10.5 To what extent and in what way do African migrants discuss sexual health, HIV, HIV testing and health service use within their social networks?

Levels of discussion of these topics varied within participants' social networks.

- Health service use was discussed reactively when people had issues, and social networks were reported to be one of the main sources of information about health services and health issues for participants. In comparison, official sources of information were sometimes perceived to be not as trustworthy.

- Sexual health, HIV and HIV testing were reportedly not discussed at all within social networks, apart from sometimes at specific points in the life-course: just prior to marriage and when being screened for HIV during pregnancy.

- Reasons for lack of discussion were reported to be ongoing high levels of stigma and participants' perception that these topics lacked relevance to their lives since they did not seem themselves as being at risk of HIV infection.

- Lack of discussion was considered normal.

10.6 How sensitive are different sub-populations of Africans to being targeted for HIV related services?

Sensitivity to targeting was highly complex and took into account a multitude of issues concerning stigma and perceptions of risk of HIV infection.

- The large majority of participants were unhappy that Africans were being targeted for HIV related services on the basis of being from Africa alone.

- Targeting was perceived to perpetuate enacted stigma against Africans as the source and vectors of HIV in the UK. This was particularly amplified in the perceived hostile environment that the UK represented for African migrants.

- Participants did not view targeting as relevant due to their low self-assessed risk of infection. Risk was understood in two ways: as environmentally based and in terms of individual behaviour. Countries in Africa were understood to be a high risk environment if they had high prevalence, weak health sectors, instability and high levels of poverty. Scotland was not perceived to be a high risk environment. Understandings of risk transference between African countries of origin and Scotland varied, but most either thought that risk was not transferrable or that it diminished considerably over time after arrival in Scotland. Behavioural risk was understood by most to be linked to promiscuity. Some participants talked about the insulating effect of living a “moral lifestyle”, i.e. observing religious precepts, however, this may have been a euphemism for not being promiscuous.

- If participants did not think the environmental or individual understandings of risk were relevant to their lived in experiences, in the context of high levels of HIV stigma and perceived antagonism of the diaspora by the host population, they would not respond to targeting for HIV related services.

- Alternatives to targeting on the basis of African origin advocated by the participants included: targeting on the basis of country prevalence;

targeting based on how recently arrived in Scotland; blanket testing for the entire population and widening the health focus to target Africans for a range of health issues, including HIV. These were all perceived to lessen the chance of perpetuating stigma and to improve the chances that Africans would find initiatives relevant.

- Prompting to test for HIV was perceived as negative if done on the basis of African origin alone. Participants reported that if a more in-depth explanation was given as to why they were being targeted or prompted it would result in a less negative reaction.

10.7 Policy Implications and Recommendations

The utility of the term "African" needs to be assessed given the resistance to its use displayed by participants in my research. This has also been suggested by the NAT policy documents on engaging Africans with HIV related services (National AIDS Trust, 2014). Policies that involve targeting Africans, particularly when dealing with sensitive and stigmatised issues like HIV, need to be checked for feasibility with their target groups. Approaches which promote "African" engagement with services risk creating more barriers and lessening chances of engagement.

Policies and interventions that fail to take into account the influential context within which African migrants in Scotland live are unlikely to be perceived as relevant. Africans are marginalised in Scotland, experience discrimination, and feel the effects of anti-migrant sentiment engendered in UK public discourse. If policy takes this into account it could lead to more nuanced approaches relevant to African migrants' lived experiences.

Collaboration with community groups has excellent potential, given that many are central to the diaspora's social networks. However, community groups need to be assessed in detail to ascertain their suitability, especially in terms of sustainability, capacity and reach.

The current approach of prompting people to test for HIV on the basis of African background alone appears to have disenfranchised Africans from the health

services and needs to be reassessed. Policy on prompting should emphasise the importance of a collaborative decision making process between health worker and service user, and highlight the importance of providing a detailed explanation of why service users are being prompted to test. More training should be provided for healthcare workers, along the lines of Sexual Health In Practice programme, so that they can give test prompts in a sensitive manner.

10.8 Strengths and Limitations of Study

A key strength of my research is that it has focussed on African migrants in Scotland. Whilst more is known about the African diaspora in England, by comparison the diaspora in Scotland has been under researched.

Another strength is that I managed to recruit a diverse group of participants. As anticipated, recruitment was challenging, but I was able to overcome this by investing considerable time in building up relationships of trust with potential participants prior to trying to recruit them. This resulted in a range of participants and the collection of rich and sensitive data from most of them.

The greatest challenge of this study was the extremely sensitive nature of the topic. Interviews often required considerable negotiation to gain insightful data without distressing the participants. For some participants I deemed it unsuitable to go into detailed discussions about their personal sexual health, or even sexual health and HIV in abstract terms. In addition to this, the refugees that I interviewed came from particularly traumatised backgrounds, and there were certain areas of discussion that I found unsuitable to raise because of this. Some of the refugee participants also had limited English language skills, which subsequently limited potential to explore topics of interest in detail. As a consequence of the tact and discretion that had to be exercised within interviews I was unable to explore the most sensitive topics fully or collect the same data systematically from all interviewees.

Linked to the highly sensitive nature of the research topic was the fact that I had to spend considerable time in interviews building up rapport in order to comfortably broach sensitive topics. This means that in many interviews much time was taken up discussing, for example, demographic details or individuals’

general perceptions of Scotland before getting on to topics relevant to the research questions.

Another limitation was that a large number of participants reported having not used healthcare services, and therefore their engagement had to be discussed in hypothetical terms or in reference to other people's accounts. Investigations of hypothetical healthcare use tended to be dismissed by participants, with most suggesting they would go to the GP and being unwilling or unable to clarify further. In some cases I found out through the participant observation that individuals who had reported not using health services had in fact had considerable health service engagement. This perhaps reflects their perceptions of what was private experience which they were unwilling to share with me.

10.9 Recommendations for future research

Identity was an important area of exploration in my research, but it would be useful to specifically ask what identities Africans deploy in using health services, and to what extent these change dependent on the service, the context of the service, and the demographics and background of the individual involved.

Many alternatives were given to targeting on the basis of African continental origin. It would be useful to gather data about the feasibility and acceptability of these alternatives. These might vary on the basis of individuals' contexts. Ascertaining whether there are patterns of acceptability would contribute to the development of future targeting efforts.

Organisation representatives suggested that collaborative approaches with their organisations were viable. However, there is little data available on the feasibility of collaborative efforts between the NHS and local community organisations in Scotland specifically dealing with HIV. Evaluation of collaborative initiatives on HIV with different kinds of community organisations would provide a useful foundation for developing and boosting chances of success for future collaborative efforts.

Refugees and asylum seekers consistently identified as the most vulnerable in this research, and had the most barriers to engaging with health care services.

This group were also among the most dissatisfied with the health services in Scotland, felt the most marginalised in Scottish society and had the highest levels of distrust for organisations they perceived to be official. This population therefore requires further focus in order to assess their needs specific to HIV related services and how to encourage their engagement.

Diversity within the African diaspora in Scotland should be taken into account to improve the salience and relevance of future HIV interventions. Attitudes towards current HIV testing and related health promotion suggest that a more cooperative approach could be taken with African communities to build on existing relationships of trust and understandings of HIV.

11 Appendices

Appendix 1: Pilot Study Information Sheet

Africans Living in Scotland

Information Sheet

Who am I?
My name is Mathew Smith. I am doing this study for my PhD project at the Medical Research Council Social & Public Health Sciences Unit and Glasgow University.

What is this research about?
The main study is about Africans living in Scotland, finding out about where they are from, what they are doing, and how easily they can get access to health services. It will also find out about the range of organisations that represent Africans in Scotland, including church groups, country associations, community groups, advocacy groups and charities, and how these organisations can help access to health care.

This is a pre-pilot study to help me develop my interview skills, find out what people want to talk about in this area, and see how people respond to sensitive questions.

What is expected of you?
I would like to conduct one interview with you between 19th March and 5th April, depending on when is most convenient for you. The interview will last around an hour.

What will be in the interviews?
The interview would find out about your background, your life in Scotland, and your opinions on various aspects of living in the UK. I would also ask you about your ideas on how sensitive certain topics are for Africans in Scotland, whether you think people will be willing to talk about them, and what kind of language is acceptable.

Do you have to take part?
No. Taking part is entirely optional, and you are free to make your own choice. If you do agree to take part but later change your mind, you are free to withdraw from the study at any point, and you don't have to give a reason.

What will happen to the information provided in the interview?

If you decide to take part, no information that could identify you will be given to anyone else. However, what you tell me will be used in my studies. If you agree I will record the interview so that I can listen to it again later. Any potentially identifying details, including your name, where you live, etc, will be removed. The recording will be typed up and the files stored on an encrypted password-protected computer. Any written information you provide will be stored separately, so that you cannot be identified.

I may quote extracts of what you tell me, but I will ensure that they do not identify you to anyone reading the report. I would be happy to provide you with a summary of what I write.

Once I have completed the project, the information you have given me will be kept safely by the MRC. If you give your consent, it may be used by other researchers, with the MRC's approval, under the strict rules governing the confidentiality of your information. So again, your name, or any material that might identify you, will never be used or be given to anyone.

What will happen if you decide to take part?
If you'd like to take part, I will get your contact details via email, and we will arrange a date and time that is convenient for you to carry out the interview. The interviews will take place at the MRC offices on Lilybank Gardens, or if you prefer at somewhere of your choosing, so long as it is private. You will be reimbursed for your time spent in the interview with a £10 love to shop voucher.

If you do not want to take part or if you decide during the process that you would like to withdraw you will not be contacted further.

What should you do if you have any more questions?
You can ask me, Mathew Smith.
Email m.smith@sphsu.mrc.ac.uk
Phone: 0141 357 3949 (and ask to be put through to Matt Smith)

You can also speak to my supervisor, Lisa McDaid.
Email: l.mcdaid@sphsu.mrc.ac.uk
Phone: 0141 357 7568

If you would like to speak to someone independent of the research, you can contact Catherine Ferrell in our Survey Office. Email: c.ferrell@sphsu.mrc.ac.uk
Freephone: 0800 389 2129

Also independent of the research is Valentina Bold, the College of Social Sciences Research Ethics Officer. Email: Valentina.Bold@glasgow.ac.uk
Phone: 01387702021

Many thanks for taking the time to read this. I would be delighted if you would be willing to take part.

Appendix 2: Pilot Study Consent Form

Africans Living in Scotland

Consent Form – Interview

Please tick as appropriate:

1. I confirm that I have read and understand the information sheet for the 'Africans Living in Scotland' study. I have had the opportunity to review the information and ask questions. ☐

2. I understand that participation in the study is entirely voluntary and that I am free to withdraw at any time, without having to give a reason. ☐

3. I agree to an audio recording of the interviews being made, and I understand that the information I give will be recorded and stored securely. ☐

4. I understand that extracts of what I say may be used by the researcher in future reports, articles or and/or presentations, but this will be done in ways that do not identify me. ☐

5. I understand that my name will not appear in any reports, articles and/or presentations. ☐

6. I understand and agree that the information from my interview may be made available to other bona fide researchers in the future for further research, but that this would be overseen by the MRC and in accordance with their strictest rules of confidentiality. ☐

I hereby consent to take part in this study and agree that my participation has been fully explained to me. ☐

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 3: Pilot Study Interview Schedule

Africans in Scotland pre-pilot – Draft interview Schedule

1. What is your background?
    What is your country of origin?
    How long have you been here?
    Why did you pick Scotland?
    What subject are you studying?
2. What do you think about your experiences in Scotland so far?
    What have you liked most? What have you liked least?
    How are you getting on with your course?
    How have you been treated by Scottish people?
    Have you come up against any barriers or difficulties?
3. How much have you used services here?
    GP or other health related service?
    Are you registered with any health services?
    If not do you know how to?
4. Who are your friends here?
    How often do you see them or do things with them?
    With Scottish people?
    With other Africans?
    Are you involved in any other social networks?
    Are most of your friends other university students or do you socialise within other circles as well?
5. Are you involved with any religious organisations in Scotland, e.g. churches or mosques?
    Do churches play a big part in the lives of Africans in Scotland?
6. What contact do you have with family from your country of origin whilst you're in Scotland?
8. How do people at home view Scotland?
    Do you read newspapers or watch domestic TV from your country of origin?
    How do you access this?

(The following questions will be asked only on the basis of a good rapport being built between interviewer and interviewee)

9. When I first contacted you through the email, how would you have reacted if I had said that the research is about access to HIV services? Would you have taken part?
    How do you think other Africans would respond to questions around HIV/AIDS?
    What areas do you think would be particularly sensitive to discuss?
    While you've been here in Scotland have you ever felt people have linked you in any way to HIV/AIDS?
    Do you think that HIV and AIDS are highly stigmatised amongst Africans in the university/ in Scotland? How does this compare with your home country? What do you think is the main cause of this stigma?
10. So in public health in Scotland, the authorities think that sexual health, particularly HIV and AIDS are an issue for African migrants. Do you think this is a fair view?
11. How do you think that Africans would react to being asked about their sexual health?

12. Do you and your friends talk about sexual health or condom use?
    What do you think are the normal behaviours with condom use in the African migrant communities?
13. Do you think that Africans are more at risk of being infected with HIV than the general Scottish population?
    Do you think that the health services should be trying to help them?
14. Have you been to a GP?
    If so did the GP suggest tests for STIs or ask you sexual health related questions?
    What would your reaction be if you signed up with a GP and they suggested going for an HIV test or other sexual health checks?
15. When you've been going out, and chatting up girls and stuff, do you think that girls have assumptions about African men and sexual health?
15. Have you ever had discussions about HIV with partners in Scotland? Do you think it's something that is discussed?
16. Would it make a difference to the interview and how you responded if I was African?
    Would it make a difference if I was white?

Appendix 4: Main Study Information Sheet

University of Glasgow | College of Social Sciences

CHIEF SCIENTIST OFFICE

MRC Medical Research Council

Africans Living in Scotland

Information Sheet

Who am I?
My name is Mathew Smith. I am doing this study for my PhD project at the Medical Research Council Social & Public Health Sciences Unit and Glasgow University.

What is this research about?
This study is about Africans living in Scotland, their social networks, health issues that affect them and how easily they can get access to general health services and HIV related services. It will also find out about the organisations that represent Africans in Scotland and how they can help their users get access to health care.

What is expected of you?
I would like to conduct one interview with you. The interview should last between one hour and 90 minutes.

What will be in the interviews?
The interview would find out where you are from, your views about your life in Scotland, and the difficulties or help you have had to access health services. I am also interested in what you think about the lives of Africans in Scotland in general, and how this might have changed recently. I will be asking questions about Africans' way of life, how they socialise, and about health issues that might affect them, including HIV.

Do you have to take part?
No. You are free to choose whether or not to take part. If you agree to take part but later change your mind, you are free to withdraw from the study at any point, and you do not have to give a reason.

If you do take part, you can refuse to answer any questions that I ask at any stage.

Is it confidential?
If you take part, you will not be identified. No information that could identify you will be given to anyone else.

What will happen to the information?

What you tell me will be used in my studies for the university. If you agree, I will record the interview so that I can listen to it again later. If you prefer, I will not record the interview but just take notes. Any identifying details, including your name, where you live, etc, will be removed from the information gathered during the interview. It will be typed up and the files stored on an encrypted password-protected computer.

In my reports or articles I may quote extracts of what you tell me, but I will ensure that the quotes do not identify you. I would be happy to provide you with a summary of the results of the research.

Once I have completed the project, the information you have given me will be kept safely by the MRC. If you give your consent, it may be used by other researchers, but without your name attached to it. Your name, or any material that might identify you, will never be used or be given to anyone.

What will happen if you decide to take part?
If you would like to take part, we will arrange a date, time and place that is convenient for you to carry out the interview. The interviews will take place at the MRC offices on Lilybank Gardens, Glasgow, or if you prefer at somewhere you choose, so long as it is private. You will be reimbursed for your time spent in the interview with a £20 'Love to shop' voucher.

If you do not want to take part or if you decide during the process that you would like to withdraw you will not be contacted again.

What should you do if you have any more questions?
You can ask me, Mathew Smith.
Email m.smith@sphsu.mrc.ac.uk
Phone: 0141 357 3949

You can also speak to my supervisor, Lisa McDaid.
Email: l.mcdaid@sphsu.mrc.ac.uk
Phone: 0141 357 3949

If you would like to speak to someone independent of the research in the Medical Research Council, you can contact Catherine Ferrell in our Survey Office. Email: c.ferrell@sphsu.mrc.ac.uk
Freephone: 0800 389 2129

If you would like to speak to someone independent of the research in Glasgow University, you can contact John McKernan, the College of Social Sciences Research Ethics Officer. Email: John.McKernan@glasgow.ac.uk
Phone: 0141 330 2000

Many thanks for taking the time to read this. I would be delighted if you would be willing to take part.

Appendix 5: Main Study Consent Form (Interviews)

University of Glasgow | College of Social Sciences

CHIEF SCIENTIST OFFICE

MRC Medical Research Council

Africans Living in Scotland
Consent Form – Interview

Please tick as appropriate:

1. I confirm that I have read and understand the information sheet for the 'Africans Living in Scotland' study. I have had the opportunity to review the information and ask questions. ☐

2. I understand that participation in the study is entirely voluntary and that I am free to withdraw at any time, without having to give a reason. ☐

3. I agree to an audio recording of the interviews being made, and I understand that the information I give will be recorded and stored securely. ☐

4. I understand that extracts of what I say may be used by the researcher in future reports, articles or and/or presentations, but this will be done in ways that do not identify me. ☐

5. I understand that my name will not appear in any reports, articles and/or presentations. ☐

6. I understand and agree that the information from my interview may be used by other researchers in the future, but that this would be overseen by the MRC and in accordance with their strictest rules of confidentiality. ☐

OR

I don't want information from my interview to be used by other researchers in the future. ☐

I hereby consent to take part in this study and agree that my participation has been fully explained to me. ☐

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 6: Main Study Interview Schedule – Organisation Representatives

Interview Schedule – Representatives of organisations/institutions

1. What is your organisation and what are its objectives?
2. What is your involvement in the organisation/institution?
3. Who are the users of your organisation/institution?
    Where are they from? Predominantly from one country?
    Do they come from the local area or are they from all over?
    What are their ages?
    What do they do?
4. Why was it decided to set up your organisation/institution here?
5. What numbers of users are interacting with your organisation/institution?
6. In what ways does your organisation interact with its users?
7. How do people socialise within your organisation?
    Do people form social networks based on your organisation?
8. What functions of your organisation/institution are important for Africans in Scotland?
9. Are there discussions in your organisation/institution about immigration issues?
10. Does your organisation/institution interact with other organisations/institutions concerning Africans?
11. What patterns have you discerned around the numbers of Africans in Scotland?
    In your experience why do you think Africans come to Scotland?
    Through what routes do they tend to arrive here?
12. Where are the authorities letting down Africans in Scotland?
    Where are they doing well?
13. What do you think authorities should do to make Africans feel more included?
14. Does your organisation/institution have any health related functions?
15. What do you think the African community wants from authorities regarding health?

16. What do you think are prevailing opinions/perspectives about HIV/sexual health amongst those who use your organisation?
17. Is there any work done by your organisation/institution around HIV or sexual health?
    If not, what are the reasons for this?
    If so, to what extent do you think it has been successful?
18. How do you think people who attend your organisation/institution would react to sexual health/HIV related discussions?
    Younger? Older? Men? Women? Africans from different countries?
    Barriers? Stigma? -> patterns of stigmatisation by gender/age/country of origin/time in country?
19. How do you think Africans would respond to specifically targeted interventions around sexual health?
20. How would you feel if your organisation was approached to be a facilitator of health promotion work? What about if it was directly related to HIV?

Appendix 7: Main Study Interview Schedule – Organisation Users

Interview Schedule- Organisation/institution users

1. What is your background?
    What is your country of origin?
    How long have you been here?
    Are you married?
        To an African person?
    Do you have children?
2. What do you do?
    Has this been the case for your whole time in Scotland?
3. What do you think about your experiences in Scotland?
    What aspects have you liked the most about Scottish society?
    What have you liked the least?
    How have you been treated by Scottish People?
    Have you come up against any barriers or difficulties?
    What assumptions have Scottish people made about you?
4. How do you socialise here?
    Who makes up your group of friends?
    How often do you do things with them?
    With Scottish people?
    With other Africans?
5. Are there differences between Africans who have been here a long time and those who came here recently?
    What are the differences you have noticed?
6. What part does religion form in your life?
    Are churches/religious groups important in the lives of Africans in Scotland?
7. What contact do you have with your country of origin?
    How do people at home view Scotland?
    Do you read newspapers or watch domestic TV from your country of origin?
    How do you access this?
8. When you came to Scotland, what was it that motivated you to come?
9. How much have you used health related services here?
    Are you registered with a GP?
    If not, what are the barriers to being registered?
    If so, what have your experiences with a GP been like?
    What were your experiences with receptionists?
    What about the dentist?
10. Have you or anyone in your family had any health problems?
    How did you respond?
    Who did you seek advice from?
    Did you go to the GP or phone NHS direct?
    If not, what were the barriers?
10. What did you think the health services here would be like?
    How did you think people would treat you before you went? Were you right?

What do you think that Africans in Scotland in general think of the health services?

Are they right?

11. Where would you tend to get your health information?

Do you look things up on the internet?

Do you get information from friends and family?

(if the interview has gone well and I feel a good rapport has been built, I will go on to the next set of questions)

11. Do you think HIV/AIDS is an issue in the African population in Scotland?

Public Health authorities think that sexual health, in particular HIV and AIDS are an important issue for Africans in Scotland. Do you think this is a fair view?

Do you think that Africans are more at risk of being infected than the general Scottish population?

What do you understand Stigma to be?

Do you think Stigma is widespread around HIV?

Have Scottish people linked you in any way to HIV? Or do Scottish people make assumptions about Africans and HIV in your experience?

12. Is HIV a sensitive area for Africans to discuss?

What areas in particular are sensitive?

13. How do you think Africans would react to being asked about sexual health?

14. Do you and your friends talk about sexual health or condom use?

What do you think are normal behaviours with condom use in African communities?

15. (depending on answer to previous question about GP engagement) When you went to the GP, was there any discussion of HIV or sexual health in general?

Did the GP recommend any testing?

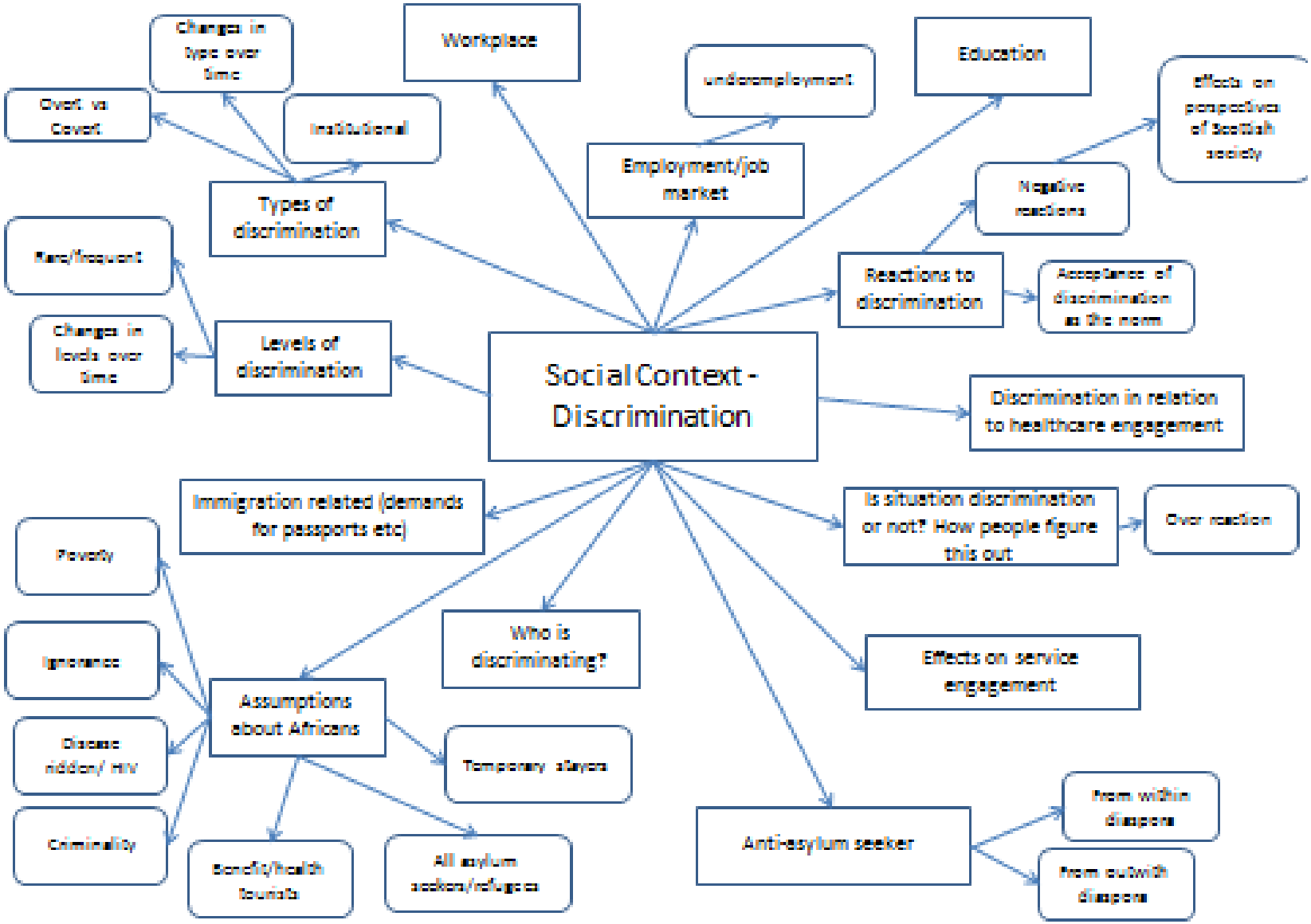
How did this make you feel? (or) How would you have felt if they did?

16. Have you ever had discussions about HIV with sexual partners in Scotland? Do you think it's something that is discussed?

17. What do you think about HIV awareness raising or promotions to get people testing that is targeted only at Africans?

Appendix 8: Sample thematic mind map

- Chapter 3- Individual knowledge of health and health services, engagement and the social context of engagement



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