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To be a man:  
Exploring masculinity and HIV service needs  
among African men in London

Robin Nobleman



## **ABSTRACT**

African migrant men are an underserved risk group in terms of HIV services in London. They tend to present late and face multiple barriers in accessing services. However, little research has been conducted to explore their unique vulnerabilities; rather, much HIV/AIDS research focuses on men as vectors of the disease, responsible for infecting women. Utilising the theory of hegemonic masculinity, this study explored the factors impacting men's use of community-based HIV testing, care and support services.

A diverse group of 23 HIV positive and negative African men living in London participated in individual interviews and focus groups. Three global themes were identified through thematic networks analysis (Attride-Stirling, 2001). The social, material and institutional contexts in which the men lived were found to affect their engagement with HIV services. Due to challenges presented by immigration status, HIV and other barriers, participants often failed to fulfil the expectations of hegemonic masculinity. Consequently, some were dissatisfied with HIV support services for their perceived failure in providing practical help in areas such as finding employment. However, some men were able to construct alternative versions of masculinity that promoted health enhancing behaviours. Implications for hegemonic masculinity theory and future service provision are discussed.



THE LONDON SCHOOL  
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**African**

HIV Policy Network

*empowering African communities affected by HIV*

# **To be a man: Exploring masculinity and HIV service needs among African men in London**



PS498 – Health, Community and Development

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## **ABSTRACT**

African migrant men are an underserved risk group in terms of HIV services in London. They tend to present late and face multiple barriers in accessing services. However, little research has been conducted to explore their unique vulnerabilities; rather, much HIV/AIDS research focuses on men as vectors of the disease, responsible for infecting women. Utilising the theory of hegemonic masculinity, this study explored the factors impacting men's use of community-based HIV testing, care and support services. A diverse group of 23 HIV positive and negative African men living in London participated in individual interviews and focus groups. Three global themes were identified through thematic networks analysis (Attride-Stirling, 2001). The social, material and institutional contexts in which the men lived were found to affect their engagement with HIV services. Due to challenges presented by immigration status, HIV and other barriers, participants often failed to fulfil the expectations of hegemonic masculinity. Consequently, some were dissatisfied with HIV support services for their perceived failure in providing practical help in areas such as finding employment. However, some men were able to construct alternative versions of masculinity that promoted health enhancing behaviours. Implications for hegemonic masculinity theory and future service provision are discussed.

**Key words:** Masculinity, HIV/AIDS, health, migrants, community-based services, African men.

# PART I

## INTRODUCTION

We live in a globalised world where the reverberation of local issues can be felt worldwide. One of the many reasons for this increased interconnectedness is transnational migration. Migration is at an all-time high with 3.1% of the world's population currently living outside their country of birth, while in the United Kingdom, 10.4% of the population were born abroad (UN Department of Economic and Social Affairs, 2009). Movement of people on this grand scale brings benefits such as the productive exchange of ideas, practices, and knowledge. However, it also exacerbates the spread of emerging infectious diseases such as HIV/AIDS and increases the already complex challenges it entails. HIV/AIDS is now a truly transnational epidemic and international migrants embody the globalised nature of the disease. Given the challenges many migrants face throughout the migratory process, it is clear that migrants can face increased vulnerability to HIV due to unstable living conditions and barriers to accessing HIV care and support services for those already infected (UNAIDS, 2009b).

Another characteristic of the current epidemic is the feminisation of HIV/AIDS. Women are disproportionately infected and affected by HIV due to biological, social and economic vulnerabilities. In fact, of young people (ages 15-24) living with HIV in sub-Saharan-Africa, 75% are women (UNAIDS, 2004). In response, research and interventions have increasingly taken a 'gendered' perspective. However, more often than not, gender in fact refers exclusively to women while demonising men (Dowsett, 2003). As Lynch *et al.* (2009, p. 15) state, 'Overtly negative and simplistic descriptions of masculinity risk positioning men as central to the perpetuation of the epidemic, while simultaneously marginalising men from efforts to curb its spread'. This marginalization only serves to reinforce negative behaviour on the part of men and even create antagonism towards HIV/AIDS interventions.

In this study, I take a step towards rectifying this bias by focusing on men as part of the solution. There are two reasons why an alternative approach is crucial. First, heterosexual transmission accounts for the vast majority of infections among sub-Saharan Africans, both in their home countries and in the UK, where 92% of HIV-positive Africans were infected heterosexually (Health Protection Agency, 2008a). If men are largely responsible for infecting women, men must be targeted to decrease the spread of HIV. However, men are also worthy of attention in their own right – they too have a human right to health

and face unique vulnerabilities that have yet to be addressed, especially in the context of transnational migration.

I explore the intersection between masculinities, HIV/AIDS and migration by investigating the HIV service needs of African migrant men living in London, England. Using the theory of hegemonic masculinity, explained below, I aim to determine the factors that impact these men's use and satisfaction with HIV services through in-depth interviews and focus groups. The need for investigation among this group is urgent, considering the extraordinarily high rates of HIV prevalence in some African countries and the layers of complexity added by their move to the UK.

### ***Research Motivations***

This research topic lies at the junction of my two main areas of interest: migration and HIV/AIDS. After working at a centre for new immigrants and refugees in Edmonton, Canada, I realised that migration is rich with both psychosocial and social justice issues. My other long-time interest is in HIV/AIDS; I truly believe it is the most pressing health issue of our time and its complexity ensures that there is always another angle from which to approach it.

Over the last several years, I have been repeatedly drawn to the issue of men and HIV/AIDS perhaps because most of the literature and interventions I came across focused on women. Indeed, this imbalance was verified by my work with a community HIV/AIDS clinic in Nairobi, Kenya. The vast majority of clients were women. When I approached the African HIV Policy Network (AHPN) in London with the idea that I wanted to study migrants' experiences with HIV/AIDS, AHPN came back to me with the same dilemma. This umbrella organisation of African community groups and AIDS service organisations continuously fielded concerns from their members about African men. They were testing late or not at all, not attending care and support services, and were harder to engage in prevention campaigns. In short, men were a problem that no one knew how to solve.

### ***Research Question***

In keeping with the participatory research approach of this project, I sought AHPN's input on the research question. Based on their input, I chose to narrow my focus to explore how to improve men's access to testing, care and support services rather than engaging men in prevention campaigns, as the last topic is worthy of a research study in itself. As AHPN's members are community-based organisations rather than statutory services, this research focused on the former.

My theoretical approach was based on the social psychological importance of identity. Our 'recipes for living' are largely determined by our social identities; who we are determines what we do (Campbell & MacPhail, 2002). It stands to reason that moving to a new country and dealing with a chronic and fatal disease both have substantial impacts on one's identity. Specifically, both of these major transitions undoubtedly influence men's ideas of what it means to be a man and how they personally fit this concept.

Given AHPN's priority of improving services and my theoretical interest in the role of masculine identity, the following questions guided my research:

What factors impact the use of community-based HIV services by African migrant men living in London?

- A) What role do men's constructions of masculinity play in facilitating or hindering service use?
- B) How successful are community-based HIV services in supporting African migrant men's health?

## **PART II**

### **LITERATURE REVIEW**

In order to explore these questions, some demographic and theoretical background is necessary. I will first outline the existing literature on Africans and HIV in the UK, and then branch out to discuss the literature on masculinity as it relates to health.

#### **Epidemiology - Africans and HIV in the UK**

Research on HIV and African migrants in the UK has grown substantially in the last decade. Prevalence rates show a pressing need for attention to this population; amongst Black Africans, diagnosed HIV prevalence is 3.7% compared to 0.09% in the general population (Health Protection Agency, 2008b). Many who are HIV-positive have never been tested, with 36% of African men and 25% of African women unaware of their status (The UK Collaborative Group for HIV and STI Surveillance, 2007).

Moreover, Africans have the highest rates of late diagnosis of any group in the UK. In 2007, 42% were diagnosed after the point when antiretroviral (ARV) treatment should have begun; African men have higher rates of late diagnosis than women (Health Protection Agency, 2008a; Chadborn, Delpech,

Sabin, Sinka, & Evans, 2006). This sex difference in late diagnosis is mirrored in differential rates of seeking medical care for HIV/AIDS (Health Protection Agency, 2008b). Late diagnosis results in poor survival rates, high health care costs and higher risk of transmitting HIV to others (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007).

### **Barriers to access**

Some barriers to service access have been explored for African communities in the UK, although without a gendered dimension. Research on barriers to HIV service use has largely focused on testing, in line with the biomedical and epidemiological focus of much HIV research. However, many of the reasons for late testing are relevant in explaining failure to access care and support services as well. First, stigma is a major deterrent to testing, with Africans twice as likely as white British people to fear discrimination after a positive test (Erwin & Peters, 1999). The stigmatised nature of HIV means that being seen attending HIV services could result in accidental disclosure to community members and family in Africa and the loss of much needed support (Burns et al., 2007; Flowers et al., 2006). A second barrier to access is immigration status; indeed, it is seen by some HIV-positive Africans as a more pressing problem than their HIV status and impacts service access in a variety of ways (Flowers et al., 2006). Undocumented migrants may fear that accessing statutory services or being found to be HIV-positive could result in deportation (Burns et al., 2007). Moreover, newcomers may prioritise daily survival needs over preventative health care such as testing (Prost, Elford, Imrie, Petticrew, & Hart, 2008). Specialist HIV services can also be prohibitively difficult to access, especially for a person unfamiliar with the NHS and/or the English language (Burns et al., 2007). A third reason for late presentation is a lack of awareness - both of being at risk and of where to test if desired (Prost et al., 2008). Although use of GPs is high among Africans in the UK, attendance at genitourinary medicine (GUM) clinics where HIV tests are available is low (Erwin, Morgan, Britten, Gray, & Peters, 2002).

Depressed socioeconomic conditions experienced disproportionately by Africans increase their vulnerability to HIV infection and compound the challenges of living with HIV. Compared to other HIV-positive ethnic minorities and white British people, those of African origin have the highest rates of insecure residency status and unemployment, and were most likely to have insufficient money to cover their basic needs. (Ibrahim, Anderson, Bukutu, & Elford, 2008). Unemployment is also a major problem; in one study, 20% of Africans living with HIV in London were unemployed, despite being well qualified (Chinouya & Davidson, 2003). Reasons for this frustrating mismatch include lack of recognition of foreign credentials, lack of UK work experience and the language barrier (Prost et al., 2008).

## **Where are the men?**

It is recognised that higher prevalence in African migrant women may also be an indicator of under-diagnosis in men (Health Protection Agency, 2008b; Prost et al., 2008). However, there is little research exploring the causes of this imbalance. At most, men merit only a brief mention in studies that discuss barriers to diagnosis and care among African migrants. For example, Burns *et al.* (2007) speculate that African men access services later than women because the latter often attend health services with their children or for prenatal care. A review of behavioural interventions among people of African origin living with HIV in Europe recognises that HIV is rarely discussed in social venues frequented by men, such as pubs and clubs (Prost et al., 2008). Furthermore, several studies recognise heterosexual African men as an underserved risk group and only a handful of studies have ever been conducted on African migrant men who have sex with men (MSM; Doyal, Papparini, & Anderson, 2008; Kesby, Fenton, Boyle, & Power, 2003; McMunn, Mwanje, & Pozniak, 1997; Prost et al., 2008). However, no strategies are proposed in this literature to meet men's needs.

An exception to this trend is a set of studies by Doyal and colleagues on the lives of heterosexual and MSM African men with HIV in London – they go further than others by exploring the subjectivities of men themselves (Doyal, 2009; Doyal, Anderson, & Papparini, 2009; Doyal et al., 2008).

## ***Theoretical approach***

### **The concept of hegemonic masculinity**

In the HIV/AIDS field, attention has been focused by a 'crisis of masculinity' in many African countries where traditional models of masculinity have become unworkable due to changes in employment structure, women's rights movements and the HIV epidemic itself (Morrell, 2001). It is therefore essential to explore how masculine identities are constructed and reconstructed with changing social environments.

Gender identity has been explained through a variety of paradigms. Sex role theory, the idea that society expects and rewards conformity to a certain gender-specific role, was the prevailing paradigm for much of the late 20<sup>th</sup> century (Robertson, 2007). However, this theory fails to engage with power inequalities between men and women and does not acknowledge the dynamic nature of gender identity (Connell, 1995). Robert Connell's theory of hegemonic masculinity addresses both of these deficiencies. He defines masculinity relationally; a place in gender relations that affects personality, culture, and bodily experiences. Rather than being a fixed personality trait or natural attribute,

masculinity is socially constructed and constantly in flux, with multiple masculinities existing in any one society (Courtenay, 2000).

However, not all of these masculinities are of equal status; hegemonic masculinity is positioned as the ideal that men strive for at a given place and time (Connell, 1995). Hegemonic masculinity refers to gender practices that legitimise patriarchy and guarantee men's domination over women; these men at the top of the gender hierarchy also subordinate men who do not conform to the masculine ideal (Connell). Although most men do not fit the ideal, they benefit from what Connell calls the 'patriarchal dividend', the advantage men gain through the subordination of women. Their position is referred to as complicit masculinity.

A third category, marginalised masculinity, refers to the relationship between the masculinities of high and low status men, for example between white men and men of less powerful racial groups. Connell argues that marginalised men can never truly enact a hegemonic masculinity<sup>1</sup>, because for them, 'the claim to power that is central to hegemonic masculinity is constantly negated' (Connell, 1995, p. 116). Finally, resistant masculinity defines itself in opposition to the hegemonic ideal. For example, men who are pacifists represent a masculinity that actively undermines the hegemonic construction (Courtenay, 2000). All of these types of masculinity are relevant to African migrant men's health-related behaviours.

The concept of hegemonic masculinity is well suited to this study as it recognises the socially constructed nature of masculinity and its ability to change over time (Lynch et al., 2009). Race, class and life events influence the ways in which gender identity is assembled and this is especially relevant given the intersectional identities of men in this study (i.e. living at the intersection of Black, African, male, migrant, and HIV-positive identities; Doyal, 2009). Furthermore, masculinities have been found to change in response to external shifts, for example, global changes in gender dynamics, labour market structures and migration (Connell & Messerschmidt, 2005). On a smaller scale, individual men may adapt their masculinity to fit the demands of a given situation, accessing multiple discourses of masculinity on demand (Wetherell & Edley, 1999).

Several studies have found that the inability to attain normative masculinity (i.e. because of unemployment) leads to feelings of failure (Doyal et al., 2009; Fitzgerald, Collumbien, & Hosegood, 2010). Some men respond to this failure by pursuing other paths to normative masculinity, such as hypersexuality and violence, while others assume resistant masculinities that devalue the very tenants

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<sup>1</sup> None of the men in this study truly enact a hegemonic masculinity, given these definitions; rather they likely fit the definition of complicit or marginalised masculinity. However, because they strive towards the ideal, their constructions of masculinity will be referred to as hegemonic for simplicity's sake.

of hegemonic masculinity (Courtenay, 2000; Lynch et al., 2009). It is important to keep in mind that hegemonic masculinity is prescriptive rather than descriptive of men's real life behaviours; no man will fit perfectly into any one category (Lee & Owens, 2002).

### **Masculinity and Health**

There has been a growing trend in recent years towards the study of masculinity and men's health. It has partially stemmed from the realisation that men's health-related beliefs and behaviours are a major reason for their lower life-expectancy worldwide (Courtenay, 2000). Identity is largely performed through behaviour, and health-related behaviours are an important way in which men demonstrate their masculine identities (Robertson, 2007). In other words, 'the doing of health is a form of doing gender' (Saltonstall, 1993, p. 12). Hegemonic masculinities often prescribe behaviours that can be health damaging; real men are expected to be tough, unemotional, aggressive, deny weakness, and have uncontrollable sexual desires (Lee & Owens, 2002). Thus, in order to achieve a culturally sanctioned masculinity, men must ignore pain and sickness and actively take risks. Conversely, concern for health is seen as feminine and thus subordinate. The resulting gender differences in health behaviour are often taken for granted; it is common-sense that men are reluctant to go to the doctor and therefore not constructed as problematic (Courtenay, 2000; O'Brien, Hunt, & Hart, 2005). Men's health behaviour thus becomes a self-fulfilling prophecy when men conform to common-sense expectations (Crawford, 1995).

### **Filling the gaps**

In conducting this study, I intended to fill several gaps in the literature. First, as mentioned earlier, there is very little research on the HIV-related needs of African migrant men living in the UK, although parallel research on African migrant women and on men in Africa has been conducted (Barker & Ricardo, 2005; Doyal & Anderson, 2005; Onwumere, Holttum, & Hirst, 2002). Additionally, much HIV research positions men as the cause of the problem rather than as people with unique needs. Although a set of recent studies go against this trend by exploring the lived experiences of HIV-positive heterosexual and MSM African men in London, they do not explore how these experiences relate to uptake of HIV services (Doyal et al., 2009; Doyal et al., 2008). I intend to establish a better understanding of how men's constructions of masculinity affect their HIV-related health behaviours and present pathways for action to improve the ability of community-based services to meet men's needs. If men are to be enlisted as partners rather than adversaries in the fight against HIV, a greater understanding of their identities, needs and behaviours is crucial.

## PART III

### METHOD

In this study, in-depth individual interviews, focus groups and a participatory planning activity were used to elicit the views of African migrant men in London. Given the under-researched nature of this subject, qualitative research was best suited to create an overview of the area. In a field that has been dominated by quantitative epidemiological studies, several authors have called for qualitative methods to explore the complexities of HIV ignored by fixed categories and statistics (Doyal, 2009; Kesby et al., 2003; Lee & Owens, 2002). Furthermore, some of the few qualitative studies on barriers to accessing services use key informants rather than service users themselves (e.g. Burns et al, 2007). Finally, Kesby *et al.* (2003, p. 1584, italics added) advocate 'working *with* not *on* African communities'. Following this recommendation, AHPN's input was sought at every stage of the study and the results will be presented to their member organisations as well as study participants. In sum, this study fills a methodological gap in the literature by using qualitative methods within a participatory design to elicit the views of African men themselves. The study received ethical approval from the London School of Economics.

Both interviews and focus groups were used to improve data quality. Methodological triangulation adds breadth and depth to the analysis by playing the strengths and weaknesses of various methods off each other (Flick, 1992). Thus, interviews were used to develop a fine-grained understanding of the relations between social actors and their situation, in this case African men and HIV services (Gaskell, 2000). Focus groups are indicated to explore an under-researched topic and to learn about how an unfamiliar phenomenon is experienced (Gilbert, 2001). These methods complemented each other; ideas brought up in interviews were member-checked in focus groups and topics touched upon in focus groups were introduced in interviews to provide more depth. The participatory planning activity, where focus group participants were asked to design an ideal HIV support service for African men, allowed participants to express any needs that did not come out elsewhere.

### ***Recruiting***

As this population is notoriously hard to reach, recruitment required creativity and sustained effort; thus, convenience sampling was employed, although care was taken to diversify the sample

within all relevant strata. As Campbell and MacLean (2003) suggest, minority ethnic communities are best contacted through a gatekeeper or trusted organisation. This was done throughout the recruitment process detailed in Table 1. Once they agreed to participate, men chose either a one-to-one interview or a focus group, depending on their comfort level with discussing the sensitive topic. The majority of participants were recruited through HIV support groups; consequently, opinions about these groups rather than other HIV support services figure largely in the results. Recruiting stopped when few new ideas emerged from interviews, signalling saturation (Gaskell, 2000).

	<b>Recruitment method</b>	<b>Number recruited</b>
<b>HIV positive</b>	E-mail to AHPN member organisations	1
	Visits to HIV support groups	16
<b>HIV negative/ Non service users</b>	E-mail to AHPN member organisations	0
	Phone and email contact with:	
	African community groups	0
	Religious institutions	0
	Community leaders	0
	Community centres	0
	Ugandan outreach worker (access to pub)	4
	Through AHPN staff	2
	<b>Total = 23</b>	

**Table 1. Recruitment process detailing number of participants recruited through each source**

Surprisingly, my position as a white Canadian woman turned out to be more of an advantage than a disadvantage in the recruitment and research process. First, my distance from London's African communities seemed to engender the participants' trust as I was unlikely to know anyone close to them. Second, as an outsider with some inside knowledge from my time in Kenya, I had an excuse to ask naive questions that would have been superfluous coming from an insider (Hermanns, 2004). Finally, participants seemed to feel at ease criticizing aspects of British life once they knew I was not British. However, some men were reticent to talk about sensitive topics such as racism and sexuality with a white woman and this may have limited my findings.

## Sample

The final sample consisted of 23 men, constructed to reflect the range of African men living in London rather than a representative sample. Inclusion criteria required participants to be male, over the age of 18, and identify as African (i.e. born and/or raised in an African country). Two adjustments were made at the request of AHPN: both heterosexual men and MSM were included and Africans of all racial groups, as opposed to Black Africans only, were included. Initially, I sought both men who had and had not accessed HIV testing, care or support services in London. However, men who had not accessed services proved extremely difficult to recruit (by definition, they did not access services, which were my main point of recruitment and attempts to recruit from alternative sources were unsuccessful) so the final sample included only those who had accessed some HIV services<sup>2</sup>. HIV negative men were recruited so as to maximise the diversity of views on HIV testing and care-seeking behaviour within the strata of HIV status (Gaskell, 2000). Several men were also involved in HIV-related service provision in a volunteer capacity and one held an administrative position at the African Men's AIDS Society<sup>3</sup> (AMAS). The men came from eight different African countries and all had been living in the UK for more than five years. The final sample is described in Table 2 (see Appendix A for detailed demographics).

Feature	Number
HIV Status	Positive n=17 Negative n=5 Never tested n=1
Race	Black n=22 White n=1
Sexual orientation	Heterosexual n= 21 MSM n=2 (Bisexual n=1, Homosexual n=1)
Age	Range: 25-75 Mean = 43
Immigration status	Permanent n=21 Uncertain n=2 (Asylum seeker n=1, Expired visa n=1)

**Table 2. Basic sample demographics**

## Data Collection

The final corpus consisted of 15 in-depth interviews and two focus groups. One focus group had three men (due to no-shows) and the other had five, all of whom were HIV-positive. The men were familiar with each other from attending the same support groups. Using a natural group was advantageous in exploring the group norms that may have been established within support groups (Morgan, 1997). Furthermore, the homogeneity of including only HIV-positive

participants in focus groups allowed for free flow of discussion as members were unafraid of disclosure.

<sup>2</sup> With the exception of one man who had never tested for HIV but had accessed other sexual health outreach services.

<sup>3</sup> A pseudonym is used here to protect the identities of the participants who attended this men-only support group.

Focus groups and most interviews were conducted at the AHPN office, while four interviews were done in a private space behind a pub. All interviews were conducted in English. The consent form was explained orally and participants were assured that their responses would be confidential and that the government was not involved in the research in any way (see consent form, Appendix B). All participants granted permission to record the interviews and focus groups. Participants were compensated five pounds for their travel costs and entered into the Institute of Social Psychology lottery for a £100 prize. Interviews lasted between 45-60 minutes (with interviews at the pub lasting only 20-30 minutes) and both focus groups lasted approximately 90 minutes.

Interviews and focus groups were transcribed verbatim with non-verbal communication (i.e. laughing, nodding, and pauses) recorded as well. The written product of the participatory planning exercise was also typed up (See Appendixes C and D for sample transcript and planning exercise). Field notes were taken throughout the recruitment and data collection process to improve reflexivity. Additionally, demographic questionnaires were completed by focus group participants to maintain the confidentiality of individuals within the group.

The topic guide was prepared in collaboration with AHPN and was piloted with a member of staff who was part of the target population and with another male. The topic guide was revised based on these pilot interviews. The aim of the topic guide was to elicit men's thoughts and experiences in two areas: regarding HIV and sexual health services in London and about what it means to be a man. Slightly different topic guides were used in interviews with HIV-negative and positive participants; for the former, questions about diagnosis and HIV care and support services were left out and more questions about HIV testing and other sexual health services were added. Different topic guides were also used for focus groups and individual interviews, given their different purpose and nature (See Appendix E for topic guides). To contextualise participants' responses, all interviews began with a short life history. The topic guide was loosely followed in all interviews and focus groups but adapted to each situation.

## ***Analysis***

Thematic networks analysis was used to group the coded data into networks of basic, organising and global themes (Attride-Stirling, 2001). This method is useful in discovering salient themes at different levels of the text and representing them in an organised manner. Open coding of the entire data set was done using ATLAS.Ti version 6.1. Manifest rather than latent themes were identified, given that the research aimed to explore men's explicit and stated needs. Analysis was an iterative process

that cycled between coding the data and arranging the codes into themes that would eventually lead to the development of theory (Flick, 2002). Although coding was inductive and bottom-up, themes were influenced by the theoretical approach of hegemonic masculinity. After the first cycle of coding and identifying themes, it became clear that the organising themes largely fell into global themes similar to Campbell *et al.*'s (2005) framework of symbolic, material and institutional contexts. Although the use of this framework was not pre-determined, it fit well and I continued to use it through later cycles of coding and identifying themes.

After all transcripts were coded, codes were merged and divided to ensure their boundaries were explicit and not redundant (Attride-Stirling, 2001). With these revised codes, the coding frame was again modified and thematic networks for each global theme were created (See Appendix F for final coding frame and thematic networks in text below). As a final step, all text segments falling under each organising and basic theme were reviewed to ensure the themes accurately reflected the data (Braun & Clarke, 2006). Discrepancies were resolved by merging or sub-dividing themes to reflect the data and produce a rich description. This final product is reflected in the thematic networks below – the findings are meant to be read with the aid of these diagrams.

## **PART IV**

### **RESULTS**

To begin, a definition of community-based HIV services is necessary. The most apt is the collective definition created by this study's participants, who described them as services targeted towards the grassroots of a particular geographic or cultural community whose remit includes raising awareness, fighting stigma, providing support for people living with HIV (PLWH) and information on how to protect oneself and others.

Through the coding and analysis process, three global themes were identified. The factors affecting African migrant men's use of HIV services fall into three broad contexts: social, material and institutional. Similar frameworks have been used to evaluate a youth HIV prevention programme in South Africa and to compare two prevention programmes run by sex workers (Campbell et al., 2005; Cornish & Campbell, 2009).

Based on these studies and the current findings, I define social context as the culture, ideologies and worldviews of a social setting, and how these shape the construction of social identity and meaning. Material context refers to the presence or absence of resources, which in this case include financial, socio-emotional, informational and physical resources; this context inevitably includes the services which do or do not provide resources. Institutional context refers to the larger policy environment that influences the way in which services are run. Taken together, the social, material and institutional contexts narrate how men's identities are challenged and reconstructed and the part that HIV services play in these dynamics.

### ***SOCIAL CONTEXT***

The social context of men in this study was dominated by traditional ideals of what it means to be a man, barriers to achieving these ideals and the alternative constructions of masculinity that some men created to rebuild their identities. This global theme encompasses the most novel findings, and I will therefore discuss each organising and basic theme in detail.



**Figure 1. Global theme: Social context**

**Hegemonic constructions of masculinity**

Many men shared an ideal of what men should do and be, and this was often defined in opposition to women's roles and actions. Certain actions were seen as rites of passage necessary to become a man, and many of these revolved around finding a partner and becoming financially independent.

*If you are still a bachelor then you are not a man, if you are still living under your parents' house then you are not a man. If you don't have an income, if you are not farming your own piece of land, then you are not a man [laughs]. – Interview 4*

In terms of sexuality, several men professed a view that heterosexuality and being the dominant partner were normative for men. Having multiple sexual partners, although mentioned occasionally, was not a key marker of masculinity among most participants.

Most participants identified strongly with the traditional breadwinner role and emphasized their financial and decision-making responsibilities within their families. The expectation to support their family in the UK and in their home countries weighed heavily on their shoulders.

*Like right now I am here, I am not allowed to work but I am supporting a lot of people back home, I have two children to look after and it's not an easy task because they expect you - being here - they expect you to have so much and you have to try to make ends meet. You can't let them go to poor schools. - Interview 4*

Highlighting the differences between men and women's health-related behaviour was one way in which support for hegemonic masculinity was expressed. These differences were often taken for granted and assumed to be natural. Differences included the ease with which women would seek health services compared men, which was often explained in terms of women's responsibility for their children's health. Women's tendency to communicate about health with other women in everyday interactions was seen as another major gender difference. Finally, men felt that they were supposed to be seen as, or actually be, stronger than women, and seeking care would belie this supposed strength.

*P2: We tend to keep it inward you know because illness in a man is weakness. A man will always be happier if he's known to be very strong and somebody who never gets sick, who never gets a cold, who never got down with flu. – Focus group 2*

Some men assumed that this gender difference was the natural order of things. As one participant stated: "*Women are a different species, everybody knows that.*" (Interview 6). Thus, hegemonic constructions of masculinity were present among the men in terms of traditional masculine roles and essentialist views of gender differences in health behaviours.

## Failure to meet expectations

Many participants experienced feelings of failure because they were not able to attain the masculine ideal explained in the previous theme. They experienced this failure primarily through unemployment; 14 out of 23 participants were unemployed and several were working at jobs for which they were highly overqualified. Unemployment had two perceived social consequences. First, attracting a partner (seen as central to being a man) was difficult without paid employment. Second, because the breadwinner role was central to some of the men's identities, unemployment brought frustration and shame. As one participant eloquently put it:

*P1: There's a group psychological burden on the man in the African context and the man is the provider, he is the supporter and when he suddenly finds himself in a situation where he's unwell he is unable to meet up with what society expects of him, it even begins to eat him even more and then he becomes more isolated, more secluded than –*

*P2: More frustrated.*

*P1: Frustration sets in and embarrassment, you can't come out and meet peers and so he suffers in silence. In some cases it can be pretty detrimental and dangerous. – Focus group 2*

Disruption of traditional gender roles was seen as another reason for men's failure to meet expectations. Many men felt that gender roles were reversed in the UK – men were sometimes expected to cook and care for the home while women worked. The conflict caused by this reversal was exacerbated by women's perceived advantages in finding employment and the 'preferential' treatment they received in the name of gender equality. Some men felt strongly that being supported by their female partner was threatening to their masculinity. For example, *"Let's say an African woman [is] working for £15 an hour and you're working for £5. She is paying most of the field ... She tends not to respect you."* (P4, Focus group 2).

Though all participants had been in the UK for over five years, many discussed social problems associated with adjustment to a new culture (distinct from struggles caused by immigration policy). Common experiences in an individualistic society including loneliness, stress and lack of support led many to speak of a desire to return home. Some saw migration as a primary cause of their unemployment (e.g. because of lack of UK work experience, language barriers, etc.), and it was thus connected with their inability to fulfil an important requirement of masculinity.

Gender role conflict and the social pressures of migration were identified as two major causes of family breakdown, which nearly all men cited as a problem. This connection (as well as the frustration

and shame associated with doing a job for which one is overqualified) is clearly articulated by one focus group participant:

*P1: The African, you know, probably had a very high position back in his own country and came and cannot do the job that he was used to and just to do some other menial job. It's the wife has a better opportunity and brings more money home. The roles are reversed and the husband feels his position is undermined; this leads to divorce, separation, domestic violence, things like that.*

– Focus group 1

In addition to the demise of relationships, men living with HIV frequently mentioned the difficulty of finding a partner and becoming a husband and father and therefore a 'real' man. Surprisingly, meeting a partner was a key motivation for attending HIV support groups. As one participant put it, "*They are lonely, many of them. They go to some of these looking for partners, it makes them come out more and more.*" (Interview 14).

For those men living with HIV, stigma and isolation blocked the achievement of hegemonic masculinity; shame, guilt and physical illness sapped their power.

*P1: Especially if you lead a very active life...for somebody to be hit by this it took some time. I've been going through that since 2002 and I was in a cocoon for about three years, I refused to come out, refused to meet -- I lost friends, it was embarrassing to come out you know, your whole confidence goes.* – Focus Group 2

In sum, a variety of factors including unemployment, shifts in gender roles, migration, inability to maintain relationships, and HIV related stigma all contributed to African men's sense that they had failed to meet expectations associated with masculinity.

### **Alternative Constructions of Masculinity**

Despite these many challenges, or perhaps because of them, some participants managed to construct alternative versions of masculinity where they saw HIV and care-seeking in general through a more positive lens. Consequently, many men expressed disapproval of others practicing hegemonic masculinity by ignoring health problems, denying HIV and failing to access services. Participants distanced themselves from these other men who they often spoke of as 'hiding'. When asked why he thought men were not attending support groups, one participant replied:

*Stubbornness, ignorance, arrogance. I've met a lady who comes who attends one of the [support group] things. The husband doesn't want to come; it's a waste of time he says. 'What do you get out of it?' You know, there is that attitude, what do you get out of it? -Interview 11*

In contrast to these 'stubborn' men, some men created alternative masculinities that were anti-normative in promoting tolerance of gay men, gender equality and expressiveness in relationships. Pride in their African heritage also stood out as being a pillar of these men's identities.

However, the most interesting aspect of their alternative masculinities was the idea that men *should* care for their health and that hegemonic masculinity is health-damaging. For some men this attitude was a cause of HIV-testing, while for other men it was a result. One man expressed pride in his new philosophy on medical check-ups, saying *"Once you cross the line and it registers in your brain, you are [the] much, much stronger man than the man who says no, no hospitals not for me, not for me."* (P3, Focus group 2)

In the same focus group, another man lamented men's lack of conversations about health in everyday settings in comparison to women.

*P2: [At the pub, men] never talk about health. Health is just a one-liner: when I say to you 'how are you?' The short approach. [All laugh] that's the end of it. You don't say 'I've been feeling...' - it doesn't go further than that. – Focus group 2*

Both of the quotes above show men's realizations that traditional notions of masculinity put their health at risk. This realization is also reflected in service users' empowered attitudes towards HIV. In contrast to the men who were 'hiding' from HIV, many participants emphasized how they had overcome challenges and were now striving to live a normal life with HIV. They felt inspired by other PLWH and supported prevention and education initiatives to raise awareness among African communities. 'Living positively' had become part of their alternative masculine identities.

In conclusion, the social context of African men living in London is instrumental in shaping their identities and therefore their use of community-based HIV services. Hegemonic masculinity places certain expectations on men, which condemn help-seeking as feminine. At the same time, a variety of social factors conspire to block men's fulfilment of traditional masculine roles. In response to conditions that put their health at risk, some men have responded to this failure by constructing alternative versions of masculinity which question hegemonic masculinity and promote caring for one's health.

**MATERIAL CONTEXT**



**Figure 2. Global theme: Material context**

This global theme refers to satisfaction and dissatisfaction with the resources provided by HIV services. Here, material refers not just to physical and economic goods but to less tangible social and informational resources that increase men's agency and decrease their vulnerability.

**Satisfaction with services**

One of the main resources that men gained from HIV services was socio-emotional support, largely through support groups for PLWH. Nearly all HIV-positive participants spoke of "*meeting people at different levels*" to share experiences between the newly diagnosed and "*seasoned people*" (Focus group 1). Participants often felt isolated by HIV, and therefore valued the opportunity to socialise with others without fear of stigma. Moreover, attending support groups provided something beneficial to do

while unemployed, a crucial resource for sustaining good mental health. However, a minority of men highlighted the lack of counselling they received after testing positive.

Information about medication, side-effects, transmission and how to protect yourself and others was also a valuable resource in living a healthy life. Participants were generally satisfied with the information provided by testing facilities and support services.

In a wider context, many men expressed appreciation for the opportunities for training and education available in the UK compared to their home countries. However, this was tempered by frustration when opportunities to use newfound skills were blocked.

### **Unmet service needs**

Despite satisfaction with socio-emotional and informational resources a major gap exists: numerous men highlighted the lack of practical support provided by some HIV services. Their most urgent needs, including poverty, housing, immigration and employment were not being met by community-based services (although it must be said that some were satisfied with the practical support they received). Socio-emotional support was appreciated, but it was insufficient to meet their daily needs.

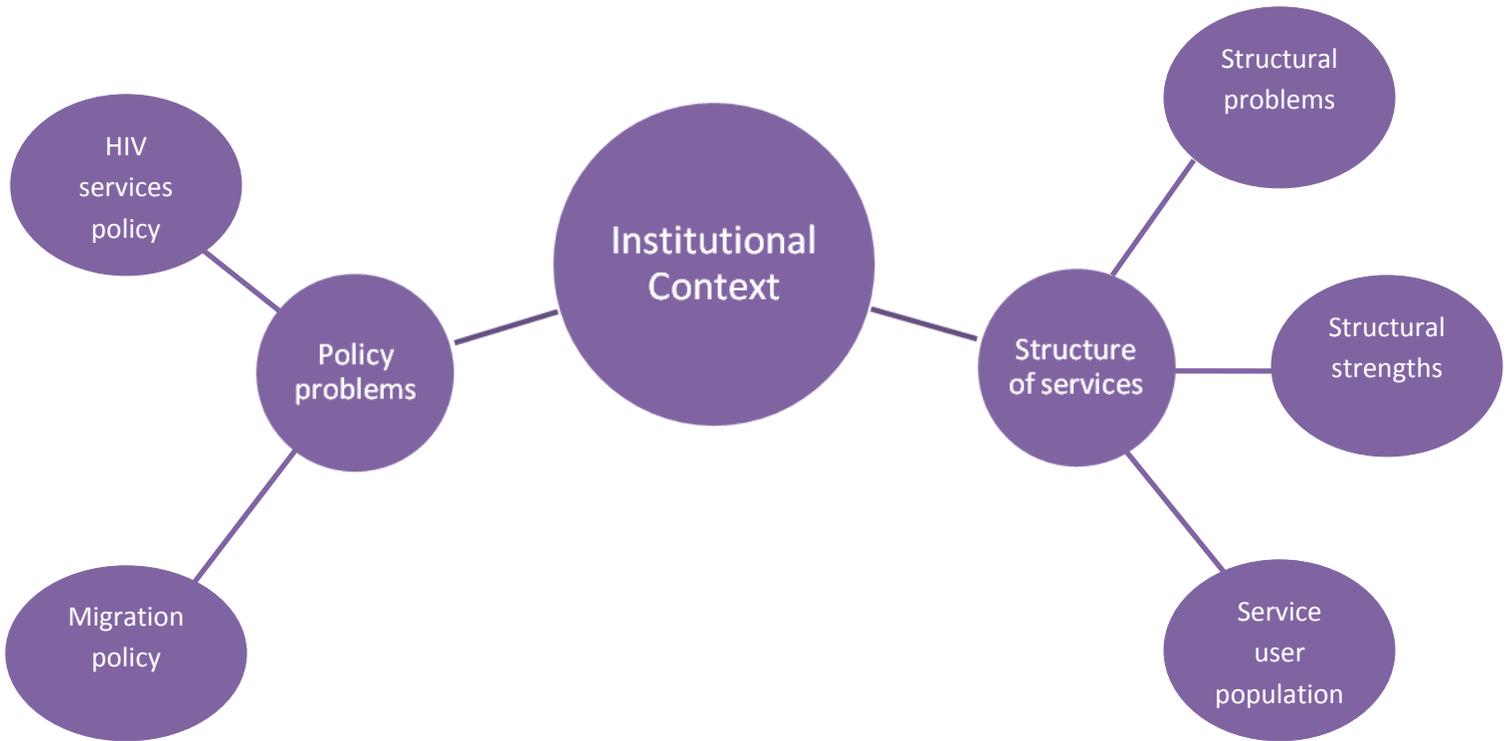
*So whether you counsel someone, that big problem is still lying there...but anyway the solution is what I have said: if people are allowed to work, if people are allowed whatever freedom they can get, all these problems would be solved. – Interview 14*

Material barriers also prevented men from accessing services. Some men explained that their peers who were fortunate enough to be employed often worked multiple jobs for long hours to make ends meet – this prohibited them from attending HIV support services. Another material barrier was lack of transport reimbursement.

*P3: When it comes to what, to having to pay the transports you have to look at this £5, what it can do. Either you can get on the bus and come to the meeting or you can get a calling card to contact your family members in Africa or you can get a shirt or trousers from the charity shop. So the value of that when you say what can I use my £5, but supposing you're going to the place where you're not going to get that £5 back you know somebody will, that'll be the last time that he comes. –Focus group 2*

Thus, the extent to which services do or do not provide necessary resources constitutes a material context where some of the men's practical needs are not being met.

***INSTITUTIONAL CONTEXT***



**Figure 3. Global theme: Institutional context**

The final global theme encompasses institutional factors such as the larger policy context and the structure of services, and their impact on service uptake by African men.

**Policy problems**

Policies set by government appear to undermine the effectiveness of community-based services in meeting African men's needs. As many participants volunteered or worked for community based HIV services, they were aware of the pitfalls of current policy. A common theme was lack of funding and restriction of funding to certain boroughs. A pan-London service accessible to men in all boroughs, such as AMAS, was seen as preferable. Some participants also felt that policy-makers showed little understanding of life with HIV when they grouped it together with other disabilities.

Although only two participants had insecure immigration status at the time of the study, many participants identified migration status as detrimental to accessing services and employment within their communities. Fear of being caught and deported by the authorities prevented migrants from

seeking HIV testing, care and support. An even larger problem was the inability of asylum seekers to work while waiting for the Home Office's decision. As paid work is illegal and official assistance is insufficient, they have few avenues to help themselves.

*Immigration here is horrible, that's the way I can...because getting someone and letting him stay there, you can't allow him to work, you can't do anything and you just let him there for 6, 7, 8 years! That tarnishes the image of human rights that they have. I mean, it's another way of torturing people. -Interview 4*

Perhaps as a result of Britain's anti-immigration legislative culture, many men had experienced discrimination and continued to feel like outsiders despite having lived in the UK for several years.

### **Structure of services**

The way that community-based HIV services are set up has repercussions for their success in meeting men's needs. Several problems with the way services are run were mentioned. One cited problem was corruption and lack of transparency in management and decision-making. Some service users also felt like they were being used as a statistic to present to funders rather than treated like a person. Others complained of a lack of opportunities to give feedback on services. As one participant stated, *"A group of people at the top, they will just decide this is that we are going to do and not giving any concentration to the people at the bottom."* (Focus group 1)

These frustrations were balanced by satisfaction with the effective cross-service referral systems and outreach programs. In terms of testing, several participants commented that HIV tests were more accessible and routine for women because of antenatal testing. Among men, routine testing and walk-in clinics were considered preferable to appointment-based GUM clinics.

On the topic of which client groups organisations should serve, participants had diverse opinions. They were split between a preference for men only versus mixed gender groups and also between services specific to Africans compared to services open to all groups. Those who preferred men only groups such as AMAS felt more comfortable discussing certain issues, such as sexual dysfunction and alcohol abuse, when women were not present. However, some men cited the advantages of being able to exchange experiences and meet prospective partners in mixed gender groups. Benefiting from others' diverse experiences was also seen as an advantage of mixed cultural group services. In contrast, some participants felt more comfortable in services run by and for Africans, viewing them as free of discrimination and more culturally appropriate. Equally divisive was whether services should separate MSM and heterosexual men. Some participants strongly objected to mixing with men they saw

as 'immoral', whereas others promoted tolerance of gay men, appreciating the part they had played in the early campaign for accessible ARV medications. This variety of opinions supports the diversity of HIV services currently available to serve all combinations of client groups.

In sum, the institutional context captures men's views on the consequences of policy and service delivery decisions for their health. Despite their best efforts, services and users are frustrated by health and immigration policy. In addition, greater opportunities for users to influence community-based services from the bottom up would result in greater success in meeting men's needs.

## **PART V**

### **DISCUSSION**

In this study, I aimed to examine the factors that influence migrant African men's uptake and satisfaction with HIV services. The social, material and institutional contexts within which these men live impact their interaction with and reaction to community-based HIV services. In the following section I will first discuss how my findings both support and critique the concept of hegemonic masculinity. I will then explore the implications of alternative constructions of masculinity for service uptake. Finally I will discuss the implications of the material and institutional context for future service directions. One caveat is necessary: the discussion below necessarily skims over variations in HIV status, country of origin and sexual orientation and does not intend to outline universal truths. My aim, rather, is to highlight interesting dynamics and ideas emerging from the findings of this study.

#### **The complexity of masculine identities**

The social context presented a story about what it means to be an African man in London. This global theme contained a narrative expressing a certain way of being a man, signified by markers of masculinity including starting and supporting a family. However, given the challenges these men faced through migration and for some, through a diagnosis of HIV, these markers of masculinity became unattainable. In response to their frustrated hopes, some men constructed alternative masculinities that allowed them to engage with services and maintain their health. Although this tells a neat story of barriers and change, the plot is not necessarily chronological. In reality, complicity with hegemonic notions of masculinity coexisted with resistance. Many men strived to fulfil the male breadwinner role and took for granted the idea that help-seeking came more naturally to women. By endorsing traditional

gendered power dynamics and expressing negativity towards gay men, they supported relations of domination intrinsic to hegemonic masculinity. However, many of these same men identified the health damaging effects of hegemonic masculinities, exemplified by men 'in hiding', and endorsed (traditionally feminine) health-enhancing behaviours. Thus, while partially rejecting hegemonic masculinity, they were still suffering from failing to attain it (i.e. feelings of failure from unemployment).

There are several possible explanations for this contradictory subject position. Perhaps, after experiencing critical illness, these men had no choice but to reject dominant masculinity by seeking support. However, the many men who remain 'in hiding' contradict this explanation – they may take ARVs but actively avoid anything above this medical necessity. Another explanation lies in their background. Perhaps these men had always been anti-normative. This seems unlikely, however, given that several participants explicitly stated that they had overcome denial and reversed their previous avoidance of health services to reach their current state. It seems most likely that their masculinities are flexible, with different ways of being a man activated as the situation demands. As Wetherell and Edley argue, many situations require individuals to take on multiple masculine positions. The intersectional identities of HIV-positive African migrant men may demand particular flexibility in 'doing' masculinity (Doyal, 2009). Moreover, their marginalised status and its accompanying lack of power blocks the achievement of hegemonic masculinity and therefore demands some alternative. The larger question, which requires investigation beyond the scope of this study, is why these men were able to adopt a healthier alternative masculinity.

What is clear is that these men's complex identities are not adequately explained by Connell's theory of hegemonic masculinity. Although he acknowledges that contradictions may exist within a man's life, Connell sets up hegemonic, complicit, resistant and marginalised masculinities as discrete entities. Men may either strive to be the ultimate man or rebel against the ideal, but by definition cannot occupy more than one position in the hierarchy.

Perhaps the deeper problem with hegemonic masculinity as a social psychological concept is that it does not delineate how exactly social constructions of masculinity regulate men's lives (Wetherell & Edley, 1999). Is hegemonic masculinity a detailed roadmap for behaviour? Is it merely a backdrop against which men live their lives? The data seems to favour the latter explanation. It explains how these men could act in accordance with hegemonic masculinity in some areas of their life, such as acting as the dominant partner in their relationship, while rebelling in others, for example, seeking emotional counselling.

### **Service use and masculinity: A process of change**

An alternative explanation is that this research captures a moment of flux. The men in this study have recently gone through multiple life-changing transitions – from their home country to the UK, from good health to living with HIV, from breadwinner to unemployed and from head of the family to subordinate partner or bachelor. Research has shown that masculinities are subject to change over time as the social context transforms (Connell & Messerschmidt, 2005). Perhaps the above-mentioned changes in their social context triggered a shift in their constructions of masculinity. The results also point to HIV testing and support services themselves as catalysts of change. In some cases, testing was a wake-up call to change behaviour among both men who tested positive and negative. For those who tested positive, initial denial and fatalism were often followed by a change in health behaviour as time went on. This hypothesis is supported by Lynch et al.'s (2009) conclusion that changes in HIV-positive men's notions of masculinity were not due to diagnosis but rather occurred through the process of accepting their status. Gaining information and learning how to better manage one's health was a way of expressing agency when other means had been blocked by their illness.

Support groups may have played a role in identity change as well. Many men spoke of learning from the experience of others in support groups and being inspired to change their health-related behaviours. Perhaps the norms of this new male peer group made resistant masculinity socially acceptable. Colvin and Robins (2009) found that a South African men's support group that emphasised open communication, dealing with emotions and living a positive lifestyle caused personal and social change among members.

However, not all men respond to disrupted masculinity in such a positive way. Messerschmidt (1993) argues that when access to power and resources is limited, men must seek other routes for validating their masculinity. Rejecting feminised health behaviours and embracing risk are accessible ways to demonstrate masculinity. Similarly, a study of men's uptake of ARV treatment in Zimbabwe found that men disengaged from HIV/AIDS activities in order to reassert their masculinity (Campbell et al., Submitted). Thus, it would be fair to expect that failure to meet masculine expectations could have pushed men further away from accessing health services rather than towards them. Indeed, it may have done so for non-service users who were not included in this study. However, for the study's participants, it seems that blockades on the road to hegemonic masculinity sent men looking for an alternative destination rather than a different route.

## **Future directions for service provision**

Men's level of satisfaction with community-based HIV services is partially dependant on their constructions of masculinity. In this study, men faulted HIV support services for failing to provide practical or instrumental help that would assist them in finding employment or subsist in the meantime. Housing and immigration support (including legal aid) was also deemed to be inadequate. There are two interesting elements to this unmet service need. First, participants had internalised the relationship between employment, the ability to provide for one's family and masculinity, a relationship strongly supported by previous research (Dixon, 1998; Lee & Owens, 2002). Thus, men wanted services to help them fulfil the expectations necessary to achieve total manhood. Without that, even the best social support and information provision would be incomplete. In fact, employment was seen as an acceptable trade-off for attending a support group, as this man articulates:

*P2: But also on the other hand if you look at it, the people who say we're working or something, it's good for them. Because at the end of the day the people who come to the meetings want to eventually get jobs. So when they already get work that keeps them busy and they don't come to meetings, if you balance the two evils, that have not come to the meetings but he goes to work. You need that balance. – Focus group 2*

The demand for more practical help could also indicate that it is more appropriate to traditional masculine forms of coping. Men prefer practical actions they can take to concretely improve their situation rather than the emotional support that tends to be preferred by women (Sullivan, 2003).

Although greater instrumental support would be helpful, the importance of counselling should not be discounted. Lee and Owens (2002) suggest that raising consciousness through counselling would be beneficial in allowing men to see how a strictly gendered lifestyle restricts health behaviours and causes family problems. In this study, some men seem to have gained this awareness regardless of whether that was the aim of the counselling services they accessed. If these men were used as peer educators, perhaps more men could be exposed to their health-enhancing alternative views.

Changing the structure of services could go far in increasing men's uptake of HIV testing. As some men recommended, testing should become as routine for men as it is for women, who are tested through antenatal care. This implies that men currently see sexual health as a women's sphere, related to pregnancy and childbirth. If testing was made accessible and routine in men's spaces, men would not need to take the risk of crossing socially constructed gender lines to get tested.

In conclusion, the policy problems identified by men, especially in regards to immigration, have been previously recognized in key informant studies (Burns et al., 2007). However, to my knowledge, the structural improvements for services that the men suggested are novel. Currently, there are inadequate avenues for men to express their recommendations. Such feedback channels would ensure that services were responsive to the needs of their male clients.

## **CONCLUSION**

This study investigated the factors impacting African men's use of community-based HIV services in London. It focused on how constructions of masculinity helped or hindered service use and to what extent current community-based services met men's needs. Through qualitative investigation with a diverse group of African migrant men, I found that the social, material and institutional contexts the men encountered were key to understanding how they engaged with HIV services.

This investigation set out to fill several gaps in the literature. First, I aimed to balance the dominant approach to gender in HIV/AIDS research where women are seen as 'victims' and men as 'perpetrators' (Lynch et al., 2009, p. 25). By examining men as complex subjects in their own right, I aimed to begin a dialogue that lends itself to constructive, inclusive action. Secondly, I focused on an under-researched population. This study has established a basic understanding of the complexity of factors influencing service use by African men in London. Although this study is necessarily exploratory, it provides directions for future research in this population.

### ***Limitations***

The findings of this study must be examined in combination with its limitations. In terms of the sample, it would have been preferable to include HIV-positive men who had not accessed services and more men who had never tested for HIV. They would have had greater insight into the reasons why men might avoid HIV services and the role their constructions of masculinity play in this avoidance. In restricting interviews to service users, I had only indirect access to non-users' point of view. An additional weakness of the sample was the inclusion of MSM. This group deserves a separate in-depth study; combining them with heterosexual men prevented fine-grained analysis of their unique experiences. For example, one man who identified as bisexual on the confidential demographic questionnaire spoke passionately about gender equality and inclusion of gay men during a focus group but never shared his own sexual orientation with the other men. Also, this study's results were

dominated by the experiences of HIV-positive men, perhaps because they had more experiences with HIV services to share and they made up the majority of participants. A separate study with HIV-negative men would have been able to elicit more feedback about sexual health services in general. Although this was one of the original aims of this study, the data collected proved insufficient to explore the use of sexual health services in adequate depth. Finally, results may have focused disproportionately on unemployment due to the high level of unemployment in the sample. Perhaps unemployed men had more time to participate in research (although interviews were held at the participants' convenience to accommodate men who worked) and were more in need of the small compensation offered.

A weakness in the topic guide was that it did not include direct questions about male sexual partners. If a participant said he was married or referred to female partners, I assumed that he self-identified as heterosexual and did not probe further to avoid causing offense in a population with polarised views of homosexuality. It is possible that some men were MSM but did not disclose this to me and this may have limited the data. Another gap in the topic guide was the lack of questions regarding the processes men went through in deciding to seek care and support. Such questions may have provided more insight into how men choose to challenge notions of masculinity that condemn help-seeking.

### ***Future research directions***

This research filled a gap in the literature by focusing on men as social actors and service users. However, what is needed now is not more separate research on masculinities and femininities. Rather, an integrated, relational approach would be more useful in determining how gender dynamics affect HIV service uptake.

Another direction for future research would be a longitudinal design that follows African migrant men from testing and diagnosis through service access or non-access. This would illuminate the process whereby men choose various health-related behaviours.

Finally, considering the growing evidence of the effect of support groups on men's behaviours (Colvin & Robins, 2009; Lynch et al., 2009), further research should investigate whether HIV support groups constitute a 'transformative social space.' This concept refers to communication networks which provide a space for a group of people to critically examine the status quo and collectively renegotiate the social norms that may damage their health (Campbell & Scott, 2009). This concept describes a possible mechanism by which men construct alternative identities and is worth investigating.

### ***Recommendations for action***

One of the aims of this study was to provide hitherto non-existent strategies for meeting African migrant men's HIV service needs. Here, I outline a number of recommendations. First, as the men highlighted, women are more likely to talk about health in everyday settings and share health information amongst themselves. For men, the only acceptable spaces in which to talk about health were support groups or clinics – facilities dedicated to health. This highlights the need for more spaces in which men can share their experiences with each other and work towards more health enabling behavioural norms. In other words, more men need the opportunity to construct healthy alternative masculinities like the ones created by some men in this study. To tackle two problems at once, perhaps income generation could be combined with a behaviour change intervention similar to the IMAGE study in South Africa (Pronyk, Harpman, Busza, Phetla et al., 2008). This study used microcredit and participatory gender and HIV education with women to successfully catalyse social change.

A second set of recommendations is for community-based HIV services. Considering the interconnectedness of employment and masculinity, a greater focus on practical help is necessary to assist men in meeting their identity maintenance needs. Additionally, it would be beneficial to promote routine HIV testing outside 'women's spaces' such as antenatal care. Although such testing is available, regular testing is not normative among African men.

Finally, the participants in this study had insightful recommendations into how policy and the structure of services could be improved to better meet their needs. It is my hope that this paper is one channel through which their views will be transmitted. However, more avenues are undoubtedly needed for men's feedback to reach the appropriate authorities.

### ***Final thoughts***

The contexts in which men live must be holistically examined in order to understand their actions. No amount of renegotiation of masculinities will change the material and institutional contexts that limit African men's abilities to live fulfilling lives in the UK. Equally, even ideal services and policies combined with full employment would not create a health-enabling context alone. The sum total of the social, material and institutional contexts in which men live must be considered to comprehend the factors impacting their use of community-based HIV services.

African migrant men face multiple vulnerabilities. However, the men in this study were also remarkably resilient. Their inspiring take on life with HIV and their ability to overcome myriad challenges are admirable. As such, it is due time to examine the other side of gender and HIV/AIDS and

the possibilities of healthier constructions of masculinity that open doors to men as well as women. For this to happen, both men themselves and professionals in the HIV field must change their view of men from part of the problem to part of the solution.

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## Appendix A- Participant Demographics

Interview/FG number	Country of origin	Level of education	Age	Sexual partners (male/female)	Marital status	Length of time in UK (years)	Employment status	Immigration status	Year of diagnosis
1	Sudan	certificates	46	F	divorced, widowed	7	unemployed	permanent	1987
2	Uganda	certificates	42	F	divorced	9	unemployed	permanent	1990
3	DRC	BA	45	F	separated	7	unemployed	permanent	2004
4	Uganda	Diploma	49	F	married	7	unemployed	asylum seeker	1998
5	Zimbabwe	diploma	75	F	married	9	retired	permanent	2002
6	Zimbabwe/Malawi	secondary	45	F	divorced	8	self-employed	permanent	2004
7	Somalia/Tanzania	certificate	49	M	single	10	unemployed	permanent	Negative
8	Uganda	degree	33	F	single	6	employed	permanent	Negative
9	Uganda	some university	25	F	married	10	unemployed	permanent	Negative
10	Uganda	masters	35	F	married	8	employed	permanent	Negative
11	Uganda	degree	27	F	single	Born here, returned 10 years ago	employed	permanent	2007
12	Uganda	some university	27	F	single	6	employed	permanent	Negative
13	Nigeria	degree	29	F	in a relationship	10	employed	permanent	Negative
14	Uganda	degree	51	F	married	23	employed	permanent	2000
15	Kenya	degree	late 50s	F	divorced?	14	unemployed	expired student visa	2003
FG 1(P3)	Nigeria	degree	---	F	separated	6	unemployed	permanent	2009
FG 1 (P2)	Zimbabwe	degree	42	F	married	6	unemployed	permanent	1992

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FG 1 (P1)	Zimbabwe	some university	57	F	divorced	9	unemployed	Permanent	2002
FG 2 (P1)	Nigeria	some university	52	F &M	single	41	unemployed	Permanent	2002
FG 2 (P3)	Zimbabwe	degree	37	F	single	10	employed	Permanent	2000
FG 2 (P2)	Kenya	degree	44	F	cohabiting	22	unemployed	Permanent	1998
FG 2 (P4)	Uganda	secondary	49	F	single	11	unemployed	Permanent	2000
FG 2 (P5)	Ghana	some secondary	37	F	married	7	unemployed	Permanent	2006

## Appendix B – Consent form

### HIV & SEXUAL HEALTH SERVICES FOR AFRICAN MEN

#### Interview Information Sheet

*What is the purpose of this interview?*

This interview is part of a research study that aims to help improve community-based sexual health & HIV services to better meet the needs of African men living in London. Your answers will help us understand the strengths and weaknesses of current services.

*Who is conducting this research?*

I am an MSc student in the Health, Community and Development programme at the London School of Economics. I also work as a Policy & Research Intern at the African HIV Policy Network. I am collaborating with them to conduct this research. The NHS and government are not involved in this research in any way.

*Why have I been asked to participate?*

Previous research on this topic has focused on African men to only a limited extent. We are interested in finding out about your thoughts and experiences of HIV and sexual health services in London.

*What will happen in this interview?*

I will be asking you some questions about your background and about sexual health & HIV testing and support services. You may choose not to answer any question if it makes you uncomfortable. There are no right or wrong answers, so please answer as honestly as possible. The interview will last about 1- 1 ½ hours. At the end, you will be reimbursed for your travel costs and given a ticket for the lottery draw.

*What will happen to the information I give?*

The interview will be recorded and transcribed by the researcher. All of the information you give will be completely confidential. It will not include your name or any identifying information. The information from all interviews and group discussions will be compiled into a research report. The report will serve as my MSc dissertation and will be used to instruct community-based sexual health & HIV services on how to better meet the needs of African men.

If you would like a copy of the final research report, or have any questions after the interview, please contact the researcher:

Robin Nobleman

0795 654 1956

robin.nobleman@ahpn.org

## CONSENT FORM - CONFIDENTIAL

For Individual Interview

**Please read the statements below carefully and initial the box if you agree.**

I have read and understand the information given to me about this interview.

I understand that participating in this interview is voluntary and I am free to leave at any time without giving a reason.

I agree that the interview can be recorded and then transcribed. My name and any identifying information will not appear in the typed copy and the recording will be destroyed after it has been transcribed.

I agree that the information from this interview can be used in articles and reports, but that my name and any identifying information will not appear anywhere except on this consent form. I will only be identified by a number.

Having understood and agreed to all the above statements, I agree to take part in this research project.

\_\_\_\_\_  
Participant's name (print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix C

### Interview 11 transcript

Friday, April 16

Country of Origin: Uganda

R: Ok so to start off with I'd just like you to tell me a bit about yourself, just your background, where you come from.

P: Um, I am J. I was born here in 1972 but I went to Africa in 1982. As a kid anyway my parents took me back to Africa and I lived there til 2000 I came here. So from 2000, I do go back like almost every year. I had a gap of about 2 years in 2007 when I started taking medication until last year. So I wasn't there for the other 2 years but I went last December, came back this January. And that's me.

R: Ok, and do you still have family there?

P: Oh yeah, I have a brother here, cousins, relatives, so many and then I have a brother here. Let's see, one brother here, two brothers at home and 4 sisters and my dad lives in Uganda, he is a doctor and my mom passed away in '93.

R: Ok, and are you currently in a relationship or married?

P: No, I was in a relationship before I came here but you know this migration problem was, moving, the change, total change area and that, so it wasn't easy for me to go on with the other relationship so it kind of died out. Then unfortunately or fortunately, I met someone who was a bit – not so into it and that so we broke up. Sometime, last year, 2007 there was an issue of me having a kid with her which I believe wasn't really true you know, some of these people come from out there like, they just jump into a situation where they can get their immigration status clear so I fell victim to that type of thing, and it brought me all this unfortunate thing of sick and all that so I just had to give it up and what helped me it was a bit, it was so stressful so I just gave it up. I don't see the kid, I don't see the lady. She just put me on the birth certificate then she started showing up with the things so I thought to help me I'll just let go so that's it. So at the moment I'm not in a relationship, like now relationship of course I would like to if I could, I hope to.

R: Ok. And can you tell me a bit about your schooling?

P: Oh yeah I did a degree in finance and accounting when I was back in Uganda. I haven't practiced much here because of getting the jobs and that but I still want to go and pursue my masters in accounting if I can which I want to do although at the moment I'm mixed up between should I go and do that one or should I go into some study like long term conditions? There's a course I saw somewhere because one of these days I will get more interested in like what we do here [at AHPN] and things related to HIV so I

kind of thinking why don't I change and get into not only some [?] but learning more about HIV and that sort of things and helping that industry.

R: Yeah! Ok. So can you tell me a bit more about how you came back to England?

P: Um it was just like after I finished my degree. Well my dad was so hard because he had lived here and just didn't want that idea of coming here. And there was a dealing point of me coming here, so it was only until me and my brother finished university that he accepted to give us our birth certificates. So we just filled out the work, we can get the passports and just go. So we just went to the embassy and sent in our what, our birth certificates and IDs and all that and they gave us the passports so we decided just to travel. There wasn't really anything. Well at first our main focus and insistence from our old man was when you come here you get back into education and try to get your masters and PhD, of course you will. But of course what is on the ground is quite different from what people think. So you know that the system here is once you've been out of the country, even if you're a citizen, once you've been out for more than 2 years, everything is kind of fresh, so we had to come in like any other person and start fitting in and when we were not just accommodated straight on and it was a trail of developing, getting back in. Then unfortunately the place became addictive and here we are. I didn't think I would stay here for too many years, I actually though I would come study if need be get a fair job, make some money and go back. And it didn't, it was a bit slow you know it just keeps on dragging you on and on, you find 2 years, 3, 4, 5, 10, it's 10 years now.

R: Wow.

P: I don't regret it though, it's still alright, I managed to do a few things I wanted to do and it's only that I didn't upgrade my education, that's one things I didn't do that's unfortunate. Then coming here also destroyed my family life because I believe if I was there I'd be in a couple, be settled with a family. Two things, yeah two things. If I didn't come here I would definitely because most of my friends left there have 2 or 3 kids, married, yeah.

R: So those are some things that are maybe sort of challenging about living here. Can you tell me about some things that you like about living here?

P: The, the – one thing I haven't exploited is of course the education. Uh, if I look at it as general living it's not really as good as what is at home. And you know it's a bit plastic in this place. Everything is like you do it under pressure. Like when I go home on holidays and I find those boys who have managed to work and upgrade their degrees and find good jobs – well, they're a bit corrupt- but you know they handle themselves and their happy. You can have some money in this place but you can't really feel it happy. I mean, you're always under pressure of this and that. The people there are relaxed they don't get, they don't stress. I didn't know stress until I came here; you know that thing wasn't there. You know it's nice out there. If I had done my second degree upgrade out there, actually you know it's a bit confusing at times I've been thinking of looking for an international job that takes me back there even if it means working under AU, or World Health Organisation in the HIV sector anyways something that's going to take me back there. I like that life there it's more relaxing. But of course you know when I look at myself and the medical care I'm getting here you find you can't be that sure what will happen in case

you get a drop in anything. And then of course if you break the train and then coming back here and starting fresh can be a problem. And actually when I was home I'd gone for 4 weeks so I packed enough medication for 4 weeks and then I extended my stay there so when I extended it I asked someone to pick medication from my house and send it to me but this fellow who went and picked the medication that I had and didn't send the one that I was running out of so when I went to the medical officers, you know they're quite good, they try and their quite good, but they did not have the medication that I was taking. Then they started all these things you know, there's an alternative, take this with this, it's an equivalent of that. But I couldn't do it, I had to stop my medication for 20 days, because I just didn't want to get into taking another medication and maybe the reactions are not that good. Although they said the alternative to what I was taking was that and that. So of course because I was off medication for 20 days my levels of things were way down, but I've regained it sort of over the 3 last months.

R: Ok. And in what year were you diagnosed with HIV?

P: In what?

R: In what year?

P: In 2007.

R: Ok. And do you have any other health related issues?

P: Um, actually no I never even had a GP until I joined rail [works in rail company] and I had to. I used to have a dental problem with wasn't serious. You know there was a time I never took medication, and then I started to every day! So...

R: Ok, so when you think about eh future here in England, what are your hopes for the future?

P: Well I just, of course I hope to be well. And I hope to get back in to study something and you know try to get on with life as it is because it looks like I'm still going to be living here for a while And there's one things also – I want to get into a family kind of thing, get a partner and that. And you know I'm kind of restricted, and people say oh, why are you restricting yourself? It's because I need to look for someone who is in the same kind of state of mind, has the same understanding which is a bit technical and high. But I'm still going about it, I'm not putting myself under so much pressure so what I want to do is if I can settle in the short run, that would be great and then get back into education, see what I can do here. I'm planning to start a business with some friends of mine, they wanted to start an errand business or something so they want me to steer it for them, and on top of that there is a cleaning company that we actually started, you know contract cleaning, offices like this. So do some business and of course I want to invest more at home because I definitely want to retire in Africa so I should work, try and save up, just try to do things as normal life like planned, and I have set that myself because of the condition I have kind of limits me you know, you know I tend to think I should give myself maybe 5 or 10 years and then move myself permanently back to Africa, but then you know you're supposed to be on medication for as long as...but then you know I ought to belief I still have a future so at times you have to switch off this thing of home and just think here.

R: Yeah.

P: what do I do? I'm here I live here and that's it. My....

R: is there anything you worry about when you think about the future?

P: Basically it frustrates me a bit if I imagine that my chances are getting into a family man is limited. Otherwise the other things I'm quite calm. I'm still really because one thing I like of myself is I got under, out of that pressure of being sick, it didn't keep me down, it didn't break me up so much. Although in the beginning it was bad because I was drinking a lot so things, it was like I was covering up the problem with drink but once I got out of that drinking thing, I don't really think like some people think, oh I'm going to die, I have to do this and this and this before I die, it doesn't come to my mind. I just tend to get on with things quite normal as I can.

R: Alright so, oh and how old are you?

R: I'm 27.

R: Ok. So as you know, I'm looking into community-based sexual health and HIV services. When I say that, community-based sexual health and HIV services, what sort of things do you think of?

P Um, I think that it is kind of like creating awareness in the what I would call the village, what we call the village, that's the community down to the ground grassroots. And I think what you're trying to do is see, you know, what happens, how are they getting help or knowledge about STIs and all that, isn't it? Yeah, I think that's what you're doing, community based. That's, you know, the grassroots kind of penetration or at the basics of it. Yeah.

R: alright, that yeah. So now we're kind of on the same page. So where did you go for the HIV test that you had?

P: Luton, actually, Luton.

R: And was it a hospital?

P: It was a hospital, it was a hospital.

R: And why did you decide to go?

P: That was because this lady was living out there and when she got out of detention, she was in detention because of her immigration thing, she was pregnant and gave birth to the baby and so when we went to the hospital I was told that she was hanging on, not going to get deported because she was HIV positive, I said whoa, someone advised me to go get a check. So it was because it was there, so I just went for the check, I was almost quite sure that I had it because I was going out with her and that was there.

R: And had you ever had an HIV test before that?

P: No.

R: Hm. And what was that experience like, being tested there?

P: wow, it was terrible. But you know the thing was because I knew that she had it, the main problem was why didn't she tell me? Why did I have to get it through an informer and you know, I mean mine was very bold in there because they just took me, slammed me in and asked me a few questions and then we did the test. And then after that when I went for the results they said what do you expect and they told me. That part was alright, the medical part. But then we sat back and said ok. Let's look and let's see when to start treatment and I went there and saw my bloods were bad and everything was bad they said now it looks like you should start treatment. And is aid yeah, fine. What I didn't like was that lying. Now I'm in a situation that I don't go out with any lady who is pos- I mean negative, I won't do that, my spirit isn't like that. So it hurts me to think that this girl knew she was sick, she still went out with me. And I knew I think I knew someone she was going out with who actually died, but I didn't know it was AIDS, I mean HIV or something, she lied to me and said it was low blood pressure, so that part hurt. But the part of going in to testing and onto medication was alright.

R: Ok, do you think that it could have been improved in any way, the, the actual testing part?

P: um, yeah what I didn't like at that place was I didn't get what I learned later on – pre-counselling and post-counselling. I did not get those two because I think they assumed because I was going out with someone who is sick then I should be. So they didn't do much it's like they poked me in, gave me the test and poked me back out. So the counsellors attending to me, I don't know whether she was a junior or something, at one point she was crying when I was telling her my situation. Oh what was happening. So I think if they had taken me on I would have had the chance to explain what was hurting me, which was the situation which that lady didn't tell me so I wasn't actually, I was self-prepared in the sense that I heard it through a rumour so it didn't shock me. But in case I didn't know it through a rumour and they just dumped me in a hospital, and they said this maybe I will break. So that standard procedure of pre-counselling and counselling I think it should be done whenever possible whether the person knows their position or not, not by assumption that well this is a fresh case because if I presented with [?] and we didn't talk about it then it's dangerous. It should be straight, everyone should have the pre-test and post- I mean pre-counselling and post-counselling.

R: yeah, that makes sense. Can you think of anything that might have made you want to get tested earlier?

P: I actually, in my life the time that I wanted to get tested was when I was with her, I got to realise she was a bad kind of lady. Well I don't know if it is just being African, but there is that tendency that we if you've been in a relationship like the girl, whether it was 9, 11 years. And personally I wasn't like cheating or messing about, and I trusted her, and I was physically I was healthy, so I just didn't think I should test. Although I came to realise, you know through all these things that whether you feel healthy or not it's good to test for STIs or anything like that because you never know what you can carry. So prior to that I didn't think of testing because you know, well we didn't have the things so much in Uganda and I was in a steady relationship and when I came here, apart from this lady I was with a lady, a

Spanish girl and I think she went to Spain she told me oh I tested I am good, she was alright in 2004. And she just tested because she is just brilliant this girl because she's been going out with someone and she was going to stop that relationship and before you go into another relationship you test yourself. And she was so good that she told me. So unfortunately if I had not just gone into this lady I would be alright...

R: Alright, so after you were diagnosed with HIV. What kind of help did you need – did you need the most?

P: Let's see... Um, of course counselling. I don't know because I was a bit strange. Once I started taking the medication i was almost self-counselling myself but with the drink. I was strong because I was depending on alcohol. But imagine I was in a situation where I wasn't drinking I don't know what I would o, I would definitely need counselling. And of course when I stopped drinking is when the problems of stress started setting in, the sadness, the loneliness all those things I believe once you're on medication you need to start getting on to those counselling courses and that because um, if I wasn't drinking at the time maybe I would have even got suicidal. And you know I came to realise something I'm actually very strong because if you look at the position that lady put me in, the position I have, my family at home and my parents, it's very hard and I really needed someone to talking about it but it's got to be frustrating when I wanted to know whether the baby was mine or not cause I've never, cause the lady has become defensive, aggressive. The best thing I did was just shut it out, which is not very good. I tell me at times it's not good to shut it out because if you don't address the issue it bothers you, but I was lucky that I managed to get out of it.

R: And how did you come to stop drinking? Did you have any outside help with that?

P: No, I didn't. I was given all these things, go to alcohol something something, but I didn't I just felt...I need to stop. One, I was drinking whisky and then I stopped drinking whisky and started taking beers and I found I couldn't cope with that so I just stopped. Not in a day, I'm not drinking a lot now but you know that occasional thing so...

R: Ok, and as time went on after your diagnosis, did the type of help you needed change?

P: yeah...yeah, yeah. Of course I needed guidance. What do you do when you need help? Because at one point I left work and then there are so many social problems that come in from housing to what to do next, how to take care of yourself, not as in like indoor stuff, but what do you do when you're there? What do you do? Someone to talk to like general counselling. I was really found St. George's because I transferred my treatment base from St. George's to Tooting. And I was attending with Agatha somebody else to talk to at one time, because it was, you know there's that time when you actually, you start realising that actually there is stress from depression. You know there's that time when you just hate yourself or you're annoyed over nothing so I just kept on talking. Well, the thing is I was talking to them but maybe just spelling off my problems because I didn't get any real feedback because there's no practical situation that can help you. Say do this, like you know...they don't really do anything. But I think really just talking releasing it will help. So...I didn't get help too typical and I actually tell people like when I come to these meetings I say it's good, it helps because I've seen people who have got diagnosed

after one year and when I meet them in groups I can tell them if you sit alone in your house it's bad so I feel it's good to get counselling and I always tell people talk to it.

R: Mm and you're still finding support from groups like Milestones and that sort of thing?

P: yeah, yeah. Recently I attended a PSMP training.

R: I'm not familiar with that.

P: That is positive self-management something. It was run by Pamela, Pamela was here the other day, Pamela and some French guy called Bernard. So it's just like what, what I have done because I've done some outreach trainings, west London HIV positive partnership something, I was going there 2 years they keep on doing outreach training...so I got quite a lot of things out of it and when I go to these support groups I'm like a bit experienced now so when I sit in there and you've got people and I like to talk to them, you know those who are just in you know you look at them and they look bad.

R: So your role has kind of changed.

P; Yeah, I feel a lot like when I hear, the other day I was in one of those PSMP and this lady looking so, she started medication and she talks and she starts to cry. And I said, look you don't need to cry. We get a long with it. Once you start breaking down and giving yourself self-sympathy then you are finished. So I actually like talking to people about their selves, that's what is mixing me up now because if I'm going to start thinking of doing that type of counselling, then what about my accounting.

R: yeah. Ok, so –

P: I always drift off the main theme...

R: no, no this is perfect; this is good information [laughs]. Well that's fine I'm going to keep leading you with questions. So actually your experiences with this trainings and being involved in so many groups and the Vital Voices program it's really helpful for my next question. So I'm wondering if you could design a support service, an HIV support service specifically for African men, what would it look like?

P: mm one thing with African men is that we need to educate them a lot. It's just like you said when you go to these groups, you find ladies. I don't know why we are a bit of like, they don't want to come up. I've reached my hospital at times, I've seen people I know and it's like they don't want to be known at all. You know, it's like they want to hide, hide. You know you get them out there trying to pretend that they are extra normal. But African men need to start getting to reality. You know, there was a time I was discussing it with someone. I said , you know ladies seem to get in great with it because you know once they go through, ladies are normally checked quicker for sexual diseases I don't know somehow. Maybe they go there and they start all these things of breast and they are really active in medical things whereas men go there only when they feel pain. So somehow they should believe why they know why are they always running out with ladies or having sex and all these things then they need to get to know what sex comes with, You know it comes with all these diseases, be it not HIV or other STIs so they need to open up a little more. And that's for those who are stuck out there, the stigma should get off.

You know they should look at it like it's routine, like ladies go for routine tests. Men also have to get, African men also have to get into that system of check ourselves up. They tend to blame it on the ladies when a disease comes; I know that, with the exception of my case.

R: Yeah, that's a good point to make it more of a routine thing. Um, so, so education and decreasing stigma would be a big part of the service and do you think that it's better to have men and women separate or together in a group?

P: um, I think it is, I feel comfortable with both being, I wouldn't feel comfortable with men only because at least when the ladies are in these groups it makes people discuss but men tend to come in and they're all stiff [sits in unfriendly posture with arms crossed] and they don't want to say it and you know so when I'm going to these few groups and they start talking and the ladies talk I don't really think we should say oh men there, go and do this, there is an organisation in West London called OPAM.

R: Yeah, I went there yesterday, they had a meeting.

P; oh, was it only men?

R: No, it was mixed actually, I was surprised.

P: Oh really? I've always been asked to go there but I haven't managed to attend any of their meetings. You found, you find B?

R: yeah, he's a very enthusiastic guy.

P; Yeah, he is. B is a nice guy. So, let me think. Yeah, I mean openness, stigma and what else should be, yea, I mean discipline and all those type of things.

R: what do you mean by discipline?

P: Discipline is almost acceptance, discipline. Men should stop this African thing of men are boss, men can't be wrong; men can't be the ones who bring the illness. You know that type of things? That's why they tend off, I know a couple of them. They don't want to accept and it is very rare for them to come into groups and forums. They tend to come into groups and say what, what is this? [derisively] They come to look for relationships in the sense that well like me you need to find a relationship with someone who is positive. But I've seen them they come and look and next time they are gone. But there are other things you need to know in that group, not only if it's that. How to manage yourself, or how to go about because like we're still the minority so we need to go out there and let other people even those who are not in our circles know that certain things can happen, they need to take care of themselves, protection you know. How to use protection.

R: Do you prefer groups that are African run or uh, British?

P: Um, it comforts me a bit when I see a mixed up thing cause you know when it's only African you know there is that thing that sets in the groups like it's an African thing, it remains an African thing, So I like it at Milestones, there was a lady who was Dutch or something, she said she'd had it since '94, a white girl.

And she's strong! She made it from the time when they were writing off people after 6 months and I was, well I wouldn't say glad to see her there, but if they come, there was a long time I was like why is it black, at these meetings why are there so many blacks? Don't white people get the disease or something? So I prefer to have a mixed time. And you know there is another question: why are we always saying African? African HIV Policy...why doesn't it just remain HIV Policy Network. Why are we always looking for a name here, why are we looking for Africans? Like if there's a white person who might not want to come in if it's African. So the thing of culture should work, it should remain HIV Policy Network.

R: Ok.

P: Empowering Africans communities – who said it's only Africans who need the empowerment?  
[referring to logo and motto on information sheet]

R: yeah that's true, that's a good point.

P: So we keep on saying African, that's why you get the money and keep on doing your business. You know, and like um, I was talking to someone from [?] and you know we joke a lot these African men but we are not practical. All these people just trying to make money out of us no we don't say ok let's do this like you're asking me, let's do what do we do to get in there and do this bring it to us? I don't know.

R: Ok, yeah that's really helpful. So considering the group at Milestones and other groups that you've attended, how did you decide to join those groups?

P; Um, my counsellor she's always informed me that oh there is this, there is this, there is this, would you like to attend? And basically once I'm free I don't mind. I'd only not – I've always liked to learn more, I've always liked to put myself in a more practical situation. If I'm on this new medication, I want to know how it works, talk to someone about their situation, I know how it works. We were discussing with someone, she wanted to change her medication. I don't know what she feels like but then I said to her it's alright, the options are there but if you start shortening your options now in the long run you're going to be limited. So it's great to know more about the thing I'm involved in it practically. You have to be involved to feel comfortable, you know., So if you're not part of it and you just get your medication and go, you don't know what your body's working like, we need to know those things, especially for the HIV, in Africa and here they have to know what happens a lot. Some will just get their medications and that's it. When they're out there, whether they are, you some of them could be as serious like they think they're having sex openly out there and maybe infecting people and not getting themselves in a mess, but they don't know if they have caught some other virus which is of another strain, they are going to worsen their own situation. So if you just came got the medication, went and kept it in your car boot, and then they pretend out there you're all fine then you think you're messing about, these are the type of things these African men should come back into.

R: And just going back to your earlier point, the counsellor that referred you, was she at the hospital or how did -?

P: yeah, she started the, she was the counsellor at the hospital at the first. She helped me one time when I was drinking a lot a lot, she said now if you're going to be drinking like that what you need to do is put the medicine in there even if you're drinking because I would think oh I've had a drink so I'm not going to take the medication. She was good. She was there for a while like for the first like 6 weeks then she moved from there to THT and she always had my contact and she always says, there is this thing, you should attend. So I've always followed up on her.

R: Oh that's good sounds like she was really helpful.

P: yeah she was.

R: Ok, and what do you like best about the services the HIV services that you attend.

P: it's the knowledge actually, the knowledge that I'm getting. The knowledge and confidence I gain in you know attending all these things. When you know someone's at least doing the research then you know there is something happening about it, you're not in vain. So every time I go out there, even if I'm listening to the same because some of them I know I've already hear, but you get personal telling you, you get practical experience, Someone was telling us how they handled depression, someone was saying how she didn't realise she was depressed until she was in hospital then they said that's this depression. So you get to learn practicals. Like food – I was telling people I'm very poor at food and when you get there the ladies are saying oh we don't get this, don't eat this because this is better and you just pick that and you're learning something. Or you sit in your house and you just keep on eating whatever's there. It's great that you get into that situation of sameness; you know we all have the same problem and we are together in that thing, not isolating ourselves from the outside world. There is a self-dispute because we definitely have to be a bit more careful, so when you attend such position, you find that you streamline yourself, you tracking yourself but when you get too open out there you can disappear into those who are perfect like 100%. They don't have to see that they don't take this because there's medication and you can't be away from a glass of water when you're supposed to take medication, or you can't be out drinking because you're supposed to – so it gives us that kind of training.

R: Ok and on the flipside, what – is there anything that you dislike about those services?

P: Mm not particularly, they do try hard. Of course I wouldn't like a society organisation that's a cheat. I wouldn't like an organisation that is doing statistics, you know they use us like numbers. How many have attended, oh today we have 12, 10 from Uganda, it must be big there. You know those who come to operations for statistical reasons and reporting. Cheats, I know there are some Africans societies who fail to run because you say African and you get a bit of funding and do nothing. The other day, that group, when you left they were telling us how they take care of a certain number of people, they are given a certain amount of people and someone else has 2 people and has the same type of money so there's some money thing they play around with. I don't like it. And what else, it's pretty good; I don't really say anything negative about it.

R: Ok, and have you ever tried to influence the way that the services are run?

P: In some cases yeah because I remember they were drawing out a questionnaire for outreach work in the [?] organisation actually, west London HIV partnership thing so there were some questions that I found I don't remember them now, they were a bit too direct, so I asked them why don't you twist it a bit to give some comfort. I would like to, like I was saying the other day that we need to get involved in the policy-making like I actually want to work with the department of works and pension. You know the disability department because like I said the other day, these people don't know where they put people like us. Well, me I'm fine I wouldn't say I have a disability but there are certain people, especially when they are just starting their treatment, when you go in there they will say ok incapacity, then you know sometimes they are saying it's a disability but the people who are working here, they are people who are not running in the condition, or they're not living with it. So I would like we should get in there and sit there and get that office so that when we are telling someone you can go and work you're ok it's because the council when deciding about accommodation they had standard blood levels. If your CD4 is above 350 and your viral load is somewhere, they don't have this possibility to taking care of you. The argument is keeping me there, maintaining me there [at a high CD4 level] because I can drop and then everything goes a mess – that's when you're going to take me? Why don't you help me get fair conditions so I can keep me there, be better. You know so we need to influence those type of decisions, they don't just put a marked level so when someone walks in there – you know these are non-medics, well I'm also a non-medical but at least I know these things, I know a CD4 count can fluctuate. For them they see oh 400 is the limit, once someone is above that they're ok. They don't know it can drop overnight. So we need to get in there influence those positions so we can make decisions. With immigration I don't know.

R: That's another mess.

P: I'm glad you didn't ask me immigration. I pity those who are getting deported like to deported, but you also need to be here the right way. You can't just imagine oh I'm sick so you've got to take care of me. The it's unfortunate like those who get deported to my country the corruption and whatever is so high. It's only those who are doing well which can get the medication, unfortunately. But with immigration I will not say anything about. And at times it looks like people, you know when I'm going to these groups and sometimes I end up quite because the basic thing in there is immigration. Those with immigration problems are the most surely have, but those who don't have immigration problems like me are not even attending these types of things. So it's a little – like whoa re coming to these organisations. If you ask people what do you want? Immigration, immigration, immigration, then the whole thing will go to immigration.

R: And that's not relevant for you.

P: No it's not relevant for me.

R: Hm. Ok.

P: I'm drifting away.

R: That's fine [laughs]. The thing is everything is interesting to me. I've got you know some ideas that I'm coming in with but I'm trying to see what you think because really you're the expert, I'm not the expert.

P: So how to better...You know I made some sort of mistake, I should have read this [information sheet] before I came in.

R: It's ok.

P: I'm just doing this like someone you picked off the street. How to better meet the needs of African men living in London.

R: But I mean all these questions relate to that. Hopefully. So yeah as it says there, I'm specifically looking at men so I'm trying to get some ideas of men and access to health services specifically. So to start out, what do you think is a good reason to go to the doctor?

P: Hmm, I've got to believe it's um general check up. I think I learned that very late because being African I was only going to hospital when I'm feeling pain but I've also realised that you need to keep on checking how the body's running it's just good to keep in touch with medics to maintain, just like on cars.

R: And you said you never used to have a GP. Do you know why you...that's a hard question, why you didn't have a GP. Can you – do you know why you were reluctant to have a GP?

P: I think when I was young it was because of my parents. Being a doctor he always I think took us to doctors but you know Africa is like you go to the doctor when you feel something is wrong. There is no, nobody is assigned to a GP like here. And it's like I was talking to my brother when we just came here. He goes to the GP and he went to register, and they told him his blood pressure was high and he said rubbish. He just said no no no so I said but he's big so I said to him you don't ignore those things. But me it's only of late I realise it's quite interesting if you went to the doctor they tell you you know the node you feel on your body, this and that, but I didn't think of those things. Going there isn't so bad for whatever it's supposed to be, then they check blood pressure, you know. But I just didn't see why I should be going. I thought I was wasting my time. I also hated going to the dentist because I've always been working, you go to the dentist they give you painkillers and they charge you £40.

R: I agree with you there, I hate the dentist too. So you kind of already answered my next question but it was more to do with testing when you were talking about. So why do you think there are usually more women than men, especially at support groups?

P: Of course when it comes to the Africans, yeah like I said African men I think like, I don't know what language I should use. It's just like the attitude towards going to the doctor. A lady maybe because of being a mother and you know ladies always have, not always but at times have a regular more medical need than men so they are always almost there most of the time. But men only go to doctors when they're feeling pain. I mean before I start feeling pain. You know African men generally, there is that tendency of thinking they are the...but when it comes to this place where let's talk in the African London context...why do men go to doctors...

R: Or support groups specifically is what I'm more interested in.

P: Support groups. I think it's I don't know whether I should say shame or shyness or stigma. But you know like ladies in any situation, you meet a new lady you've never known yet you click like that in a minute. Because I realise when I go into these support groups men tend to like [sits with arms crossed, eyes down]. Nobody's going to sit and feel free. But ladies go 'lalalala' you are very quick telling them. There was a day I went to one at King's Cross and they were all 'This man cheated on me, I was also going to cheat on him' [woman's voice] and I said 'Eh, woman!' They talk like they had been friends for 10 years. But men won't come like that. I don't know what that attitude I should call, but it's an attitude also. There is that thing because we are, there are some like what's his name, Lazarus I met him and he's open, he talks but there was a guy who was there the other day I thought I'd never seen him before and he disappeared before. [interruption]. So that's the thing I don't know it can't be stigma, because with stigma you must know what you face. You kind of I don't know what language I should use but ignorance, what do you call bullyness, not bullyness, feeling big or something –

R: Like stubbornness?

P: Stubbornness, ignorance, arrogance. I've met a lady who comes who attends one of the PSMP things. The husband doesn't want to come; it's a waste of time he says. What do you get out of it? You know, there is that attitude, what do you get out of it? You expose yourself. Attitude, attitude.

R: Do you think he means what do you get out of it in terms of a material reward or what you learn?

P: More what do you learn. Because some when you go for, most of the things are repeated anyway but it doesn't mean you don't need to go. Yeah, I don't know what language I should use, I think I should start thinking about why don't they turn up.

R: yeah, what you've said so far makes sense. So in your culture, how does a boy become a man? Change the topic a little bit.

P: Um, that's a good one, how does a boy become a man. Well physical sense, authoritative sense or?

R: What sort of things do you have to do or things you have to have or how you should act.

P: Oh yeah yeah. When you get a certain age and you start feeling you can, generally in our culture it's like, I think mine is a bit spoilt because my dad did it kind of the English way like you leave home once you're done your education. But to other people in our culture you'll see that it looks like once they get into is it 18 or something, you know that age where you start going out with girls, it looks like the parents tend to let the boys start moving out of the main house into those small huts which are like the boys quarters kind of thing then they start getting kids in there then that's it. They start to drift off when they reach a certain age. Physical mature age, you're having a lady and that's it. If you look at the lady that's not, the non-educated people like I have cousins most of my cousins are married with 5, 7 kids but they are not educated so some of us at least who went to school an were locked up in school until about 25 and that is when you start getting to girlfriends. Until by that type of age you don't even take a girlfriend home. At 20 and that. So in our culture we've been mixed up with this, those that have

education tend to stay at home longer and then there's those who didn't go to school so so much, they just get primary and then they start getting women once they are sexually at that age. But some of us were restricted, like you don't you don't because you're still under your parents, you're still going to college, uni, they're still paying for that so you don't have a right to bring her home, you don't have a right to have a girlfriend, although towards university they tend to ease up a bit. So when does a boy become a man. I didn't answer your question.

R: No I think you did, that makes sense.

P: When you start deserting out of home, when you start going out with girls, actually that's true in African setting, when you start going out and feeling you can have a girlfriend, that's when you are a man, when you start leaving your parents house to start your own family.

R: Ok and what sort of things does your family expect of you once you're a grown man.

P: yeah, like money. You're supposed to watch over the young ones. That's another this, that's why I like the English culture, there's nothing like take care of your small brother. It's you and get on with your life. So me I'm expected to take care of our younger ones, I pay for the school fees of my little brother. I pay for him to finish his university; actually he should be the last. Then there are girls that they are, and of course I have the same problem, they have a tendency = of course those are my step-mom's children – they seem to get to a certain class and get pregnant before they finish university. So I'm almost telling them I'm not ready to pay for girls who are supposed to reach that age and they simply get pregnant after me paying their fees, we need to change it. So responsibility, like me I am the first born so you start making decisions. The life here is nothing like that. So you get yourself here. So that's why I have a big problem. People came to tell you what you need to tell you counsellors here. Maybe you need to talk to family about your condition but me I've never told. But if some people, friends, suspect rumour, they rumour monger, you know our culture rumour mongering, there's also this thing men don't want to come to these things because where ladies are they are talking so openly. Like oh this guy he is this and they don't want...Because I've also realised when I've travelled back when we are like out of this setting we don't want to talk about HIV, the men. I think on men. It's only when they come into such a meeting they talk about it. When you are out there there is always a thing that you don't mention it. You see but I think the ladies are good, when they go out there they still talk to each other but for us when you're out there you don't talk about it. Where was I?

R: [laughs] You were talking about expectations of your family.

P: Yeah, yeah so that's the thing I haven't told even my parents but my dad being a doctor one time he drinks a bit and he says oh so you're skinny thing, are you ok? And I just looked at him and I didn't answer him. But that time I was drinking quite a lot. So this time when I went home he actually said you're looking a bit better this time and I said 'Ah, dad I don't drink as much these days.' But the other time I was not yet diagnosed and I was drinking heavily and I was all stressed about the lady situation but I think I really got it and he looked at me and I think he was really suspecting there was something wrong with me. So I can't tell him you know he expects too much out of me. He expects me to be running the home and here I am going to tell him that I'm HIV positive. And you know it's like even if I

had sex when I was 13 and he thinks oh you're becoming stubborn and playing around with the neighbour's daughter and that. And he comes home with all these – because he used to go to the conference of AIDS in Zimbabwe when it was just starting. Once you have sex you are dead in 6 months, that's it. So I even the first time I was having sex I was very scared of that thing. 13 well, I used condoms for the first half of my sex life you know. And then always I said after all that training from even before you're having sex and you go back home and say dad, me I'm HIV positive. [tsk, tsk]. After it's hard. I just think if he's going to get it through a rumour and ask me, maybe one day, maybe I'll answer but I would never go to him and say look.

R: And the expectations that you r family has of you, do you think those have changed since you came back to England?

P: It's gone up; you know there's that silly expectations financially they think, well yeah. But my dad is great because he lived here and he knows it's not easy but when it comes to sibling, relative, friends and that, they look at you like they expect, you work for them at times.

R: Well, I just have one more question for you then.

P: Ask me things that are related to you study.

R: Well, see...

P: You will see I have told you nothing. I have always told people that when I talk to my counsellors, I have to tell then look, man you have to keep me on topic or I drift away.

R: [laughs} But it's all important. These are all things that I'm going to use to answer that question. But the thing with research is, especially in psychology, we have to be a little sneaky, you know we can't directly ask the question because people will tell us what we want to hear sometimes, so I kind of have to ask questions that relate to it and then I'll figure it out from there. But my question is, so the fact that you're an African man, is that a big part of your identity? Is that a big part of who you are?

P: yeah.

R: It what ways?

P: I just feel too good to be African, I don't know why. I'm so much that unless I'm supposed to present documentation I don't call myself British. Um, being African, I don't know. What is the ...

R: Is being an African man an important part of your identity?

P: Yeah, It is. I just love being African, I don't know why. Yeah, it is important. I don't know why it is but I just feel great being African...man actually, African man. Um, there is also these African British, you know who grew up here and that type of thing but I don't admire the way they do their things. Because they're mixed up. They want to behave African, they wan to take the English – are you English?

R: No, I'm Canadian.

P: Canadian. To take the English culture which is a bit bad, most of it. See they are lost. See me I am proud because I am that bold African catholic kind of thing, which doesn't help at times because we are too disciplined, but it's nice to be African. It hasn't answered your question.

R: It has, it has! Don't worry. So that's all the questions I have for you. Is there anything else that you'd like to add? You were saying you don't feel you've answered this, is there something you'd like to say to - ?

P: No, I want you to ask me something that's related to health and HIV services to better meet the needs of African men [reading off info sheet]. What are the needs of African men?

R: well, maybe that's my question then. How do you think the services can be improved to meet the needs of African men in London?

P: The services that are being provided are quite good. The thing is creating awareness, I don't know but that is what we've been trying to do with that outreach work in west London. But still when I go out there and I'm trying to get people, because it's also a BME thing, a Black minority thing, I tend to find more ladies willing to talk to answer my questionnaires than men. And I don't really see the reason why. They look like, it seems they are like, we thought maybe they think everything they're going to do there should be a financial gain, which cannot be it because London is a different place; people attend to so many things. And why the men are not on there really freaks me out. Awareness, I don't know where we should pull in these men from cause that's one thing we've really been struggling on down there but you know like the outreach, outreach should be pushed a bit more into men's organisations and that but if it's done like I thought OPAM was only for men, I think it's hard. And because this is a country with GPs I think GPs should have an avenue for getting men into testing for sexual things. Somehow the women are all around. The cancer, ovarian cancer is going to make them all check almost every sexual disease, breast. I think also with men once they get to the GPs they should also be pushed into testing for not HIV particularly but all the STIs. They should get a way of driving them to the GUM clinics or something. Which would be good. And what else...And maybe a few more should start showing up, I wouldn't do that but then maybe, but there are some there, behind magazines you find a man and he is ok, he's doing well. Yeah a couple of celebrating men who have come up. Like Uganda in those days, the musician who said he was HIV positive. A couple of Ugandans have done that but still it's true, the number of men who are showing up I mean going out in the open are few. Unless we are not getting the truth, unless they really are just fewer than the ladies.

R: it's possible, I mean there are more women testing so therefore there are more women knowing they're HIV positive and in the African context there's a higher prevalence in women. So it's not necessarily all that men are hiding out, but the research seems to say that that's part of it.

P: yeah. Yeah, because I really don't see why, like especially once you're living here then there's a little more openness in England that people don't hide. You've got a condition, people don't hide. People should come up. Yeah, they they hide a lot. I think I've known a couple of men that I know who are not well but they're always jumping out there and pretending they are ok. They get their medication and go and drink on top of it and just stay there. And actually they don't get involved so much – oh the other

one is sick, the other one – they don't talk about it. It's almost like what would we call it – it's a taboo to talk about HIV in the African men. Which is just ignorance. It's ignorance.

R: Well, I think it's people like you that they need then to, you know get out there and you obviously are.

P: Although I have not, I haven't gained that confidence of showing up, but what makes me now sure, by then I have reached situations where I know people have talked. Oh he is sick. The other day we were talking about Christianity then there was one of these boys who was yapping g too much, so I told him something. He said you people there must have been something drastic that happened in your life, like health. So I didn't really answer him, there are those whose attitudes who become aggressive, they are very hard to convince. And I think like when some of them are in their dying beds, they still wouldn't accept, which is wrong.

R: Alright, that's just great.

P: Don't you have anything else.

R: No, that's all I have.

P: I hope I was a help.

R: Of course! Thank you.

## Appendix D

### Participatory planning activity: Focus group 2

**Who would run it?**

Quality leadership

Positive person with knowledge of governance of a charity organisation

Clarity

Transparency

Vision

**Who would attend?**

Members, families and carers of people affected or infected by HIV

**What would it include?**

BME groups

Advocacy

Peer support

Early testing

Prevention

Other STI treatment and prevention

Information dissemination

Signposting

Therapies

Training

Volunteering/outreach work

Stigma and issues around sexual orientation

Path to employment

**Where would it take place?**

Pan-London venue

**When would it take place?**

Office and out of office hours depending on issues (i.e. emergencies)

**Why would you design it that way?**

Based on individual experiences

Nature of disease demands a holistic approach

## Appendix E

### Topic Guide

**Individual interviews with HIV negative men who have or have not accessed sexual health/HIV services**

#### Life Narrative

Tell me a bit about yourself

Where were you born?

Family – brother, sisters, parents?

Are you currently married/in a relationship/single?

Tell me about your schooling.

How did you come to England?

What are the 3 best things about living in England and the 3 most challenging things?

How old are you now?

Currently employed?

What are the 3 things you like best and least about yourself? (examples of all)

What are your hopes for the future? What do you worry about when you think about the future?

**Transition:** What do you think of when I say community-based sexual health services?

#### Testing

Have you ever gone for an HIV or other STI test?

- Where did you go for the test? (NHS service or community organisation)

Why did you decide to go?

What was that experience like?

- Was pre- and post-test counselling offered? Was it helpful or unhelpful?

- What was good about it?
- How do you think it could have been better?

**If not:** why have you never tested?

Do you know where to go if you wanted to test?

Can you think of anything that would make you want to go? (personal reason or change in the services offered)

## **Other services**

What other sexual health services have you accessed?

- advice
- contraception
- STI treatment

Have you ever been reluctant to go to a sexual health service? Why?

How did you decide to go to X for that service?

- How did you find out where to go?

Can you tell me 3 good things about the sexual health services you've experienced?

Can you tell me 3 things you disliked about those services?

- Have you ever tried to influence the way services in your area are run?

Were the services that you accessed African run/run by a particular community or British?

Have you had any bad experiences/reasons for discontinuing services that you have accessed?

### **If never accessed services:**

Where do you get condoms?

Can you think of any reason you might want to go to a sexual health service?

Do you think that's typical of most men like you?

## **Men and access**

Why do you think there are usually more African women being tested for HIV than men?

In your culture, how does a boy become a man?

What's expected of you as an African man?

- by partner, family, friends

Has that changed since you came to England?

What part does being an African man play in your identity? Is that an important part of who you are?

Anything else you would like to add?

Thank you!

## Topic Guide

### Individual interviews with HIV positive men who have accessed services

#### Life background

Tell me a bit about yourself

Where were you born?

Family – brother, sisters, parents, children?

Are you currently married/in a relationship/single?

Tell me about your schooling.

How did you come to England?

What are the 3 best things about living in England and the 3 most challenging things?

In what year were you diagnosed? Any other health related issues?

How old are you now?

Currently employed?

What are the 3 things you like best and least about yourself? (examples of all)

What are your hopes for the future? What do you worry about when you think about the future?

**Transition:** What do you think of when I say community-based HIV and sexual health services?

#### Testing

Where did you go for an HIV test?

- NHS service or community organisation?
- Was it your first test?

Why did you decide to go?

What was that experience like?

- Was pre- and post-test counselling offered? Was it helpful or unhelpful?
  - What was good about it?
  - How do you think it could have been better?
  - Can you think of anything that might have made you get tested earlier?

#### Support

After you were diagnosed HIV positive, what kind of help did you need most?

Probe for:

- Practical information (e.g. housing, benefits, where to go for support)
- Emotional support (Counselling , peer support)

- Medical
- Immigration advice
- Advocacy

What sort of services did you find useful as time went on after your diagnosis?

- What sort of services are most useful to you now?

What would an ideal support service look like to you?

Probe for:

- 1-on-1? Group?
- Mixed?
- With professionals or peers?
- What kind of support offered? HIV specific/general support?
- What would you talk about?
- Led by/with other Africans/European/BME
- Close to home/in another borough
- Religious?

Considering the support group at \_\_\_\_\_ and any other services you've experienced:

- How did you decide to join the group at \_\_\_\_\_ (or seek other services)?
- What do you like best about these services?
- What is the worst part about them?
- Are you still attending these services? Why or why not?
- Have you ever tried to influence the way services in your area are run?

Do you prefer to attend African-run services or non-African run services?

Have you had any bad experiences/reasons for discontinuing services that you have accessed?

## **Men and access**

What do you think is a good reason to go to a doctor?

Why would you wait to go?

Why do you think there are usually more African women accessing HIV services than men?

In your culture, how does a boy become a man?

What's expected of you as an African man?

- by partner, family, friends

What is your role in your relationship/family as a man?

Has that changed since you came to England?

Anything else you would like to add?

Thank you!

## Topic Guide

### **Focus group with positive men who have accessed services**

#### **Intro and icebreaker: 15 min**

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Consent, information.

Name (first name only), country of origin

Ice breaker: What's your favourite place in London and why?

#### **Designing a service: 20 min**

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What do you think of when I talk about community-based HIV services? What do they include?

When you attend these services, what benefit do you get from them?

Probes:

- What is it like?
- How do you feel when you're there?
- How would you describe them to someone else?

If you had to design a service specifically for HIV positive African men, what would it look like?

- brainstorm idea of who would attend, offered/run by whom, what would it include, where would it take place, when would it take place?

#### **Access: 15 min**

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How did you decide to access the support group/other services?

What has prevented you from accessing services in the past?

- Psychosocial barriers (stigma, fear of looking weak)
- Practical barriers (work schedule, location, fear of disclosure, fear of statutory services)

Considering the services you have accessed in the past and at this time, what is the best part about these services?

What would you change about them?

## **Masculinity & Migration: 15 minutes**

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Why do you think there are often more African women accessing services than men?

How many of you are currently employed?

What are the challenges in finding employment in the UK?

Do the HIV services you attend help you overcome any of those challenges?

What's expected of you as a man?

- By your partner, family, friends

Has that changed since you came to the UK? How?

Anything else you would like to mention?

## Appendix F – Coding Frame (Part 1)

Global Themes	Organising themes	Basic themes	Description	
<b>Symbolic context</b>	Hegemonic constructions of masculinity	Behaviours that define men	Rites of passage and ongoing behaviours that make a man a real man	
		Responsibilities of men	What men are expected to do	
		Gender differences in health behaviours	Men and women are essentially different - this shows in how they care for their health	
	Failure to meet expectations	Unemployment blocks masculinity	Without a job, men can't fulfill their responsibilities	
		Gender roles disrupted	Gender equality changes relationship dynamics, different roles here than in Africa	
		Migration-related failures	Migration and cultural adjustment make it hard to meet expectations	
		Family-related failures	Inability to fulfill family roles of being a husband and father due to family breakdown	
		Negative representations of HIV	Experiences of stigma and isolation due to HIV	
	Alternative constructions of masculinity	Service users are not like other men	'Other men' have problems, service users have gotten past them	
		Empowered attitudes about HIV	A normal life is possible, new activist role taken on	
		Protest identities	Pride in African identity and promotion of gender equality, tolerance of gay men, expressiveness	
		Men care for their health	Seeking care and maintaining health is a way of being a man	
	<b>Material Context</b>	Satisfaction with services	Socio-emotional support	Support groups provide inspiration and learning from others, social support
			Information	Information about HIV, nutrition and medications provided
Opportunities for training			Appreciation of the many opportunities in the UK	
Unmet service needs		Lack of practical help	Most urgent needs are practical and not being met	
		Material barriers	Financial and time barriers due to work block men from attending services	
<b>Institutional Context</b>	Policy problems	HIV services policy	Problems with the way funding is distributed and how HIV is approached in a policy context	

MASCULINITY AND HIV SERVICE NEEDS

		Migration policy	Immigration policy limits access to services and employment, migrants face discrimination
	Structure of Services	Structural problems	Problems with the organisation and delivery of services
		Structural strengths	How the structure of services serves clients well
		Service user populations	How can services best serve their particular client groups?

### Coding Frame (Part 2) - Codes and quotes

Basic themes	Codes	Descriptive quotes
Behaviours that define men	Circumcision	'There is a boundary from childhood to manhood. We define that, we define that through circumcision.' (Interview 9)
	Getting a girlfriend	'So I think that was, it was the thing of having a girlfriend, you know I've got a girlfriend walking in the street.' (Interview 6)
	Getting married	'You cannot be called an adult before you get married. That is the main reason that a man can be called an adult once he's married.' (Interview 5)
	Starting a family	'Maybe I should have a great family sort of, so that brings you to be a man' (Interview 2)
	Making money	'Furthermore, when he joins either the government or the businessmen working to support himself, they say he's a man now, different from teenagers who are not employed, yes.' (Interview 5)
	Having several partners	'Myself, myself I can get what I want - 3 girls who want me.' (Interview 6)
	Moving out of parents' house	'And also when you understand the difference between living by yourself, looking after yourself that makes you feel like you're independent now, you don't ask your dad, mommy this and that.' (Interview 12)
	Socializing outside the house	'But man as you say they're probably going to a pub to watch football. To go have a drink and he does that every day so going to support group is not something of a need that creates a recreational facility.' (Focus group 2)
	Men have power	'We have got a certain power sharing that goes more than 50% to the man and that makes the man more powerful in the family' (Interview 3)
Responsibilities of men	Man is breadwinner	'Well most groupings in African are very patrilineal so you know the male is the dominant voice at the home. [pause] He's the breadwinner, all decisions about the welfare and what happens with the family lie on the man.' (Focus group 1)

	Responsibility for family in UK	'...If I can help my family. I want to see myself attending to their needs and see what my contribution can be though they are growing, you want to provide any assistance you can provide as parents.' (Interview 3)
	Expectation to support family at home	'It's not easy but when it comes to sibling, relative, friends and that, they look at you like they expect, you work for them at times.' (Interview 11)
Gender differences in health behaviour	Men are reluctant to seek care	'For many it is not easy to raise on my feet and go to the centre and say I come for testing. I mean it is not the problem of pride but there is a certain reluctant, we are reluctant, I don't know why, it's probably...it's ...our culture' (Interview 3)
	Women are quick to seek care	'But for ladies for example, or children, they can get some, something and quickly they go for the GP' (Interview 9)
	Men & women are essentially different	'P: Women are a different species, everybody knows that. ' (Interview 6)
	Men are naturally healthier than women	'Or the men already, maybe the men they are fitter, but again maybe I am... R: Biologically more fit? P: I think so.' (Interview 1)
	Women talk about health	'You see but I think the ladies are good, when they go out there they still talk to each other but for us when you're out there you don't talk about it.' (Interview 11)
	Women use support groups to socialise	'But also the same time we must also think about the nature of women staying at home most of the time they are not working. And the only activity that they have that will be able to take them out of the house usually if they're not going to the market something like a group support group meeting.' (Focus group 2)
	Men are supposed to appear healthy	'We tend to keep it inward you know because illness in a man is weakness. A man will always be happier if he's known to be very strong and somebody who never gets sick.' (Focus group 2)
	Women access care because of children	'You find that the women come with the children, that man is working. The women have got to go for a number of tests at clinics and hospitals with the

		children, those tests are not for men so you see most of them there.' (Interview 14)
Unemployment blocks masculinity	Need for employment	'Men need to work. Let them have work, let them have a steady source of income and then everything will take care of itself.' (Interview 4)
	Barriers to employment	'All the machines are here, I've gone to college but then it's like I can't start up my own business and even getting work is so so hard because they ask you experience and whereas for my side I've never worked in this country.' (Interview 2)
	Unemployment is failure	'Because I mean 14 years and maybe they can't afford buying a ticket to go to America, you really feel bad...it's embarrassing for some of us.' (Interview 2)
Gender roles disrupted	Traditional African gender roles	'Very few of our women back home work, so they depend for more of their needs from the man, so the man has got that power as father and breadwinner in the family.' (Interview 3)
	Shift in gender roles	'It's one of the reasons that we have got for example clashes in the family once in UK because women have got a certain portion of power in families and for most cases that leads to the break of families, of marriage.' (Interview 3)
	Women are advantaged here	'And yeah, even the law itself it's kind of lenient the women rather than the men.' (Interview 2)
	Women need men less here	'Even sometimes it's not good because the women say ok, I've got benefit, I've got accommodation, why I looking for a man? Is become hard.' (Interview 1)
Migration related failures	Desire to go back to home country	'I'll tell you we'd all rather be in African but we're here for one reason [ARVs], that's the sad thing about it. A happier place to live.' (Focus group 1)
	Failure to support family at home	'I avoid calls that are coming from Africa or change numbers simply that you can't meet the demands of people back home in Africa when you are unwell.' (Focus group 2)
	Challenges of migration	'Some of them had very good, had good education standards but after all this frustration with immigration, they started drinking, they started taking

		med- drugs.' (Interview 4)
	Loneliness	'And you know also solitude as well, you can be lonely, because some people in this country, not our culture there is hospitality, but not here.' (Interview 1)
	Unhappy with life in UK	'You can have some money in this place but you can't really feel it happy. I mean, you're always under pressure of this and that.' (Interview 11)
Family-related failures	Lack of discipline for children	'But the environment where they are growing has made them to feel much freedom to the point that they don't look back at the culture or the way things should be done.' (Interview 3)
	Difficulty in finding a partner	'Basically it frustrates me a bit if I imagine that my chances are getting into [being] a family man is limited.' (Interview 11)
	Difficulty in maintaining relationships	'But maybe disappointed sort of in that case of not managing to keep my family together, yeah.' (Interview 2)
	Migration is tough on families	'It really does come within the family thing. Most of the people here they've separated and we are having family problems and it wouldn't be the case back home.' (Interview 2)
Negative representations of HIV	Stigma in African communities	'In African it's terrible, you're never going to say it. Someone will be dying in silence and you say it's very bad.' (Interview 12)
	Stigma in general	'Sometimes, the ladies they are not fancy me, I am not fancy them, or there is a barrier still there, a stigma.' (Interview 1)
	HIV brings shame	'You talk to people, you feel at least, because you know the big problem that people suffer from is to keep that guiltiness, you feel as you are guilty by being HIV+' (Interview 3)
	HIV is isolating	'Because I keep myself isolated. No one is know [my status], that's why I keep in myself and that makes it hard for me. ' (Interview 1)
	Fear of disclosure to people at home	'To disclose to say to your family in Africa. The perception HIV and AIDS in Africa is very different from how we see it here. ' (Focus group 2)
Service users are not like other men	Other men are hiding	'I've reached my hospital at times, I've seen people I know and it's like they don't want to be known at all. You know, it's like they want to hide, hide.' (Interview 11)
	Other men ignoring health	'Even let's assume they're having problem with their sexuality, they're not

	problems	very strong or, they can't go to a GP and say I'm this I'm that. No, they won't. ' (Interview 7)
	Other men in denial	'And I think like when some of them are in their dying beds, they still wouldn't accept, which is wrong.' (Interview 11)
	Other men must change their attitudes	'It's a question of educating them, tolerance and understanding the diversity of sexuality.' (Interview 14)
	Non-normative male role models	'Yeah a couple of celebrating men who have come up. Like Uganda in those days, the musician who said he was HIV positive.' (Interview 11)
Empowered attitudes about HIV	Change in attitude towards HIV	'But we have come to the point, most of us, we have come to the point where no longer keep it as a taboo. So we have to overcome that position' (Interview 3)
	Get on with life after HIV	'I find it also empowers me to try and live a normal life as possible.' (Focus group 1)
	Inspired by other PLWH	'You feel that you find more people who socialise and come there and yourself you think no, it's not that there's no more life, so I can get on with my life as they are doing.' (Interview 3)
	Less stigma in UK	'And in here, it's like a normal thing, it's like having flu and say oh I have catch some flu and you tell someone because then they will advice' (Interview 12)
	Men need HIV education	'They need to get to know what sex comes with, You know it comes with all these diseases, be it not HIV or other STIs so they need to open up a little more.' (Interview 11)
	Overcoming challenges of HIV	'Oh...I like my life! It's the life really, yeah. And I mean I'm kind of amazed the way I've brought it up sort of.' (Interview 2)
	Protecting others from HIV	'So it means that you know that you are positive and you have to make sure that you protect those who are outside' (Interview 3)
	Support for prevention/testing	'The awareness should be to all and standard. It is to their best advantage to know their status, test themselves.' (Focus group 1)
	Work in HIV sector	'I was fortunately part of the people who were selected to engage with a

		group of clergy and I felt that was very fulfilling experience.' (Focus group 1)
Protest identities	Proud to be an african man	'To be an African, I'm very proud to be an African...because I think if you are an African firstly you have an identity.' (Interview 7)
	Questioning male norms	'Could be your dad your brother or whatever is very strong but you're very weak. It could happen to anybody but they won't accept it. They want to show yes, I'm a macho man, I'm this...'. (Interview 7)
	Tolerance of gay men	'You got to be positive about the different sexualities in the reality of the world we live in here. You've got to embrace, that's the bottom line.' (Interview 14)
Men care for their health	Care seeking should be natural/routine	'You know they should look at it like it's routine, like ladies go for routine tests. Men also have to get, African men also have to get into that system of check ourselves up.' (Interview 11)
	Change in care-seeking	'You know there's a time when you disagree and denial and all the rest, but we get another level where, I speak for myself, I've got that level where now I understand that you know I go for my three monthly checkup. I'm the much stronger man who is in tune with their health.' (Focus group 2)
	Traditional masculinity damages health	'Well, to be honest African men they will always, they are having this problem: every African man is a strong man, is a this, is that [sarcastic] every good thing about it and they never address them self even if they do have a problem...'. (Interview 7)
	Testing changed behaviour	'When I got through kind of things like that I slow down because you get a little bit of advice from the GPs, they say you have to be careful with partners basically.' (Interview 12)
Socio-emotional support	Learning from others' experiences	'Yes, in the groups you'll meet people at different levels and I think it is the shared experience that we benefit the most both the seasoned people on treatment for a long time and the newly diagnosed.' (Focus group 1)
	Sharing your experiences with others	'But I think being there as someone who has had HIV for quite a long time, the newly diagnosed people you become somebody who can be a comfort to them.' (Focus group 2)
	Social support	'It's great that you get into that situation of sameness; you know we all have

		the same problem and we are together in that thing, not isolating ourselves from the outside world.' (Interview 11)
	Socializing	'So it's a big family. Once in a while in the summer we get a day out, I mean you just feel at home.' (Interview 2)
	Take your mind off HIV	'Secondly, because I want to gain or to make new friends, to learn more information, more experience, to meet some people, to talk, to enjoy yourself, to forget you are in this situation.' (Interview 1)
	Satisfaction with counseling	'She was good. She was there for a while like for the first like 6 weeks' (Interview 11)
	Come to groups to find partner	'We would go to different groups to enjoy food and something else, especially my sight I was finding a lady to marry because I could not manage living alone.' (Interview 5)
Information	satisfaction with information	'So you know it's good to have your regular screening tests and stuff but it's also informative and education the way the actual process, so it's good. ' (Interview 13)
Opportunities for training	opportunities in UK	'But I've tried to learn and I really like to learn different cul- language and to improve my quality. Because I believe if you - I didn't have a chance in Africa to do it and now as I'm here I feel I have to use the opportunity. ' (Interview 7)
Practical help	Dissatisfaction with practical services	'Even some people they have got immigration issue. There's no legal aid or something like that. If you go to solicitor, lawyer, you have to pay.' (Interview 1)
	Emotional help doesn't solve practical problems	'So whether you counsel someone, that big problem is still lying there...if people are allowed to work, if people are allowed whatever freedom they can get, all these problems would be solved.' (Interview 4)
Material barriers	Men can't access because they're working	'nd the rates of pay are so low they have to spend a lot of time working to support their families, you know just to keep them. So the issue of even a regular medical check up is out of the question.' (Focus group 1)
	Lack of financial incentives for access	'supposing you're going to the place where you're not going to get that 5 pounds back you know somebody will, that'll be the last time that comes.'

		(Focus group 2)
HIV services policy	Health policy problems	'The funding starts deteriorating so sometime like now most of these have been streamlined because of the funding, yet still people need those services.' (Interview 4)
	Desire to influence policy	'We need to get involved in the policy-making... sometimes they are saying it's a disability but the people who are working here, they are people who are not running in the condition, or they're not living with it.' (Interview 11)
Migration policy	Immigration status causes problem	' But generally because of the difficulty that people have with immigration, they are not sure that this information will not pass into the wrong hands and that here, in my opinion, is a very major barrier.' (Focus group 1)
	Discrimination	'The most challenging thing about living here is constantly being remind that you're...not one of them [laughs] an ethnic minority and stuff.' (Interview 10)
Structural problems	Improvements for services	'Now I think the risk is we don't have walk in services or if they're there, they're not known to the people' (Interview 9)
	Feeling used by services	'I wouldn't like an organisation that is doing statistics, you know they use us like numbers.' (Interview 11)
	Organisations not open to feedback	'A group of people at the top, they will just decide this is that we are going to do and not giving any concentration to the people at the bottom.' (Focus group 1)
	Corruption in services	'Pretty discouraged myself about some of these organisations cause they've gone bankrupt, a bit of corruption' (Focus group 1)
Structural strengths	Referral systems	' They've got a lot of information and access to other organisations where they can send you and kind of get hope. ' (Interview 2)
	Outreach is important	' it might be best to have an African person there with qualifications and stuff with the right qualifications obviously to tap into those areas where no one else has been able to.' (Interview 13)
	Satisfaction with testing personnel	' Yeah, very, they are good, very professional, I really appreciate and it's something that because they give you confidence to say this is confidential' (Interview 7)

	Open to feedback	' When we meet, they give the sheets to make some comments. Yeah, you can mention what is good' (Interview 3)
Service user populations	Preference for mixed white/African groups	' Um, it comforts me a bit when I see a mixed up thing cause you know when it's only African you know there is that thing that sets in the groups like it's an African thing, it remains an African thing,' (Interview 11)
	Preference of Africans only	'There is a bit of discrimination. White people don't want to talk about HIV mixing with, with us.' (Interview 5)
	Preference for mixed gender	' It's just the women they attend, they do attend a lot. And I mean you can learn, I've learned more from women, I mean rather than the men.' (Interview 2)
	Preference for men only	' And I found there a better space because you can feel free to talk about anything what with your fellow African men, all those problems affecting men' (Interview 4)
	Male staff	' You feel embarrassed, it's something, I mean it's normal thing but you don't want to go to a woman and ask for condom.' (Interview 7)
	Cultural groups	' But in terms of when you talk about community and here because you know religion itself can be, you know define a community.' (Focus group 2)
	Cultural appropriateness	' To be having the fellow Somali people and they are talking their language is, possibly another Somali would be more accepting to what they are talking then this person because the Christian man you tell me about this HIV.' (Focus group 2)