An investigation into newly diagnosed HIV infection among Africans living in London

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I, Fiona Margaret Burns, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

ABSTRACT

In the UK substantial numbers of new HIV diagnoses are within migrant African communities. A continuing feature of HIV in this population is the late presentation to HIV services. This dissertation sets out to explore HIV testing among Africans in the UK, the factors associated with late presentation to HIV services, and the extent of HIV acquisition within the UK in African communities. The main focus of the thesis is the 'study of newly diagnosed HIV among Africans in London' (the SONHIA study), which combined qualitative and quantitative methods in a multi-centre study.

The thesis begins with the work undertaken in preparation for SONHIA. It presents a literature review to provide epidemiological, cultural and historical background. Next is an analysis of the 2nd National Survey of Sexual Attitudes and Lifestyles to explore the factors associated with HIV testing among black Africans in Britain. Finally, the findings from in-depth interviews with key informants to identify the issues affecting utilisation of HIV services for Africans in Britain are presented.

The SONHIA study consisted of survey of 269 Africans newly diagnosed with HIV. All respondents self-completed a questionnaire linked to clinical records, and 26 in-depth interviews with a purposively selected sub-sample were performed. The findings show that Africans are accessing services but clinicians are failing to use these opportunities for preventive and diagnostic purposes with regards to HIV infection. HIV presentation patterns appear governed by factors linked to the characteristics of, and response to, the HIV epidemic operating within people's sociocultural networks. UK acquisition of HIV in this population appears substantially higher than acknowledged by national surveillance data, with a quarter to a third of HIV possibly acquired in the UK.

The qualitative findings provide contextual understanding of the factors contributing to late presentation. They highlight the central role of HIV-related stigma and discrimination in influencing HIV testing behaviours. Failings within the health care system offer insight as how clinicians can better address HIV in the future.

The key findings are summarized and contextualised with the literature and the current socio-political climate. The study's limitations are addressed, and the thesis concludes with the public health and policy implications of the study.

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Glossary

AIDS	Acquired immunodeficiency syndrome
ACRG	African community reference group
AHRF	African HIV research forum
AOR	Adjusted odds ratio
ART	Antiretroviral therapy
CAPI	Computer-assisted personal interview
CASI	Computer-assisted self-interview
CDC	Center for disease control & prevention
CI	Confidence interval
CSW	Commercial sex worker
FPC	Family planning clinic
GB	Great Britain
GP	General practitioner
GRID	Gay related immune deficiency
GUM	Genitourinary medicine
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HPA	Health Protection Agency
IMD	Index of multiple deprivation

IVDU Intravenous drug use

KS Kaposi's sarcoma

MREC Multi-centre research ethics committee

MSM Men who have sex with men

NATSAL National Survey of Sexual Attitudes and Lifestyles (1990/1)

NATSAL 2000 National Survey of Sexual Attitudes and Lifestyles 2(1999/2001)

NHS National Health Service

OR Odds ratio

PCP Pneumocystis jiroveci pneumonia

PAF Postcode address file

PSU Primary sampling unit

Ro Case reproduction number

SOPHID Survey of prevalent HIV infections diagnosed

SONHIA Study of newly diagnosed HIV infection among Africans in London

STARHS Serological testing algorithm for recent HIV seroconversion

STI Sexually transmitted infection

TB Tuberculosis

VCT Voluntary counselling and testing

UK United Kingdom

UNAIDS Joint United Nations Programme on HIV/AIDS

USA United States of America

Publications arising from this work

- BURNS FM, Arthur RG, Johnson AM, Nazroo JY, and Fenton KA, on behalf of the SONHIA collaboration group. (2009) UK acquisition of HIV infection in Africans resident in London: more than previously thought. *AIDS*, 23(2): 262-266.

- BURNS FM, Johnson AM, Nazroo JY, and Fenton KA, on behalf of the SONHIA collaboration group. (2008) Missed opportunities for earlier HIV diagnosis and prevention within primary and secondary health care settings in the UK. *AIDS* : 22: 115-122.

- BURNS F, Imrie J, Nazroo JY, Johnson, AM, Fenton KA. (2007)Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilisation of HIV health and social care services by African migrants in Britain. *AIDS Care*: 19; 102-108.

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- BURNS F, Fenton KA, Morison Linda A, Mercer C H, Erens Bob, Field J, Copas A, Wellings K, and Johnson AM. (2005) Factors associated with HIV testing amongst black Africans in Britain. *Sexually Transmitted Infections*; 81:494-500.

- Forsyth S, BURNS F, French P. (2005) Conflict and changing patterns of migration from Africa: the impact on HIV services in London, UK. *AIDS*; 19:635-637.

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Chapter 1: Introduction, Aims and Study Outline

1.0 Introduction

The first cases of a new acquired immunodeficiency syndrome (AIDS) were recognised in 1981, heralding the emergence of the human immunodeficiency virus (HIV) pandemic that continues to affect the lives of tens of millions of people worldwide, especially in sub-Saharan Africa.

When this work commenced concern was beginning to be expressed about the numbers of Africans presenting with advanced disease to services for treatment of HIV in the United Kingdom (UK), and the consequent impact late presentation had on the potential for onward disease transmission. This dissertation sets out to explore HIV testing among black Africans in the UK, the factors associated with late presentation to HIV services, and the extent of HIV acquisition within the UK in black African communities.

This opening chapter provides an overview of the emergence of HIV, its history and epidemiology, and the determinants of HIV spread. It concludes with the aims, justification, and an outline of the programme of work presented within this thesis.

1.1 The emergence of an epidemic

1.1.1 Europe and North America

In 1981 an unusual cluster of Pneumocystis jirovecii pneumonia (PCP) and Kaposi's sarcoma (KS) among previously healthy men who had sex with men (MSM) in New York, California and London alerted the world to the presence of a new immune deficiency syndrome (Gottlieb et al., 1981; du Bois, Branthwaite, Mikhail, & Batten,

1981). Both of these conditions were known to occur only in severely immunocompromised patients, and none of the men had known cause of immunodeficiency.

Initially referred to as gay related immune deficiency (GRID), the clustering in homosexual men and the association with high numbers of sexual partners and previous sexually transmitted infections, alerted epidemiologists to the possibility of a sexually transmitted agent being responsible (Jaffe et al., 1983; Centers for Disease Control and Prevention, 1982a). However others believed it may reflect exposure to some substance (rather than an infectious agent) that was associated with a 'particular type of style of life' (Marmor et al., 1982; Centers for Disease Control and Prevention, 1982a). Possible agents at this time included cytomegalovirus, inhaled nitrates, and an as yet unrecognised agent in semen (Gottlieb et al., 1981; Marmor et al., 1982).

It soon became apparent that groups other than homosexual men were also at risk, and by 1982 the term acquired immune deficiency syndrome (AIDS) had replaced GRID (Centers for Disease Control and Prevention, 1982b). The evidence swung in favour of an unrecognised infectious agent being responsible for AIDS as groups not associated with a homosexual lifestyle (haemophiliacs, injecting drug users, and heterosexual Haitians) were also affected (Centers for Disease Control and Prevention, 1982b). Accounts of cases in the heterosexual sexual partners of injecting drug users and haemophiliacs were also reported (Masur et al., 1982; Kreiss, Kitchen, Prince, Kasper, & Essex, 1985). Importantly index cases were often asymptomatic, suggesting possible transmission without recognisable illness.

Surveillance and epidemiological studies indicated that the major modes of transmission of HIV were via sexual intercourse (anal or vaginal), needle-sharing, transfusion of contaminated blood or blood products (e.g. factor VIII), and vertical transmission from

mother to foetus (Curran et al., 1985; Friedland & Klein, 1987). Breast milk was also recognised as a potential vector early in the epidemic (Lepage et al., 1987; Ziegler, Cooper, Johnson, & Gold, 1985). Fortunately transmission to household contacts, other than via sexual intercourse, was not found to occur (Friedland et al., 1986).

In 1983 a retrovirus was established as the causative agent for AIDS (Barre-Sinoussi et al., 1983; Gallo et al., 1984), and in 1986 international agreement was reached that the virus be referred to as human immunodeficiency virus (HIV) (Coffin et al., 1986).

Cases rapidly increased on both sides of the Atlantic and within 10 years of first identifying the clusters of PCP and KS, 22,423 new diagnoses of HIV, 7822 notifications of AIDS and 5647 HIV related deaths had been reported in the UK (Health Protection Agency Centre for Infections, 2008).

1.1.2 Sub-Saharan Africa

The first descriptions of AIDS in African patients were reported in France and Belgium in 1983 (Clumeck, Mascart-Lemone, de Maubeuge, Brenez, & Marcelis, 1983; Clumeck et al., 1984; Brunet et al., 1983). Immunologically these cases were identical to those in the United States and London. Clinically they resembled Haitian AIDS cases with a predominance of gastrointestinal symptoms, Cryptococcosis, and mycobacterial infections (whilst KS and PCP accounted for the majority of AIDS cases in MSM). Epidemiologically these cases arose in male and female migrants from Central Africa (Zaire (now Democratic Republic of Congo (DRC)), Chad and Rwanda) with no history of homosexuality or injecting drug use.

These observations led to investigations in Central Africa, which rapidly identified large numbers of AIDS patients with similar clinical and immunological features (Melbye et al., 1986; Piot et al., 1984; Van de Perre et al., 1984). AIDS cases in Africa were

equally distributed between men and women, and most prevalent in people in the sexually active age range (20-49 years); This later finding suggesting that non-sexual forms of parental transmission such as use of non-sterilised needles or insect vectors were unlikely. In addition, clusters linked by frequent heterosexual contact were identified with no reports of sex between men or injecting drug use. The case distribution supported heterosexual transmission as the principal mode of acquisition.

Meanwhile in the Rakai district of Uganda there were also reports of an immunodeficiency syndrome referred to as 'Slim disease' (as the major symptoms were weight loss and diarrhoea). In 1985 HIV (then known as human T-lymphotrophic virus type III) was found to be associated with Slim disease, thus establishing a definitive link between the simultaneous epidemics occurring in African heterosexuals and in MSM in Europe and North America (Serwadda et al., 1985). Subsequent serological studies in Uganda demonstrated almost complete absence of HIV in non-sexually active persons, and again demonstrated that non-sexual household contacts of infected persons were not at risk of infection (Carswell, 1987; Sewankambo et al., 1987).

1.1.2.1 Spread of infection

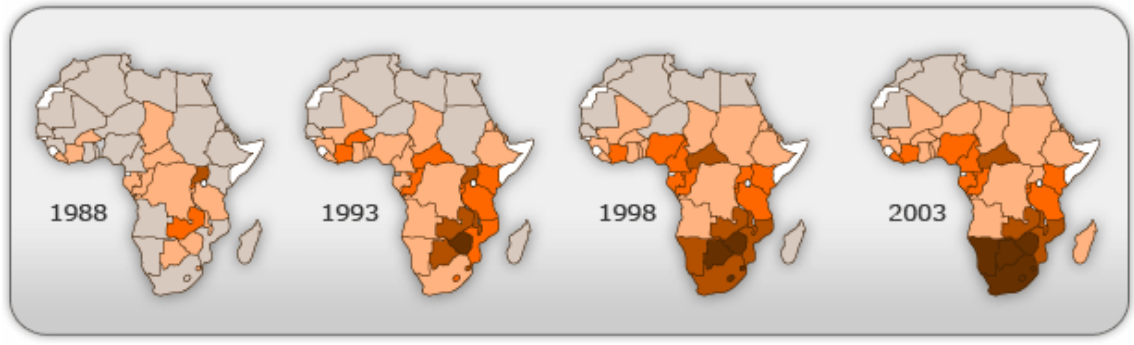
It is now believed that the first HIV/AIDS epidemic occurred in Kinshasa in the 1970s (Quinn, Mann, Curran, & Piot, 1986). One theory is that an infected individual brought HIV into the Congolese capital from neighbouring Cameroon, and upon entering an urban sexual network it was able to establish itself and spread. Cameroon is assumed to be the country of origin of HIV as this is where the chimpanzee subspecies *Pan troglodytes troglodytes*, the source of HIV-1, is found (Gao et al., 1999).

HIV spread rapidly to neighbouring Central and Eastern African countries (see figure 1.1). Truck drivers and other migrant groups (soldiers, traders and miners) engaging

with sex workers facilitated the initial spread of HIV along transport and trade routes (Carswell, Lloyd, & Howells, 1989; Kreiss et al., 1986; Serwadda et al., 1985). The lack of circumcision, limited use of condoms, and a high prevalence of sexually transmitted infections (STIs) also contributed to the accelerated spread throughout the region (Mann et al., 1987; Quinn et al., 1986; Weiss, Quigley, & Hayes, 2000).

Sex workers and their clients in particular were identified from the onset of the epidemic as a high risk group important in sustaining the spread of infection (Van de Perre et al., 1985; Vittecoq et al., 1987). In 1986 between 27 and 88% of female sex workers in East Africa were HIV positive (Van de Perre et al., 1985; Kreiss et al., 1986). Dissemination throughout the sex worker population was rapid, seroprevalence increasing from 4% to 61% over a period of 4 years in Nairobi (Piot et al., 1987). Condoms were not widely used by African sex workers in the 1980s and this is thought to have contributed to the rapid spread of infection (Mann et al., 1987).

Figure 1.1 The spread of HIV in Africa



Source: UNAIDS (2004) report on global AIDS epidemic. Geneva

The early 1980s saw HIV spread further into Equatorial and Western African nations. As in Central and Eastern Africa sex work was a major driver in the early phase of the epidemic in West Africa (Lowndes et al., 2002). Southern Africa was affected comparatively late by HIV but the virus spread rapidly to epidemic levels throughout the general population, such that it is now the region most affected. Southern Africa accounted for a third of all HIV diagnoses and AIDS related deaths globally in 2007, and eight countries in the region[1] currently have a national adult HIV prevalence in excess of 15% (UNAIDS & World Health Organization, 2008).

Initially HIV was equally distributed between the sexes in Africa, however women now account for 61% of all adult infections (UNAIDS & World Health Organization, 2007). Consequently Africa has also experienced large numbers of infections acquired vertically and in 2007 2.2 million children were estimated to living with HIV in sub Saharan Africa (UNAIDS et al., 2007). The other consequence of a primarily heterosexual epidemic, in which effective medication has largely been unavailable, has been the number of children orphaned; by 2004 12 million children in Africa had lost one or both parents to HIV (UNAIDS, 2004).

1.2 The origin of HIV

Human immunodeficiency virus is now firmly recognised as the aetiological agent of AIDS. There are two types of HIV: HIV-1 and HIV-2. HIV-1 is the predominant virus worldwide, with HIV-2 being relatively concentrated in West Africa. Whilst both cause clinically indistinguishable AIDS, HIV-2 is less infectious and clinical progression is slower (Marlink et al., 1994). HIV is thought to be a descendant of simian immunodeficiency virus (SIV) having crossed over from chimpanzees (in the case of

[1] Botswana, Lesthoto, Mozambique, Namibia, South Africa, Swaziland, Zambia & Zimbabwe.

HIV-1) and sooty mangabeys (HIV-2) (Sharp, Bailes, Stevenson, Emerman, & Hahn, 1996; Gao et al., 1999). Crossover for HIV-1 M group, the main virus group, probably occurred sometime in the 1930s (Korber et al., 2000; Zhu et al., 1998).

HIV is a lentivirus (a member of the retrovirus family) characterised by a long incubation period and persistent infection. It slowly and progressively attacks the immune system by incorporating itself into the DNA of host cells via the glycoprotein CD4 receptor (Stebbing, Gazzard, & Douek, 2004). CD4 receptors are predominantly found on the T-helper lymphocytes. T-helper cells help orchestrate the immune response, especially towards viral, fungal and protozoal infections. The destruction of CD4 positive cells is the major cause of immunodeficiency observed with HIV infection.

HIV is transmitted by sexual contact, by blood and blood products, and from mother to child either during pregnancy or birth, or via breast milk.

1.2.1 AIDS case definition

The definition of AIDS has changed over time as knowledge about the syndrome has increased. In 1982 the Centers for Disease Control (CDC) in Atlanta defined a case of AIDS as a disease 'at least moderately predictive of defect of cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease. Such diseases include Kaposi's sarcoma, Pneumocystis carinii pneumonia, and serious opportunistic infections' (Centers for Disease Control and Prevention, 1982b). The definition was revised in 1985 following the development of a laboratory test for HIV and again in 1987. The current definition used throughout Europe is the 1993 expanded European AIDS case definition (Ancelle-Park, 1993). This includes all HIV-infected persons who fulfil the clinical conditions listed in box 1.1 below.

The CDC use a slightly different definition that includes all HIV-infected persons who meet the conditions in box 1.1 and 'all HIV-infected persons who have less than 200 CD4+ T-lymphocytes/μL, or a CD4+ T-lymphocyte percentage of total lymphocytes of less than 14' irrespective of clinical manifestations (Centers for Disease Control and Prevention, 1992). European experts decided against inclusion of a criterion based on CD4 count alone as there was concern about the completeness of AIDS surveillance based solely on the degree of immunosuppression, potential negative psychological effects on symptom-free HIV infected patients, and the fact that in Europe access to medical care and social benefits is not conditional upon a person meeting the AIDS definition (Ancelle-Park, 1993).

Box 1.1 AIDS Defining conditions

- Candidiasis, oesophageal
- Cervical cancer, invasive
- Coccidiodomycosis, disseminated
- Cryptococcosis
- Cryptosporidiosis (>1 month)
- Cytomegalovirus disease or retinitis (other than liver, spleen or lymph nodes)
- Encephalopathy, HIV related
- Herpes simplex (>1 month)
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis (>1 month)
- Kaposi's sarcoma
- Lymphoma, Burkitts, immunoblastic or equivalent, or brain
- Mycobacterium avium complex or Mycobacterium, disseminated/extrapulmonary
- Mycobacterium tuberculosis
- Pneumocystis carinii (or jiroveci) pneumonia
- Pneumonia, recurrent bacterial
- Progressive multifocal leukoencephalopathy
- Salmonella septicaemia, recurrent
- Toxoplasmosis of brain
- Wasting syndrome

AIDS represents the end stage of a continuous, progressive, pathogenic process. In clinical practice symptoms, together with measures of immune function, particularly CD4 cell levels, HIV viral load, and patient wishes, are used to guide treatment of HIV-infected persons.

As well as redefining AIDS, the CDC 1993 Revised classification system categorised people on the basis of clinical conditions associated with HIV infection and CD4+ T-lymphocyte counts. The system is based on three ranges of CD4+ T- lymphocyte counts and three clinical categories and is represented by a matrix of nine mutually exclusive categories (Table 1.1) (Centers for Disease Control and Prevention, 1992). This nomenclature has been adopted to define clinical status throughout this document. The 1993 expanded European AIDS case definition (box 1.1) has been used in classifying AIDS cases, but for the purposes of this work late presentation is defined solely according to CD4 criteria at the time of initial HIV diagnosis (see chapter 5).

Table 1.1 Summary of the 1993 classification of the clinical manifestations of HIV

Clinical Categories	CD4 categories		
	≥500 cells/μL	200-499 cells/μL	<200 cells/μL
Asymptomatic, acute (primary) HIV or PGL[1] (A)	A1	A2	A3
Symptomatic HIV[2] (B)	B1	B2	B3
AIDS defining conditions[3] (C)	C1	C2	C3

[1] PGL = persistent generalised lymphadenopathy. Conditions listed in categories B & C must not have occurred

[2] Symptomatic patients with conditions attributed to HIV or indicative of cell-mediated immunity defect not listed in category C. Includes: recurrent thrush (oral and vulvovaginal), cervical dysplasia, fever or diarrhoea lasting more than one month, oral hairy leukoplakia, herpes zoster greater than 1 episode or more than one dermatome, idiopathic thrombocytopenia, peripheral neuropathy.

[3] AIDS defining conditions (see box 1.1). For classification purposes once a category C condition has occurred the person remains in category C.

1.2.2 Natural history of HIV infection

After acquisition of HIV a flu-like syndrome may develop within days to weeks, unfortunately this is rarely recognised as primary HIV infection even if health care is sought (Sudarshi et al., 2008). Following primary HIV infection most infected persons

enter a period of asymptomatic infection. Untreated the duration of asymptomatic HIV infection can vary substantially, for example 5% will develop AIDS within 3 years of infection (Munoz & Xu, 1996; Phair et al., 1992) but 12% will remain AIDS free for greater than 20 years (Sheppard, Lang, Ascher, Vittinghoff, & Winkelstein, 1993; Munoz et al., 1996). The median time from seroconversion to AIDS, without effective medication, is approximately 10 years (UK Register of HIV Seroconverters Steering Committee, 1998; Koblin et al., 1999; Morgan et al., 2002). In Europe AIDS is defined according to the 1993 revised European definition (Ancelle-Park, 1993; European Centre for the Epidemiological Monitoring of AIDS, 1993). It differs from the definition used in the USA in that it does not include a CD4 lymphocyte count criterion (Centers for Disease Control and Prevention, 1992). Without access to antiretroviral medication survival following an AIDS defining illness is usually less than 12 months (Martin, Cox, & Beck, 1996; Morgan et al., 2002).

Despite clinical latency viral replication is highly dynamic and continuous with approximately 10^{10} virons produced per day (Ho et al., 1995), progressively reducing T-helper cells (Holodniy, 1999). There is a strong association between HIV viral load (measured as the concentration of HIV-1 RNA in plasma) and the rate of CD4 decline (Mellors et al., 1997). Clinically the combination of viral load and CD4 count are used to provide prognostic indicators to guide management decisions. Transmission of HIV can occur at any stage of infection although it also appears to be strongly correlated with the viral load (Quinn et al., 2000; Connor et al., 1994; Jackson et al., 2003).

The immediate risk of HIV related pathology, and time since acquisition, is associated with an individual's CD4 count (Phillips et al., 1991; Fahey et al., 1990; Satten & Longini, 1996), hence it is used as a surrogate marker in monitoring HIV infection. A CD4 count below 200 cells/μL represents advanced HIV disease, hence it's inclusion as

an AIDS defining condition in the United States (Centers for Disease Control and Prevention, 1992).

1.2.3 Antiretroviral therapy

The first antiretroviral medication, zidovudine or AZT (a nucleoside analogue), was released in 1985 but randomised controlled trails showed no long-term benefit in survival with either mono, or subsequently dual, nucleoside analogue therapy (Ioannidis et al., 1995; Delta Coordinating Committee, 1996). It was not until the approval of protease inhibitors in 1995 and the advent of triple combination therapy that significant improvements in the health of HIV infected people could be demonstrated (Hammer et al., 1997).

Highly active antiretroviral therapy (HAART) has been responsible for marked declines in HIV related morbidity and mortality (Palella, Jr. et al., 1998; Porter et al., 2003; Mocroft et al., 2003; Sterne et al., 2005). Whilst a reduction in viral load occurs almost immediately on initiation of HAART, immunological and clinical benefits can take considerably longer depending on the baseline CD4 count, viral load, and presence of co morbidities (Lepri et al., 2001; May et al., 2007; Gazzard, 2008). Delay of initiation of HAART until the CD4 count is below 200 cells/μL is associated with a poorer virological and clinical response than when therapy is commenced with a CD4>350 cells/μL (Gazzard, 2008; May et al., 2007).

1.2.4 AIDS and HAART

The incidence of AIDS cases has fallen markedly across Europe since the advent of HAART (Mocroft et al., 2003; Sterne et al., 2005; Palella, Jr. et al., 1998). Unfortunately for many HIV infected people the benefits of HAART remain elusive, either because they have no means of accessing therapy or because they are unaware

that they are HIV infected. In Europe the majority of people now developing AIDS already have advanced disease at the time they present to HIV services (Hamers & Downs, 2004). In 2002 72% of AIDS cases among heterosexually infected persons occurred within six months of initial HIV diagnosis (Hamers et al., 2004).

1.2.5 HIV testing and national surveillance.

An enzyme-linked immunosorbent assay (ELISA) for non-neutralising HIV antibodies was developed in 1984 and a commercial kit became available in 1985 (Weiss et al., 1985), enabling widespread HIV testing as a diagnostic and screening tool. HIV testing was introduced in Genitourinary Medicine (GUM) Clinics in the UK in 1985.

Surveillance systems for HIV/AIDS were established nationally and internationally. In the UK in 1982 a system for voluntary reporting of AIDS cases by clinicians was established at the Communicable Disease Surveillance Centre, Colindale – now known as the Health Protection Agency (HPA). The World Health Organisation set up a global network for the control and prevention of AIDS in 1986, and in 1996 the Joint United Nations Programme on HIV/AIDS (UNAIDS) became operational (World Health Organization, 1986)

In addition to the voluntary reporting of AIDS cases the HPA now monitors (Health Protection Agency, 2009):

1. HIV prevalence via unlinked anonymous HIV testing in pregnant women, injecting drug users and GUM clinic attendees;
2. Accessing of HIV care via the survey of prevalent HIV infections diagnosed (SOPHID);

3. New HIV diagnoses via the voluntary case reporting of HIV/AIDS from laboratory reports of newly diagnosed HIV infections by microbiologists and HIV/AIDS diagnoses by clinicians;

4. HIV incidence using the serological testing algorithm for recent HIV seroconversion (STARHS) – currently this is restricted to testing samples from MSM;

5. HIV resistance based upon genotypic reports received by the Medical Research Council held UK HIV Drug Resistance Database;

6. The National CD4 Surveillance scheme which monitors trends in immunosuppression associated with HIV infection by collecting data on CD4 cell counts performed by laboratories in England and Wales.

National surveillance of country of acquisition is based on data collected in the voluntary case reporting by clinicians of new diagnoses, with a research nurse/counsellor following up incomplete data (Dougan, Gilbart, Sinka, & Evans, 2005). Currently where region of acquisition is uncertain, for example when an individual may have had sex in both the UK and Africa, the region with the higher prevalence will be assumed to be the region of acquisition.

1.3 Epidemiology of HIV

1.3.1 Current Epidemiology of HIV

Globally 33 million people were estimated to be living with HIV in 2007, 67% (22.1 million) of whom reside in sub-Saharan Africa (UNAIDS, 2008). Many African countries experience generalised epidemics (UNAIDS, 2006). This means that HIV is spreading throughout the general population rather than being confined to high-risk groups such as sex workers or their clients. In sub-Saharan Africa in 2006, an estimated

2.8 million people became infected with HIV and 2.1 million adults and children died of AIDS (UNAIDS, 2006). The majority of adult HIV infections in this region are acquired heterosexually.

In Western Europe there are over half a million persons living with HIV (UNAIDS et al., 2007). The numbers of newly diagnosed individuals continues to rise across Europe. Originally the primary mode of transmission was sex between men, however since 2000 heterosexual contact has become the dominant mode of transmission in those newly diagnosed with HIV in Europe (UNAIDS, 2004). A substantial proportion of these new diagnoses are migrants, in particular people from sub-Saharan Africa (Hamers et al., 2004; UNAIDS et al., 2007).

1.3.1.1 Epidemiology of HIV in the UK

At the time this study commenced 53,000 people were estimated to be living with HIV in the UK (The UK Collaborative Group for HIV and STI Surveillance, 2004) with an estimated 27% of prevalent infections being undiagnosed. In 2003 58% (3801/6606) of new HIV diagnoses were believed to be acquired heterosexually, 26% (1735/6606) via sex between men, 2% through injecting drug use, and 2% via vertical (mother to child) transmission (Health Protection Agency, 2003). For the first time in 2002 more people were estimated to be living in the UK with heterosexually acquired HIV (47.5%) than with HIV acquired via sex between men (45.7%) (Health Protection Agency, 2003). In 2003 947 people developed AIDS for the first time, and 575 died due to HIV related illnesses (Ribeiro, 2009).

The majority (74%) of heterosexually acquired HIV infections in the UK were described by the HPA as amongst people who were probably infected in sub-Saharan Africa (Health Protection Agency, 2003). In 2002 African born men and women were

estimated to account for 69% (16200/26000) of prevalent infections in heterosexuals, with an estimated 31% (4800) of infections undiagnosed (undiagnosed HIV estimated at 39.7% in African men and 25.3% in African women) (Health Protection Agency, 2003).

In 2002 the prevalence of previously undiagnosed HIV infection[2] in genitourinary medicine (GUM) clinic attendees among heterosexuals was 0.8% in London and 0.3% outside London. The ratio of undiagnosed HIV infection in UK born heterosexuals to sub-Saharan African born was 1:11 inside London and 1:79 outside London (Health Protection Agency, 2003). The prevalence of previously undiagnosed HIV infection outside London more than tripled between 1997 and 2002. Since most of this is in sub-Saharan Africans it is thought to be related to dispersal of migrant populations from high HIV prevalence countries to areas outside London (Health Protection Agency, 2003).

Whilst the prevalence of previously undiagnosed infection among UK-born heterosexuals provides an indication of HIV transmission among heterosexuals in the UK, the high prevalence seen in African born heterosexuals is believed to primarily reflect the high levels of HIV infection in the home countries of these migrant populations (Health Protection Agency, 2003). However a 1997 study of diagnosed HIV infection in south London estimated that up to 5% of heterosexually acquired HIV infections among Africans had been acquired within the UK (Paine et al., 1997). A further 12% were either probably or likely to have been infected in the UK. National surveillance data up to 2001 suggests that 3.0% of HIV infections amongst black Africans diagnosed in the UK were acquired in the UK, but there is acknowledgement

[2] Previously undiagnosed infection includes those who were diagnosed at a clinic visit as well as those who remain undiagnosed, but it excludes those who had an HIV infection diagnosed previously.

that this figure is likely to be an underestimate (Sinka, Mortimer, Evans, & Morgan, 2003).

Of course not all HIV infections in African communities within the UK are heterosexually acquired. SOPHID data, which collects data on those individuals with diagnosed HIV infection accessing care in England, Wales and Northern Ireland, show that 12,688 black Africans accessed HIV care in 2003: Of these 11,068 (87%) were infected heterosexually; 226 (1.8%) through sex between men; 31 (0.2%) through injecting drug use; 940 (7.4%) via vertical transmission; 61 (0.5%) via blood products; and 362 (3%) by other/unreported means (The UK Collaborative Group for HIV and STI Surveillance, 2004).

Similarly 'Black Africans' do not represent all Africans. In 2001 only 37% of all African-born UK residents were Black (table 2.1), this is predominantly due to the large migrant communities of white South Africans and Zimbabweans, Asians migrating from Kenya, and Arabic communities from North Africa (Department of National Statistics, 2003). In 2003, of those with reported ethnic group, black Africans comprised 70.3% of individuals with heterosexually acquired HIV accessing care in the UK (The UK Collaborative Group for HIV and STI Surveillance, 2004).

The association between country of birth and ethnicity is important as many assumptions about HIV risk are based on ethnicity. Many non-black African individuals come from countries of high HIV prevalence where HIV transmission between different ethnic groups could be occurring. Conversely, 34% of the black African population in England and Wales were born in the UK (Department of National Statistics, 2003); risk, knowledge and beliefs about HIV for this group are probably more likely to reflect those of the general British population.

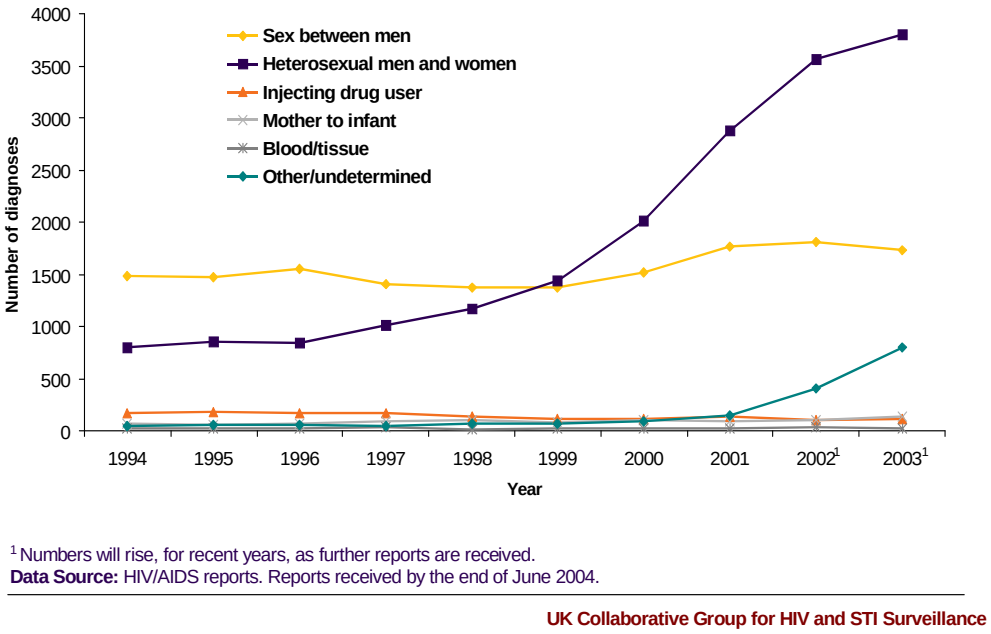
As the prevalent pool of HIV infection increases in overseas-born communities within Britain, so will the potential for transmission within these communities, and also from them to UK born communities. This is because people with HIV will have sexual relationships with other people within the UK, some of who may already have HIV but some of who may not. If there are more people with HIV then there are likely to be more sexual encounters involving someone who has HIV, and hence an opportunity for HIV transmission if there is discordance in the HIV status between the parties.

In the UK 3.6% (788,841/21,660,475) of households have different ethnic identities within partnerships (Department of National Statistics, 2003). The issue of country of birth and ethnicity is of particular interest as much HIV surveillance data are unable to provide an in-depth profile of high-risk populations within Britain.

1.3.1.2 The UK African HIV epidemic

Due to its historical links with Southern and Eastern Africa, the region of the world most affected by HIV, the UK has been particularly affected by the African HIV epidemic. In the UK an estimated 77,400 people are currently living with HIV (Health Protection Agency, 2008a). As in the rest of Europe, infections acquired through heterosexual transmission have progressively increased over the past decade, to the extent that since 1999 the number of HIV diagnoses attributable to heterosexual acquisition has exceeded that from sex between men (see figure 1.2) (Health Protection Agency, 2008a). In 2007, 55% (4260/7734) of new HIV diagnoses were thought to be acquired heterosexually (Health Protection Agency, 2008a).

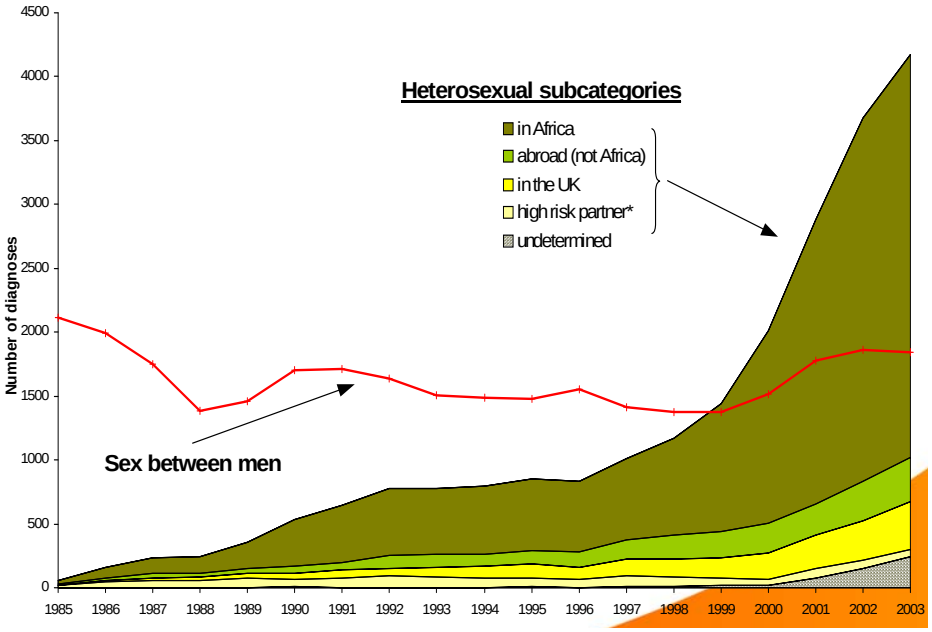
Figure 1.2 Exposure category of HIV-infected individuals by year of diagnoses, UK, 1994-2003



Source: UK Collaborative Group for HIV and STI Surveillance, 2005.

The majority (67%) of heterosexually acquired HIV infections in the UK are amongst people of black-African ethnicity, and most were probably infected in sub-Saharan Africa, (figure 1.3) (Health Protection Agency, 2008a). Black-Africans form the second largest social group affected by HIV in the UK, with 18,719 15 to 59 year old black Africans living with diagnosed HIV(Health Protection Agency, 2008c). It is estimated that 30.1% of people with heterosexually acquired HIV in the UK are unaware of their HIV seropositivity (Health Protection Agency, 2008a).

Figure 1.3 UK HIV diagnoses by the two main routes of transmission 1985-2003



Numbers for 2003 will increase as further reports are received.
*High risk partner includes sex between men, injecting drug use or receipt of blood or blood products.

Source: UK Collaborative Group for HIV and STI Surveillance, 2005.

Late diagnosis of HIV disease, defined as a CD4 count below 200 cells/µl, increases the risk of death within one year of diagnosis 8 to 10 fold ($p<0.01$), compared to those diagnosed with a CD4 greater than 200 cells/µl (Chadborn et al., 2005; Chadborn, Delpech, Sabin, Sinka, & Evans, 2006). In the UK African men and women with heterosexually acquired HIV are more likely to be diagnosed late than men acquiring HIV through sex between men (Health Protection Agency, 2008c). In 2007 42% of all new HIV diagnoses among black Africans were with advanced, or late stage, disease (Health Protection Agency, 2008c). For heterosexuals earlier HIV diagnosis could reduce short-term (within a year of diagnosis) mortality by 56% and all mortality by 32% (Chadborn et al., 2006).

Africans in the UK have the same rates of disease progression as non-Africans once they begin HAART (Del Amo et al., 1998), yet no national reduction in AIDS diagnoses has yet been seen within the African community in the UK (Sinka et al., 2003). This is due to the continuing late presentation to HIV services and the increasing prevalence of HIV within these communities due to increased life expectancy and ongoing immigration (The UK Collaborative Group for HIV and STI Surveillance, 2007). Late diagnosis not only denies an individual optimum therapy options, but also reflects missed opportunities to limit onward transmission.

Why Africans in the UK continue to present late to HIV services in the era of HAART is poorly understood due to a relative lack of research.

1.4 Access to care

1.4.1 Why it is important epidemiologically

In populations the incidence and prevalence of sexually transmitted infections (STIs), including HIV, are determined by patterns of sexual behaviour; the efficiency of transmission of an organism; the duration of infectiousness of infected individuals; the effectiveness of control programmes to limit spread; and the current burden of infection in the population. The case reproduction number (Ro) is the average number of secondary cases from a single case in a totally susceptible population (Aral, 2002). When Ro is greater or equal to one the organism will be sustained in the population (Garnett, 2002).

A simple model for the case reproduction number for STIs is: $Ro=\beta cD$. Where β is the probability of transmission per partnership (infectivity); c is the rate of contact between infected and susceptible individuals; and D is the duration of infectivity. The simplicity of the model belies the complexity of the components and the interrelationships

between them. By identifying the parameters of the individual components below it is possible to demonstrate how the accessing of appropriate healthcare is fundamental to HIV prevention strategies.

1.4.2 Efficiency of transmission (β)

The efficiency of transmission or the infectivity (β) of HIV is influenced by viral load, the use of condoms, the presence of other STIs (in particular genital ulcer disease), and circumcision. Of these HIV viral load is probably the dominant variable affecting infectivity when mode of transmission is unprotected sexual intercourse, vertical transmission, or contaminated blood or needles (Quinn et al., 2000; Dickover et al., 1996; Thea et al., 1997; Cardo et al., 1997).

HIV viral load varies over the course of HIV infection. It is highest at seroconversion, lowest during the asymptomatic phase, and rises again during symptomatic disease or with concomitant infections (Coombs et al., 1989; Ho, Moudgil, & Alam, 1989; Michael, Vahey, Burke, & Redfield, 1992; Burke, Fowler, Redfield, Dilworth, & Oster, 1990). Models also suggest that the infectivity/risk of transmission is linked to stage of infection, with heterosexual transmission per coital act following a U-shaped curve, again highest at seroconversion, lower during latency and increasing with advancing disease (Shiboski & Padian, 1998; Anderson & May, 1988; de Vincenzi, 1994; Leynaert, Downs, & de Vincenzi, 1998). In 2000 Quinn *et al*. demonstrated that the chief predictor of the risk of heterosexual HIV transmission is viral load (Quinn et al., 2000).

Whilst it could seem plausible that widespread use of highly active antiretroviral therapy (HAART) may reduce the risk of onward sexual transmission via reduction in viral load, the population level effects of HAART are yet to be seen. The viral load

benefits may be offset by the increased HIV prevalence (due to increased survival), increased unsafe sex (due to reduced risk perception), and selective pressure for resistant viruses (Johnson, 2001). Additionally, there is typically lack of treatment amongst the most infectious fraction - those recently infected (Sudarshi et al., 2008), and those not on treatment because they remain undiagnosed or are as yet ineligible for treatment (for clinical or legal reasons).

Condom effectiveness in reducing heterosexual HIV transmission is approximately 80% (Weller, 2001). 'Safe sex' is now synonymous with condom use during sex, however uptake of consistent condom use can be problematic (Wald et al., 2001). A meta-analysis has shown that people who know they are HIV positive or in a sero-discordant relationship (where one person is HIV positive and the other HIV negative) are less likely have unprotected sex and are more likely to use a condom consistently, than people untested; Unfortunately people testing HIV negative did not show improved condom usage despite counselling and testing for HIV (Weinhardt, Carey, Johnson, & Bickham, 1999). Promotion of condoms as effective protection against HIV may again be partly offset by reduced risk perception and subsequent compensatory behaviour change (Richens, Imrie, & Copas, 2000).

Co-infection with other STIs, especially herpes simplex virus 2 (HSV-2), is also associated with increased transmission of HIV (Weiss et al., 2001; Cohen, 1998). Treatment of STIs can decrease shedding of HIV (Cohen et al., 1997), and one major study found STI control an effective means of reducing HIV incidence (Grosskurth et al., 1995), but another did not (Wawer et al., 1999). The ability of STI control to reduce HIV incidence may relate to what phase the epidemic is in; with evidence of its benefit in emerging epidemics but not in mature epidemics (Gray, 2001; Sangani, Rutherford,

& Wilkinson, 2004). Antiviral agents against HSV-2 are currently being evaluated as a means of HIV control.

Male circumcision is also associated with reduced heterosexual acquisition of HIV infection, (Gray et al., 2000). The preputial mucosa, located on the foreskin, appears to be an important target tissue for HIV due to its high density of readily accessible Langerhans cells (immune cells that are primary targets for HIV) (Patterson et al., 2002). The effect of circumcision appears to be modified by the age at circumcision, the degree of circumcision, and the background prevalence of HIV and STDs (Hayes, 2001). Circumcision does not appear to effect acquisition of other STIs (Gray et al., 2004). As with HAART and condoms the population level effects of circumcision remain to be seen. The reduction of infectivity by circumcision may result in behavioural changes that impact on duration of infectiousness and the contact rate between infected and susceptible individuals. It is currently unknown whether circumcising men in the UK will reduce heterosexual or homosexual HIV transmission.

1.4.3 Rate contact between infected and susceptible individuals (c)

The numbers and patterns of sexual contacts in the general population, and within high-risk (or core) groups, are a crucial determinant of HIV transmission. There remains debate as to the relative importance of the behaviours of the general population compared to those of 'core groups' (persons with large numbers of sexual partners who are interconnected with each other through sex links) (Aral, 2002). The infectivity (β) and duration of infectiousness (D) may influence the importance of one over the other, as may the phase of the epidemic.

A consensus definition as to who or what is a 'core group' does not exist; most definitions and research focus on categorically defined populations such as 'gay men' or

'sex workers'. Whilst black African migrants in the UK may not have 'large numbers of sexual partners' they are 'interconnected with each other through sex links' and have a high HIV prevalence relative to the general population (The UK Collaborative Group for HIV and STI Surveillance, 2004), thus they can be regarded as a 'core group'.

Mathematical models suggest that for infections of low infectivity and long duration, as with HIV, the sexual behaviour patterns of the general population may be more important than that of core groups (Garnett, 2002). When STIs including HIV are concentrated within core groups relative to the general population, as in initial growth and late low endemic phases, the behaviours of core group members assume more importance in determining the spread of infection (Wasserheit & Aral, 1996).

Whether focusing on the general population or core groups the frequency of concurrency (sexual partnerships overlapping in time), the gap between sexual partnerships (time duration between the end of one sex partnership and the beginning of the next), and the pattern of sexual mixing, all influence the rate of contact between infected and susceptible persons (Service & Blower, 1996; Garnett & Johnson, 1997; Aral, 2002).

Concurrency may be more important in the early phases of an epidemic, and in disseminating high infectivity – short duration infections (Garnett, 2002). HIV is regarded as a low infectivity - long duration infection, but the period of maximum HIV infectivity (seroconversion) is short. Modifying the duration of gaps between sexual partnerships may also be important, especially given the huge numbers of the population who practice serial monogamy (Johnson et al., 2001). Data from a national probability survey in 2000 reports that black African men in Great Britain were significantly more likely to have concurrent partnership over the past year compared to white men (34.5% vs. 13.9%) (Fenton et al., 2005).

Sexual mixing patterns also influence the spread of HIV through populations (Doherty, 2001; Service et al., 1996). The degree of mixing between people of similar (or dissimilar) sexual activity and health seeking behaviours, and between populations with high or low STI (including HIV) prevalence, all impact on the rate of contact between infected and susceptible individuals (Aral, 2002). Another important component influencing rate of contact is the size of sexual networks, especially those involving core groups (Garnett, 2001). Both the absolute and relative size, and the absolute and relative contact, between core groups and the general population are thought to be important (Aral, 2000; Laumann & Youm, 1999), although the impact of these parameters on HIV transmission has yet to be tested.

Like the general population core groups are not static entities. There is often high population turnover with new individuals entering and others leaving. Size, distribution and functioning of core groups can rapidly change; both the rate and type of change influencing the rate of contact between infected and susceptible individuals (Aral, 2002). Africans in the UK are a mobile population with many persons in transit between Africa and the UK at any point in time (Fenton, Chinouya, Davidson, & Copas, 2001; Migration Statistics Unit, 2004). Whilst concentrated in London, African migrants seeking asylum are currently experiencing dispersal throughout the country. Migratory influxes are reflected in HIV diagnoses in the UK (Sinka et al., 2003; Forsyth, Burns, & French, 2005). How these population dynamics impact on HIV transmission remain unexplored however.

Reducing or influencing partner change requires, amongst other things, concerted education at both individual and population level. The process of voluntary counselling and testing (VCT) when undergoing an HIV test has been shown to be effective in reducing unsafe sex for those testing HIV positive but not in reducing number of sexual

partners (Weinhardt et al., 1999). Whether sexual networks or timing of sexual partnerships changed in response to VCT was not assessed in the meta-analysis. There was however an overall reduction in STI incidence in those testing HIV positive. The reduction in HIV prevalence seen in Uganda is largely attributed to a reduction in casual sex, achieved through intensive publicly available information about HIV/AIDS (Asiimwe-Okiror et al., 1997; Stoneburner & Low-Beer, 2004). Currently in the UK health education is primarily available through the accessing of health and community services including schools, and targeted interventions.

1.4.4 Duration of infectiousness (D)

As HIV cannot yet be cured accessing HIV services may not reduce duration of infection, but should (in fact) increase people's life expectancy. However accessing HIV services may reduce the duration of high infectivity via access to antiretroviral medication and through diagnosis and treatment of concomitant infections. Delays in time to diagnosis (time between accessing health services and diagnosis of HIV), treatment delay (time between diagnosis and receipt of antiretroviral medication), and the time to effective suppression of virus, can all prolong the duration of infectiousness. There is no evidence to suggest delays in treatment or viral suppression exist differentially for Africans resident in the UK compared to the non-African population, the exception being for those ineligible for free National Health Service (NHS) treatment of their HIV. However as mentioned previously, Africans are diagnosed at later stages of HIV infection than non-Africans. It is unknown if this reflects diagnostic delays or differential accessing of health services; either way late diagnosis likely increases the duration of high infectivity.

Immigrant populations may lack adequate access to preventive and health care services, may have lower levels of condom use, and subsequently have longer duration of

sexually transmitted infections (Aral, 2002; McLeish, 2002; Fenton, Chinouya, Davidson, & Copas, 2002). Dispersal of asylum seekers may contribute to diagnostic and treatment delay as migrants will be seeking health care in regions with lower HIV prevalence and clinicians could be expected to be less familiar with HIV and its presentations and management (Creighton, Sethi, Edwards, & Miller, 2004).

Reducing the duration of the period where an individual is HIV positive but unaware of their serostatus is a key component of HIV prevention interventions. This is in part to ensure timely access to medication to optimise health outcomes, and in part to reduce transmission opportunities for HIV via: reduction of the duration of high infectiousness (D) with medication; by treating concomitant infections, suppression of virus to low or undetectable levels with HAART, and by preventing progression to late stage disease – all impacting on efficacy of transmission/infectivity (β); and via uptake of safer sex strategies including condom use, and reducing partner change (c).

1.4.5 The impact of delayed access to HIV services.

Delayed access to HIV services may influence β, c and D for the reasons mentioned above, delayed access also impacts on the individual seeking care, their sexual contacts and partners, and the population generally.

On an individual level an inability to access HIV services leaves people at risk of serious morbidity and death, as well as increasing their duration of high infectivity (and with it the potential for onward transmission to partners and offspring). In the UK short-term mortality for those diagnosed with late disease is approximately ten times that of people diagnosed with less advanced disease (Chadborn et al., 2005). In Spain between 1995 and 2000, AIDS diagnoses declined by 36% among those diagnosed late in the course of their disease, compared with a decline of 67% for those previously

aware of their diagnosis ($p<0.01$); the median CD4 count at AIDS diagnosis was significantly lower (50 versus 81; $p<0.0001$) among late testers than all other cases; and 12.5% of late testers died within three months of diagnosis (Castilla et al., 2002).

Estimation of the public health impact of delayed access to HIV care should take into account the potential for onward transmission of infection; late identification and management of infected contacts; increasing treatment costs associated with expensive therapies and hospitalisation; and, of course, avoidable morbidity and mortality. Few studies have been done to qualify the economic impact and this remains an area for future research.

People with undiagnosed advanced HIV disease are likely to suffer symptomatic disease necessitating general practitioner (GP) or hospital visits, yet studies have shown these opportunities to initiate discussion about HIV and testing are being missed (Madge, Olaitan, Mocroft, Phillips, & Johnson, 1997; Burns et al., 2004a). When HIV is not readily identified as the underlying pathologic process significant health and personal resources can be unnecessarily spent. An inability to establish the underlying disease process could also undermine confidence in the health care system generally. Undiagnosed HIV positive individuals are likely to continue the chain of transmission to new partners, and diagnosis at a later date, for example during a new relationship or due to complications, could have considerable clinical and psychosocial consequences.

In 2001 the Department of Health estimated the economic cost of treating each new HIV infection at between £135,000 and £181,000; and the monetary value of preventing a single onward transmission at between 0.5 and 1 million pounds sterling due to individual health benefits and treatment costs (Department of Health, 2001). Reference as to how these figures were obtained is not provided. A Canadian study found that direct costs (i.e. medication, investigations, inpatient, outpatient, and home care) were

twice as high for late presenters ($18448 vs. $8455), due predominantly to the HIV related hospital care costs which were 15 times higher (Krentz, Auld, & Gill, 2004). Few other studies have been done to quantify the economic impact of delayed access and this remains an area for future research.

1.5 Rationale for interest

From a public health perspective, improving access to and utilisation of HIV treatment and prevention services are key primary and secondary HIV prevention strategies for African communities by:

1.5.1 Improving clinical outcomes

Proportionately more HIV positive Africans in London presented late to HIV services in 1998/99 than they did between 1982-1995 (Del Amo et al., 1998; Burns, Fakoya, Copas, & French, 2001). In 1998/99 35% of Africans had an AIDS defining illness within one month of diagnosis of their HIV infection compared with 13% of non-Africans (Burns et al., 2001).

Starting therapy with a CD4 count below 200 cells/μL is associated with a substantially greater risk of disease progression and death; this risk persisting for a significant period after treatment is started (May et al., 2007). Better survival from AIDS diagnosis has also been associated with a longer awareness of HIV diagnosis prior to AIDS diagnosis (Easterbrook et al., 2000). Early diagnosis of HIV infection enables timely access to effective treatment and care, and optimises clinical outcomes.

1.5.2 Reducing onward disease transmission

Earlier diagnosis of one's HIV infection facilitates the uptake of individual prevention strategies to reduce onward transmission of infection (Weinhardt et al., 1999; Crepaz et

al., 2006). After adjusting for population differences between groups, the sexual transmission of HIV is estimated to be 3.5 times higher in groups unaware of their HIV infection than in groups who are aware (Marks, Crepaz, & Janssen, 2006).

The continued in-migration and establishment of African communities in the UK (Home Office, 2008) has raised concerns about the potential for HIV transmission and acquisition among individuals *resident* within the UK. Current surveillance systems are limited in providing any detailed understanding of the contribution UK HIV acquisition has to the increasing reported HIV infections in this population.

The relatively high HIV prevalence within African communities in the UK compared to the non African communities (Health Protection Agency, 2003; Sadler et al., 2007) and the known assortative (like-with-like) sexual mixing patterns (Barlow, Daker-White, & Band, 1997; Ford, Sohn, & Lepkowski, 2002) means there is substantially higher risk of HIV exposure for an African resident in the UK than a non-African resident. This coupled with high proportions of undiagnosed infection and high viral loads as a consequent of late presentation to HIV services (Burns et al., 2001; Health Protection Agency, 2003), increases the potential for onward sexual transmission within the UK.

Our poor understanding of the factors that influence the uptake of HIV testing and treatment services by Africans in the UK limits our ability to develop effective HIV prevention programmes.

1.6 Aims and objectives

This thesis presents a programme of research designed to explore the factors contributing to the continuing late diagnosis of HIV among Africans living in London. The main focus of the thesis is the 'study of newly diagnosed HIV among Africans in London' (the SONHIA study), which combined qualitative and quantitative methods in

a multi-centre study, to describe and explain the health beliefs, heath care utilisation and clinical presentation patterns of newly diagnosed HIV positive Africans. It also explores UK acquisition of HIV in this population.

Specific objectives are:

1. To describe the uptake of HIV testing and the factors associated with HIV testing in Africans in Britain.
2. To describe the demographic characteristics, migration history, HIV/sexual health history, and patterns of service utilisation and levels of psychosocial support in newly diagnosed HIV positive Africans.
3. To determine the extent to which acquisition of HIV infection may have occurred within the UK through ascertainment of migration history, HIV/sexual health history, and sexual partnership history.
4. To determine if there are opportunities for earlier diagnosis of HIV disease within the UK.
5. To determine the demographic, behavioural and social factors independently associated with delayed presentation (CD4<200 cells /μL) to treatment services
6. To explore qualitatively, the contextual, social and economic factors, which influence timely access to and uptake of HIV prevention and treatment services among newly diagnosed HIV positive Africans.

1. 7 Study outline

The thesis is divided into 10 chapters.

Chapter 1, an introductory chapter, provides an overview of the history and epidemiology of HIV, the determinants of HIV spread, and the rationale for this work.

Chapter 2 presents a literature review to provide epidemiological, cultural and historical background. It reviews African migration to the UK and what we already know about why some communities access care late. It explores the interaction between ethnicity, inequality and health, and the concept of 'normalisation' of HIV.

Chapter 3 is an analysis of the 2nd British National Survey of Sexual Attitudes and Lifestyles to explore the factors associated with HIV testing among black Africans in Britain.

Chapter 4 presents the findings from in depth interviews with key informants to identify the key issues affecting utilisation of HIV services for Africans in Britain.

Chapter 5 presents the study of newly diagnosed HIV infection among Africans in London (SONHIA). It describes the methodologies employed, the development and validation of the study instruments (questionnaire, clinical data form and topic guide), and the principles behind the study design. The chapter concludes with the challenges of implementation of this study, and the strategies to address them. The results are presented over the following three chapters.

Chapter 6 details the response rate to the survey, and provides a descriptive overview of the study population. It uses the survey data to identify missed opportunities for earlier HIV diagnosis in Africans in the UK.

Chapter 7 uses survey data to identify factors associated with late presentation to HIV services.

Chapter 8 explores the extent to which HIV acquisition in UK resident Africans may have occurred in the UK rather than abroad.

Chapter 9 presents the qualitative findings thematically to enable contextual understanding of the factors contributing to late presentation.

Chapter 10. The final chapter contextualises the findings with the literature and current socio-political climate. It addresses the study's limitations and concludes with the public health and policy implications of the study.

Chapter 2: Background

Abstract

In the UK substantial numbers of new HIV diagnoses are within migrant African communities. Current surveillance shows that despite health promotion efforts and advances in therapy these communities are accessing HIV care late. This literature review explores the issues influencing the access and uptake of HIV care by migrant Africans in Britain. Using Kleinman's model of health care systems (Kleinman, 1980) as a theoretical framework the importance of placing health within it's broader context is demonstrated.

The findings within this chapter are published in *Psychology, Health & Medicine* (2006); Access to HIV care among migrant Africans in Britain. What are the issues? F. Burns & K.A. Fenton. v.11:pp.117-125.

2.0 Introduction

This thesis aims to describe the health beliefs, heath care utilisation and clinical presentation patterns of newly diagnosed HIV positive Africans in London. This chapter reviews what is currently known regarding HIV epidemiology, HIV testing and health access for African communities in the UK. An overview of relevant demographic patterns, migration to the UK by African communities, and current policy regarding access to care for asylum seekers and refugees is also provided.

2.0.1 Literature review strategy

The following sources of information were utilised between September 2002 and December 2004.

1. PubMed using the terms UK and Africa* limited to AIDS, English language, humans and adults (386 articles identified of which 36 were relevant)

2. Internet search engine (Google Scholar) to identify relevant papers, reports and policy documents. Search terms included Africa*, UK, HIV, health care access, immigration and emigration.

3. Selected journals (AIDS, British Medical Journal, Sexually Transmitted Infections and International Journal of STIs and AIDS) were reviewed by hand or online.

4. Websites of relevant organisations such as the Home Office, African HIV Policy Network (AHPN), Sigma and National AIDS Trust (NAT) were explored.

5. The abstracts of relevant conferences were reviewed by checking available abstract books of scientific or medical events. Additionally, all references cited in included papers were checked and included if pertinent.

2.1 Migration & the population of Great Britain

The population of Great Britain[3] (GB) is estimated to be 57.6 million - 49.6 million in England; 2.9 million in Wales; and 5.1 million in Scotland. Overall 91.9% of the British population classify themselves as being white, of whom 96% are defined as 'white British' (Department of National Statistics, 2003). The population of GB is steadily increasing due to both natural change (births outnumbering deaths) and net migration. Since 1998, migration has accounted for a greater proportion of population change than natural change (Migration Statistics Unit, 2004). In 2001, 8.3% (4.9 million) of the total UK population was born abroad; this is almost double the proportion in 1951 (4.2%). The overseas-born population had a greater increase between 1991 and 2001 than in any other post-war decade (Migration Statistics Unit, 2004). Migrants from relatively developed OECD (organisation for economic co-

[3] Great Britain is comprised of the countries of Scotland, Wales and England; it is part of the United Kingdom of Great Britain and Northern Ireland.

operation and development) countries account for the surge over this decade, with 85% of migrants coming from the old commonwealth, Europe and the United States. Whilst two fifths of black Africans resident in the UK entered the country post 1990 (2003), there was no upward trend in net immigration from the new Commonwealth[4], including Africa, over this period (Hatton, 2005).

Although country of birth and ethnicity are not so closely linked in the overseas-born population within the UK, the rise in international immigration has corresponded with the ethnic minority population increasing from 3.1 million (5.5% total population) to 4.6 million (8.1% total population) over the past decade (Migration Statistics Unit, 2004). London has greater ethnic diversity than the rest of Great Britain; 28.8% of Londoners identify themselves as 'non-White'. In 2001 78.2% of all black Africans resided in London and black Africans comprised 5.3% of the population (Department of National Statistics, 2003).

2.1.1 International migration

An international migrant is defined as someone who changes his or her country of usual residence for a period of at least a year, so that the country of destination effectively becomes the country of usual residence (Migration Statistics Unit, 2004). The Government Actuary's department project a long-term annual net inflow into the UK of 130,000 persons per year.

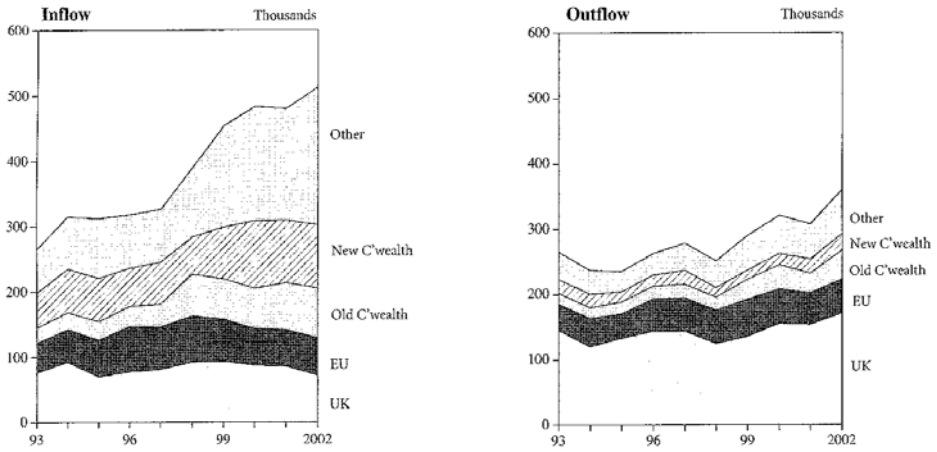
The past decade has seen marked changes in the country of origin of migrants to the UK (figure 2.1) with proportionately more persons arriving from the new commonwealth

[4] The old commonwealth countries constitute Australia, Canada, New Zealand and South Africa.

New commonwealth is defined as all other commonwealth countries, British dependent territories and British Overseas citizens. Excludes Hong Kong. This includes all African commonwealth countries except South Africa – Botswana, Cameroon, The Gambia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Sierra Leone, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

and countries outside the EU[5]. England, and London in particular, receive the majority of net international migration to the UK (Migration Statistics Unit, 2004). Large numbers of Pakistani and Indian subcontinent migrants have also settled in the West Midlands, Bradford, and Greater Manchester (2003).

Figure 2.1 Total international migration by country of birth; United Kingdom 1993-2002



Source: Migration Statistics Unit 2004

The relatively high migration inflow to the UK (and Europe generally) in recent decades has met with increasing restrictions on immigration. These measures include visa requirements to enter the country and tightening of criteria for asylum. As global movement of people generally is expected to continue to increase, the increased barriers to immigration are expected to increase significantly the numbers and the proportions of illegal and marginalised migrants (UNAIDS, International organisation for migration, & Duckett, 2001).

[5] European union as defined in 2002, i.e. Austria, Belgium Denmark, Finland, France, Germany, Greece, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden and the Irish Republic.

2.1.2 Internal migration

Traditionally migrants have been geographically concentrated in London and the Southeast of England. Internal migration, which is migration within the borders of the UK, has not historically been a feature of overseas-born migrant communities. In 2000 the National Asylum Support Service (NASS), whose role is to provide accommodation and subsistence for asylum seekers, started a policy of asylum seeker dispersal in order to spread the cost of care throughout the UK (UK Parliament, 2002). This policy has resulted in individuals residing in regions with limited experience with asylum seekers, and outside of established community support networks.

2.1.3 African migration to the UK

Large-scale migration from Africa to the UK began following the Second World War. However the Commonwealth Immigrants Act of 1962 denied many migrants full social and political rights, and the Immigration Act of 1972 further limited immigration from former British colonies (2003). Until the 1990s migration from Africa was often motivated by 'pull' factors, in particular the seeking of higher education or employment opportunities. More recently however the motivations behind migration have shifted to reflect more 'push' factors as people attempt to escape political and economic upheavals (Bingham, 2002; Maharaj, Warwick, & Whitty, 1996). This is reflected in migrants accepting lower skilled jobs despite coming from the more skilled or educated classes in their home countries (Fakhouri et al., 1996; Chimanikire, 2003).

Migration out of Africa often reflects historical ties, with global flows mainly to ex-colonial states: South Africans, Kenyans, Nigerians, Ghanaians, Ugandans, and Zimbabweans have migrated to the UK (table 2.1 and figure 2.2), Central and West Africans to France, and the Congolese to Belgium (Chimanikire, 2003; Bingham, 2002). Recently there have been noticeable influxes of populations to the UK associated with

conflicts in African countries such as Eritrea, Somalia, and Zimbabwe (figure 2.3) (UK Parliament, 2002), these influxes are reflected in those accessing HIV services (Forsyth et al., 2005; Sinka et al., 2003). Despite the increase in those seeking asylum, chain migration, the process in which family formation drives migration, continues to account for the majority of migrants from Africa who settle in the UK.

Table 2.1 Ethnicity of English and Welsh residents born in Africa

Country of birth	Ethnic Group				Total
	White	Black African	Indian	Other	
Kenya	16,565 (13%)	13,421 (11%)	82,727 (65%)	14,609 (11%)	127,322
Nigeria	5,895 (7%)	76,291 (88%)	295 (1%)	4,477 (4%)	86,958
South Africa	119,129 (90%)	4,218 (3%)	3,622 (3%)	5,332 (4%)	132,301
Zimbabwe	24,664 (52%)	17,852 (38%)	1,081 (2%)	3,561 (8%)	47,158
North Africa	34,997 (51%)	9,527 (14%)	593 0.9%)	23,598 (34%)	68,715
Central & Western Africa (other than Nigeria)	7251 (7%)	89,980 (81%)	6,119 (6%)	7,253 (7%)	110,603
South & Eastern Africa (other than Kenya, South Africa, and Zimbabwe)	31,606 (13%)	88,757 (38%)	73,173 (31%)	42,348 (18%)	235,884
Total	240,107 (29.7%)	300,046 (37.1%)	167,610 (20.7%)	101,178 (12.5%)	808,941 (100%)

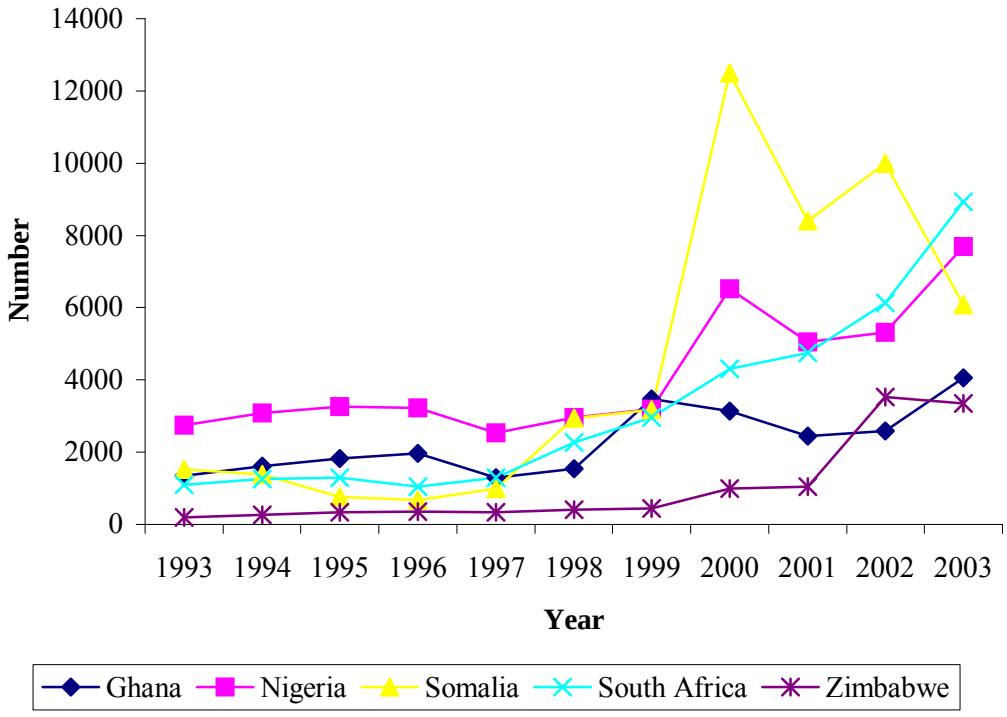
Source: Table S102. Census 2001.

In 2003, 45,835 Africans were granted settlement in the UK, including 7,530 recognised refugees and persons granted exceptional leave to remain (ELR)[6]; 71,350 Africans were granted extension of leave to remain; and 18,825 applications were refused asylum after full consideration, although many of these would go for appeal. Ten percent of all asylum applicants in 2003 were Somalian and 7% were Zimbabwean (figure 2.3). The

[6] In April 2003, exceptional leave to remain in the UK was replaced by Humanitarian Protection and Discretionary Leave. Humanitarian Protection is a grant of limited leave made to someone who hasn't been granted asylum but who, subject to certain exclusion provisions, has been able to demonstrate a need for protection in the UK. A person who is not able to demonstrate a need for protection under either the asylum or Humanitarian Protection provisions may qualify for a grant of Discretionary Leave (Home Office, 2005).

black African population in Britain increased by 37% over the 1990's (Migration Statistics Unit, 2004).

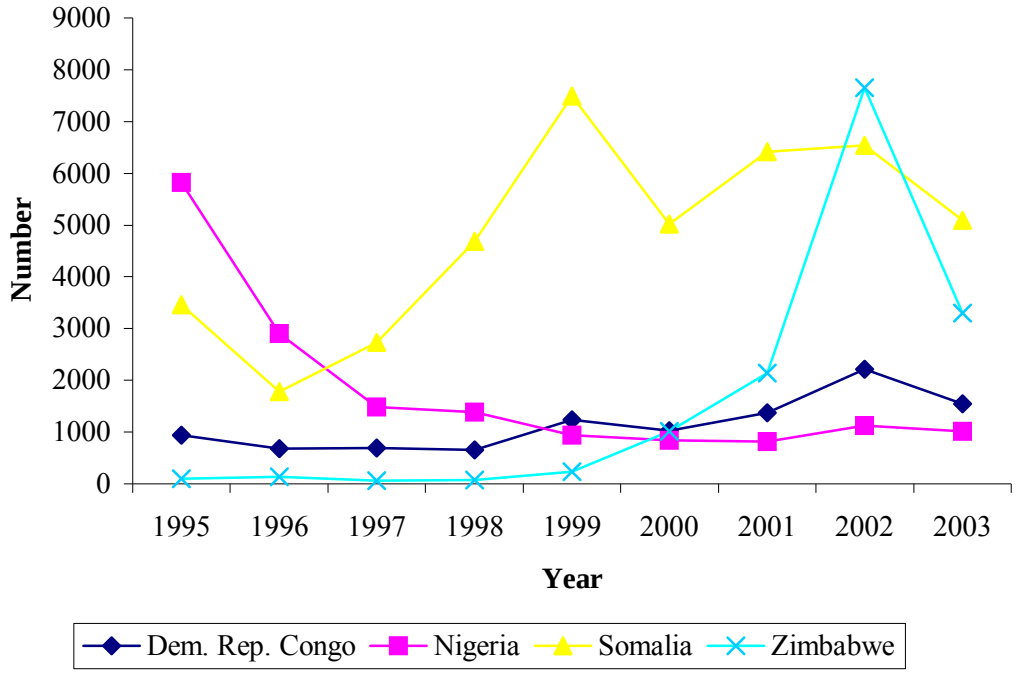
Figure 2.2 Grants of settlement to African nationals, 1993 to 2003



Data provided for the five African countries receiving the majority of settlement grants in the UK. Total grants of settlement to all African nationals over this period ranged between 10,900 (in 1993) to 44,845 (in 2000).

Source: National Statistics, November 2004.

Figure 2.3 Applications received for asylum in the UK from African nationals, excluding dependants, by nationality, 1995 to 2003



Data provided for the four African countries making the majority of asylum applications over this period. Total applications from African countries over this period ranged between 9,515 (in 1996) and 29,390 (in 2002).

Source: National Statistics, November 2004.

The former British colonies, in particular Uganda, Zimbabwe, Malawi, Zambia and South Africa, have been particularly affected by the HIV epidemic (UNAIDS, 2004). It is not surprising that the UK is now seeing significant levels of HIV infection among its African migrants (The UK Collaborative Group for HIV and STI Surveillance, 2004).

Migrant Africans comprise a heterogeneous aggregation of population sub-groups, which vary geographically, temporally, socio-economically, and culturally. There is much diversity within the African communities resident in the UK and reducing all these communities into one broad category, whilst necessary for research purposes, will undoubtedly obscure important differences.

2.2 Migration and HIV infection

Two thirds of all heterosexually acquired HIV in Europe (see chapter 1) is diagnosed among migrants from high prevalence countries (2004). The UK heterosexual HIV epidemic reflects historical and recent migratory patterns, and to a lesser extent, ongoing transmission of HIV infection within the UK (Sinka et al., 2003). The majority of HIV infections among Africans in the UK have occurred among those from, or having partnerships with, individuals from high HIV-prevalence countries outside of the UK. As such, a significant proportion of these infections are assumed to have been acquired before migration to the UK (Health Protection Agency, 2003).

However, migration differentially favours those who are younger, economically productive and healthier and therefore more likely to be sexually active with reproductive ambitions (de Putter, 1998). Migration is also often associated with the rupture and re-establishment of sexual relationships, particularly as many individuals initially migrate without their primary partners. Migration has been identified as a critical factor in high-risk sexual behaviour independent of marital and cohabitation

status, social milieu, or awareness of AIDS (Brockerhoff & Biddlecom, 1999). This is thought to be in part due to the concept of the migrant, particularly the voluntary migrant, as a 'risk-taker'. Migrants are individuals who gamble that a different environment will be beneficial. This risk-taking may permeate into the choices they make in their private life (UNAIDS et al., 2001). The non-voluntary migrant is usually fleeing social and political upheaval, conditions known to facilitate HIV transmission via the breakdown in infrastructure (including health services), poverty, rape, and rupture of family units (Haour-Knipe, 2000).

2.3 Access to care

The term "access to services" incorporates a variety of concepts including whether and how patients attend services, whether they do so at the optimal time, and which services they attend. Access is influenced by patients' health seeking behaviour, as well as the availability of appointments, convenience, and visibility of services. Access is likely to differ between individuals, patient groups, and in different localities.

Studies from the USA identify lack of knowledge, stigma towards HIV, denial, lack of employment opportunities or supportive working environments, distance to medical facilities and inadequately trained, or mistrust of, medical professionals as significant barriers to accessing HIV care (Heckman T et al., 1998; Raveis, Siegel, & Gorey, 2003). However as socio-demographic characteristics are very different in the USA we cannot assume that the same issues and processes are automatically applicable to the UK.

2.4 Ethnicity, inequality and health

> 'Not only are [migrants] exposed to poor working and living conditions, which are per se determinants of poor health, but they also have reduced access to health care for a number of political, administrative and cultural reasons which are not necessarily present for the native population, and which vary in different societies and for different groups. Language, different concepts of health and disease, or the presence of racism are examples of such selective barriers.'
>
> (Bollini & Siem, 1995)

The high concentration of migrant and ethnic groups in lower social strata play an important role in determining poor health outcomes, but reducing health problems for these groups to one of social class does not give justice to the complexity of issues (Nazroo & Davey Smith, 2001). Different barriers to health care exist for these groups than for natives from the same social class; for example different entitlements according to their legal status, and real or perceived racism and discrimination will create additional barriers in the utilisation of health care services (Donovan, 1984). Of course migrants are not homogeneous – different subgroups may experience different health outcomes (according to position in society, religion, level of integration, racism, etc) - but the general trend to poor health outcomes for migrants holds true in most parts of world. The term 'ethnic distance' is used to illustrate the elements of cultural differences that influence risk inherent in migration (Tan, 1998). The ethnic distance for a woman from a small village in Africa with no knowledge of English seeking asylum in Britain will be much greater than for a businessman from that same country transferring his job to Britain – even if they are from the same country and migrate at the same time (Tan, 1998).

2.4.1 Health care systems & health service research

Kleinman (1980) defines *health care systems* as socially organised responses to disease that constitute a special cultural system. It is a concept as opposed to an entity, and is derived by understanding how people think about health care, as well as how they act in it and use its components (Kleinman, 1980). Health care systems include people's beliefs and patterns of behaviour, which are governed by cultural rules. Many factors, including the health problem itself, treatment options, social institutions, economic, political, environmental and historical constraints, influence these beliefs and behaviours.

Traditionally health service research has been quantitative and focused on the use of health services. This has allowed for measurement of health seeking behaviour but has failed to answer the 'how or why' questions relating to health care access. Health seeking behaviour is but one component of the *health care system.* Similarly limiting are the models of behaviour change traditionally used in health care research, be it the health belief model, the theory of reasoned action, or social learning theory. In these models the onus of health is predominantly placed on the individual but they largely fail to account for the external influences of the social, political or ecological environment.

The configuration of health care systems is shaped by internal factors, and factors external to it, that is political, economic, social structural, historical and environmental determinants. Kleinman's model sees the internal factors as comprising of the popular, professional and folk sectors (Kleinman, 1980). People beliefs comprise part of the *popular sphere* of health care. This is the area in which illness is first defined and health care activities initiated. It is the most immediate determinant of care as people generally decide when and whom to consult, whether or not to comply, whether care is effective, and whether they are satisfied with its quality. Within Britain the *professional*

sector is essentially modern scientific medicine. The differences in cognitive and communicative processes or treatment styles within the professional sector are important factors in determining differences and acceptability in clinical care. The *folk sector* of health care is the non-professional, non-bureaucratic, specialists, for example herbalists. It incorporates both sacred and secular traditions. In Britain all three sectors (popular, professional and folk) are operating, whilst in some more rural African societies the folk and the popular sector are likely to constitute the majority of the health care system.

Most researchers study isolated components of health care systems without exploring the linkages between the components or the system as a whole. Freidson argued that to understand any single component one needs to locate it within its social context and see how it functions within that setting. The system is formed and guided by the interrelationships between the components (Freidson, 1970). Such a holistic approach is required to understand the influences affecting access to HIV care for migrant Africans in Britain.

2.4.2 Access to HIV services and African communities in Britain

For an individual to consider accessing HIV care, they first need to appreciate either a transmission risk or a change in health status. It is not yet known how the non-specific symptoms of HIV are perceived, recognised or related to decisions to seek help among Africans in Britain. For Africans in the UK negotiating a pathway to sexual health services can be a complex process involving a lay referral system of friends and social kin (Chinouya, 2001).

Risk (perception) awareness is likely to differ according to home-country experience. For example, the perceived or actual ability to modify risk of HIV

transmission/exposure or outcome following diagnosis will be influenced by, amongst other things, gender politics and accessibility of ART in their countries of origin. For many Africans it is likely that the perception of modifying either HIV risk or outcome is extremely low. Studies have demonstrated that a substantial proportion of London's population remain unaware of many of the benefits of testing in terms of pregnancy or the availability of medicines to treat HIV (Burns et al., 2004b; Ndofor-Tah et al., 2000). A lack of perceived risk of HIV, or lack of perceived benefit in knowledge of HIV status and potential interventions, may contribute to poor accessing of HIV care in Britain. It may also reflect 'structural forces' whereby the degree to which patients are able to access services is significantly limited by forces quite beyond their control (Farmer, 1997). These structural and social forces include poverty, gender and economic inequality, political violence, racism and institutional barriers.

2.4.3 Institutional barriers

One such institutional barrier may be confusion over eligibility for NHS care. Currently the Department of Health has different criteria for entitlement to primary and secondary care. Whilst any person living here lawfully and on a settled basis is regarded as resident in the UK and therefore entitled to free primary medical services, hospital care is provided free only to people who fulfill certain criteria. Persons who are intending to seek asylum or refugee status within the UK but who have not yet submitted an application to the Home Office are not eligible for NHS treatment; nor are illegal immigrants, or visitors and students (on a course less than six months) from countries without a reciprocal agreement. No African country has a reciprocal agreement entitling its citizens to free NHS treatment (Department of Health, 2004a). Exceptions, in which free care is available to all, are: treatment given only in an accident & emergency department; treatment for certain infectious diseases (excluding HIV/AIDS

where it is only the first diagnosis and connected counselling sessions that are free of charge); compulsory psychiatric treatment; and family planning services (Department of Health, 2004a). To add to the complexity there are proposals to exclude overseas visitors from eligibility to free NHS primary medical service (Department of Health, 2004b), designed to align primary care with hospital care.

The Venereal Diseases (VD) regulations (NHS Venereal Diseases Regulations 1974, NHS Trusts (Venereal Diseases) Directions 1991, and NHS Trusts & Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000) however guarantee any individual anonymous free open access medical services for the management of STIs; HIV testing is also freely available to all (Department of Health, 2000). Different GUM clinics interpret the Venereal Disease regulations differently. As HIV treatment prescribing is often done under the auspices of GUM clinics, and patients can remain anonymous, there may be no way of checking eligibility to HIV treatment and many clinics choose not to ask about eligibility. However, if patients are admitted or referred to hospital services they may be expected to pay. In summary, all individuals within the UK are entitled to free HIV testing, but HIV treatment may only be available to eligible individuals.

Research suggests that the quality of consultation is less adequate for ethnic minority people than that for white people (Burns et al., 2004a; Nazroo, 1997). Whilst patients intention to test, or uptake if offered an HIV test, did not vary according to ethnicity in a previous study it was demonstrated that non-white patients were less likely to be offered an HIV test during a GUM clinic consultation (Burns et al., 2004a). Factors that may contribute to the disparity include the clinician's perception of the patient's health issues, prejudice (both on a personal and institutional level), language barriers, and time constraints of staff.

The length of residence in Britain will influence the above factors. It is likely that increasing time in Britain correlates with increased knowledge of the health services and how to access them, however this may be offset by heightened awareness of HIV and its treatment options in more recent migrants.

2.4.4 Education and social exclusion

Despite having higher education levels relative to the indigenous population (Fakhouri et al., 1996), migrant Africans in the UK experience high levels of social and economic deprivation with high unemployment and poor housing (Mason 2000) (UK Government, 1992). Financial, housing or childcare issues may take precedence over accessing health care (Anderson & Doyal, 2004).

The immigration process is one of the first exposures many migrant Africans have to UK government agencies. This process can take years and may be perceived as hostile, racist and disempowering to the communities involved. The increase in in-migration, and asylum seeking in particular, has met with hostility from sections of the general public and tabloid press (Browne, 2003). The hostility expressed in public discourse has been mirrored in the politicisation of the immigration issue; immigration has become a politically sensitive topic and was one of the key general election issues in Britain in 2005. The tightening of measures in the asylum decision-making process meant that 83% of initial asylum decisions in 2003 were refusals (National Statistics, 2004). The hostility the lay public, some sectors of the media, and the home office currently feel towards immigrants as a whole, and those who require state support in particular, may make people unwilling to come forward for diagnosis and treatment.

2.4.5 Heterosexual issues

Addressing the issues of a predominantly heterosexual epidemic are complicated by the fact that much of the sexual liaisons responsible for HIV transmission are occurring within the context of marriage, a climate of gender inequality, and are underpinned by reproductive drive. Perceptions of HIV risk may be influenced by marriage, an institution associated with expectations of trust and monogamy. Condom use, as a safer sex measure, may only be considered necessary in the early stages of relationships or for unmarried people; use also lessens when there is a desire to conceive (Elam, Fenton, Johnson, Nazroo, & Ritchie, 1998). Gender inequalities can influence the uptake of safer sex measures, such as condoms, and the accessing of HIV testing opportunities, decisions both often controlled by men (Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001; Chinouya, Ssanyu-Sseruma, & Kwok, 2003). Similarly the fear of rejection, violence, or both may dissuade women from HIV testing or in disclosing their HIV status to partners (Maman et al., 2001; Gielen, O'Campo, Faden, & Eke, 1997; Anderson et al., 2004).

HIV testing programmes need to account not only for transmission risk between partners but also that associated with mother-to child, or vertical, transmission. The efficacy of zidovudine in reducing vertical transmission by two thirds (in the absence of breast feeding), was established by the multicentre AIDS clinical trials group 076 in 1994 (Connor et al., 1994); and universal antenatal HIV testing was introduced in the UK in 1999 (NHS Executive, 1999). Whilst largely successful in helping to reduce the undiagnosed fraction of HIV infection among African women attending these services (The UK Collaborative Group for HIV and STI Surveillance, 2004), its effectiveness in reducing undiagnosed HIV within the wider community has not been assessed.

2.4.6 Stigma

HIV is greatly stigmatised in African communities (Goldin, 1994; Dodds et al., 2004; Anderson et al., 2004). Stigma can be viewed as an attribute that makes an individual both different and less desirable, than others (Goffman, 1963). In effect, stigma reduces in our minds a whole person to a tainted and discounted one. This attitude or belief is not always imposed upon the stigmatised individual; they themselves may hold the same beliefs about identity. Individuals with a 'spoiled identity' may seek to avoid the consequences of others reactions by trying to conceal their stigmatising condition – thus perpetuating an illusion of normality whilst simultaneously compounding their sense of social isolation (Goffman, 1963).

Stigma however is not merely an act of exclusion between individuals it also a process with social, economic and political functions which serve to maintain power inequalities (Parker & Aggleton, 2003). HIV-related stigma is heavily related to other forms of discrimination such as racism, sexism, homophobia and xenophobia (de Bruyn, 2002; Dodds et al., 2004); compounding the vulnerability of the individual and the communities involved. These power inequalities in turn augment the HIV epidemic. For example, one-reason women are more vulnerable to HIV is that as they are often unable to protect themselves because of cultural norms in the negotiation of sex; similarly the negotiation of health care by migrants may be impeded due to laws and policies. The stigma and discrimination associated with HIV make people reluctant to test for the infection; and those with diagnosed HIV infection may be reluctant to access services due to real or anticipated prejudicial behaviour from healthcare providers (de Bruyn, 2002).

Fear of discrimination has a profound effect on people with HIV even if only a minority of the population acts on its prejudices (de Bruyn, 2002). HIV education campaigns

directed at specific populations are unlikely to be supported by the target population because of the adverse reaction they expect from others (Terrence Higgins Trust, 2001).

Exactly why HIV remains so stigmatised in African communities is not fully understood, but may in part reflect the continuing poor prognosis of HIV in much of Africa due to lack of widely available affordable and effective treatment options. For many Africans there is a stigmatising and immediate connection between HIV/AIDS and death. This can manifest in a ritualised 'social death' for those who choose to disclose their HIV diagnosis (Dodds et al., 2004).

It is in the social context of this perceived racism, secrecy, financial and economic insecurity and uncertainty over immigration status that many migrant Africans have to consider HIV (McMunn, Mwanje, & Pozniak, 1997).

2.4.7 Mistrust

Historically medical science/ public health was often used as a means for social control in Africa (Comaroff & Comaroff, 1992). More recent experiments such as the Tuskegee Syphilis Study in the USA would further erode any faith in western biomedicine (Kampmeier, 1972). Distrust of the medical profession by the black community is evident in the conspiracy views expressed by many (Klonoff & Landrine, 1999). The origin of HIV/AIDS is perceived by some to be a man made virus developed to wipe out black people, others express a belief that they are being experimented upon with HAART, whilst others believe they receive either inferior or detrimental care (Erwin & Peters, 1999; Klonoff et al., 1999). The medicalisation of sex inherent in HIV prevention could be seen as an expression of 'internal colonialism' (O'Neil, 1986). Rejection of HIV care in this circumstance becomes a political act, a gesture of rebellion.

The mistrust of the 'professional sector' may mean the 'folk sector' is utilised in preference or in addition to biomedicine. Traditional therapies are widely used in Africa (Njanji, 1999) although their influence within the UK has not been studied. Utilising traditional forms of health care is also a means of retaining a sense of cultural identity for displaced communities.

2.4.8 Religion

Faith and traditional sacred beliefs are important to many Africans (Tiendrebeogo & Buykx, 2004). In the 2001 census, 68.8% of black Africans identified as Christian and 20% as Muslim (Department of National Statistics, 2003). Religious faith appears especially important for Africans, in particular African women, living with diagnosed HIV infection (Anderson et al., 2004; Chinouya & Davidson, 2003). The interaction between faith, health and HIV can manifest itself in different ways: for most the church provides a means of spiritual, emotional and practical support; for a few the direct healing potential of religious faith is important; whilst for others the church is a place where an HIV identity can be forgotten (Chinouya et al., 2003; Erwin et al., 1999; Anderson et al., 2004). HIV is apparently almost never discussed at church (Chinouya et al., 2003; Erwin et al., 1999; Anderson et al., 2004).

The more evangelical sects have been known to actively discourage people from taking antiretroviral medication, preaching that faith alone could cure HIV (Anderson et al., 2004; Erwin et al., 1999); the need for medication being a reflection of inadequate prayer or belief. The extent of these beliefs and impact on adherence to medication is not yet known.

The issues of sexuality, gender and HIV/AIDS have often found themselves juxtaposed to those of diametrically opposed religious doctrines and morality (Tiendrebeogo et al.,

2004). For example condom promotion has faced considerable opposition from certain religious groups who are unable to disentangle HIV prevention from family planning; Historical religious interpretations of leprosy or skin-diseases as the entry of evil spirits, have reinforced the stigma and discrimination attached to HIV, which often manifests itself with skin complaints (Tiendrebeogo et al., 2004); And religious leaders have also expressed judgemental attitudes toward people living with HIV, with HIV considered a 'curse from God' for sins such as homosexuality or promiscuity. In these ways religion may have contributed to the stigmatisation of HIV (Tiendrebeogo et al., 2004). Despite this people with HIV obviously seek solace in their personal faith and there is increasing acknowledgement of the role the church/mosque could play in facilitating an environment of acceptance and understanding for people with HIV.

The influence of religion will differ widely between communities however it is important to be aware of its integral role within the healthcare system.

2.4.9 Dispersal

Government implementation of asylum seeker dispersal (see 2.1.2 Internal migration above)(UK Parliament, 2002) may impact on HIV presentation and prevention measures. By moving people outside of their communities, access to quality, culturally appropriate health promotion activities and services may be compromised. There is the potential to isolate HIV positive Africans in centres less aware about HIV and without readily accessible specialist services, exacerbated by the fact that dispersal often occurs at short notice and without appropriate transfer of medical details (Creighton et al., 2004). Dispersal may further delay presentation and hence facilitate HIV spread (see 2.4.4 above).

Whether regional differences in clinical attitudes and knowledge of HIV infection exist has not been assessed. However one study with GPs in the north of England found that none of them were aware that antiretroviral medication could reduce vertical transmission of HIV (Kellock & Rogstad, 1998).

Currently very little information is known about the influence factors such as support of family and friends play in HIV presentation and accessing of services, especially within marginalized groups.

2.5 African communities & HIV testing

Despite advances in therapies and health promotion efforts Africans continue to present late to HIV services. Africans are more likely to have an AIDS defining illness within one month of diagnosis of their HIV infection compared with non-Africans (Burns et al., 2001); and 87% of AIDS diagnoses in black Africans are made within 3 months of HIV diagnosis (Sinka et al., 2003).

Erwin (1999), working with HIV positive Africans in London, found that Africans were reluctant to present themselves to health services until ill-health made it unavoidable due to fears around disclosure to immigration services, mistrust of the medical profession, and perceived discrimination (Erwin et al., 1999). Given the social context of the lives of many migrant Africans in Britain it is not surprising that this sentiment is expressed.

In many migrant communities and Britain generally, HIV testing is still viewed predominantly as a diagnostic rather than a screening/ prevention tool, which may inadvertently discourage people who view themselves as low risk to test earlier (Danziger, 1998). Little is known about HIV testing behaviours among migrant Africans. In 2000 a community-based survey of sexual attitudes and lifestyles among

746 Africans in London, found that 34% had ever tested for HIV. HIV testing was significantly associated with having previously been diagnosed with a sexually transmitted infections, and in men, perceived HIV risk (Fenton et al., 2002). This high proportion having ever had an HIV test suggests there is awareness of HIV within the black African community. However compared with non-Africans, Africans are more likely to HIV test because of a preceding event suggesting the possibility of HIV infection (Burns et al., 2001). This includes the development of AIDS or a positive diagnosis in a symptomatic child. Africans are also more likely to be diagnosed via antenatal screening.

Despite the apparent awareness of HIV as a health issue for their communities black Africans appear less likely to have suspected that they were HIV positive prior to diagnosis than non-Africans (Erwin, Morgan, Britten, Gray, & Peters, 2002; Anderson et al., 2004; Erwin et al., 1999); this may relate to perceptions that HIV is a disease of people with multiple partners and its association with profound ill health (Anderson et al., 2004). If Africans did suspect they may be HIV positive they were more likely to wait more than one year before testing (Erwin et al., 2002). Knowledge of where to test, concern over entitlement to care, discrimination and confidentiality were all identified as significant factors delaying access to services for people within the African community; 14% reported concerns about immigration and notification to the authorities (Erwin et al., 2002; Erwin et al., 1999). Whilst these fears create barriers to accessing services recent work suggests that once within the health care system HIV services are very highly rated by African patients and are regarded as safe environments (Anderson et al., 2004).

2.5.1 HIV testing: barrier to care?

In the pre-HAART era a diagnosis of HIV infection was often accompanied by stigma and discrimination, with very little to offer in the way of effective medication. Civil libertarians and gay rights advocates feared that HIV may become defined as a 'dangerous disease' with registries of infected persons, and the possibility of behavioural restrictions, and even quarantine, imposed on those infected (Bayer, 1991). There was broad consensus that people should only be tested with informed, voluntary and specific consent; this differs from other blood tests, which are usually obtained with the 'presumed consent' of the patient. As a result pre and post-test counselling usually accompany HIV testing. This process of managing HIV differently to other chronic and infectious health conditions became known as HIV exceptionalism (Bayer, 1991).

Because of the social, financial and medical implications of an HIV diagnosis the General Medical Council advises that pre-test discussion is necessary before performing an HIV test except in exceptional circumstances (General Medical Council, 1997).The Department of Health issued guidelines for the pre-test discussion on HIV testing in 1996 (Department of Health, 1996). Although the guidelines specified that HIV testing should be part of mainstream clinical care, they also stipulated that a health care worker (HCW) conducting pre-test discussion should:

> '… ensure they are aware of current developments in the management of HIV and AIDS. Health care workers who do not feel able to conduct pre-test discussion should refer the individual seeking an HIV test to another trained health care worker.'
>
> (Department of Health, 1996)

In the guidelines this paragraph was followed by a list of publications that would facilitate training in pre-test discussion, hence creating an assumption that to offer an HIV test a health care worker should be specifically trained.

The guidelines identify five main components of the pre-test discussion:

1. Ensuring the individual understands the natures of HIV infection (including difference between HIV and AIDS); provision of information about HIV transmission and risk reduction (including the modes of transmission, methods to reduce risk, and written material available to support risk reduction).
2. Personalised discussion of risk activities, including date of last risk activity and perception of need for test.
3. Discussion of the pros and cons to the individual, their family and associates of having a test and knowing the result.
4. Provision of details about the test and how the result will be provided.
5. Obtaining an informed decision about whether or not to proceed with the test.

The exception to this practice of detailed pre-test discussion is HIV testing that occurs as part of the screening of all blood donations. In recognition of the time constraints involved only written information is made available. The risk assessment and the need for a test (stage 2 above) occurs when potential donors are sent information to allow them to exclude themselves if they fall within several higher risk categories; written information on HIV/AIDS is provided in the form of a leaflet; and stages 4 and 5 (test details and informed consent) are established by asking potential donors if they have read and understood the leaflet (Department of Health, 1996).

The average time for pre-test voluntary counselling in the UK in the early 1990's was 21 minutes, with 18% of people requiring two visits (Department of Health, 1996). To have the time and knowledge to address all the specified components of a pre-test discussion a health care worker would probably need to be specifically working in the field of HIV. In the 1980s and 1990s the majority of HIV care in the UK, including

counselling and testing, was restricted to specialist settings with general practitioners (GP's) typically not involved nor often notified of the diagnosis.

This emphasis on voluntary counselling and testing (VCT) may in itself be a barrier to HIV testing. Outside of antenatal HIV testing, HIV testing in Britain predominantly occurs within genitourinary medicine (GUM) clinic settings (Rogstad, 2004; Department of Health, 1996). A study with GPs following attendance at a STI study day found that there was significant anxiety associated with broaching the subject of HIV testing. The anxiety was significantly more pronounced when the GP was asked to consider HIV testing to an at-risk heterosexual compared to homosexual men or intravenous drug users. The GPs were also likely to actively discourage testing in individuals they considered low risk. Only 14.6% (7/48) of the GPs would 'usually discuss' HIV testing with at-risk heterosexuals, and the majority were reluctant to offer an HIV test themselves and preferred instead to recommend attendance at a sexual health clinic (Kellock et al., 1998). Qualitative research with GPs is required to establish whether these findings are associated with the emphasis on VCT.

Even within GUM clinics the principal barrier to HIV testing was identified as lack of time, especially of health advisors (British Co-operative Clinical Group, 2000). Whilst not specifically mentioning VCT as a barrier the majority of clinics used health advisors to conduct the pre-test counselling for 75-100% of patients having an HIV test.

Clinicians, including GPs, often request investigations that have social, financial and medical implications, for example X-rays to diagnose lung cancer or sputum analysis for tuberculosis. Similarly all clinicians are trained in delivering bad news. Admittedly HIV/AIDS is a relatively new infectious disease and many older clinicians may not have received formal training on this condition at medical school, however the focus of

extensive pre-test discussion may be contributing to the anxiety the GPs expressed when asked to consider discussing HIV with patients.

For most other disease processes, including chronic and terminal illnesses, clinicians would try to establish a diagnosis first and then refer to specialist services. It is inevitable that the process of onward referral creates a barrier to HIV testing. Referral to a GUM clinic may be a particular barrier for African communities given the stigma associated with HIV, the barriers to accessing services generally inherent for migrant communities, and the fact that GUM clinics are an unfamiliar service to most Africans.

In African communities within Britain HIV remains highly stigmatised (Goldin, 1994; Dodds et al., 2004; Anderson et al., 2004). Fear of stigma and discrimination has been identified as a barrier to Africans presenting for an HIV test (Erwin et al., 2002). Stigma also acts by creating a sense of 'otherness' (Busza, 1999), that is only certain types of people get certain conditions. Erwin identified that Africans in particular may not identify as being at risk of HIV (Erwin et al., 2002). In a national survey on HIV testing in GUM clinics the majority of patients at high-risk of HIV actually requested an HIV test, the exception to this were heterosexuals from sub-Saharan Africa (British Co-operative Clinical Group, 2000). In this context it becomes more important that health care professionals ensure institutional barriers to the accessing of HIV testing and care are kept to a bare minimum. Normalisation of HIV testing is one means by which this issue can begin to be addressed.

2.5.2 Normalisation of HIV

HIV exceptionalism arose largely because of fears about stigmatisation and discrimination in an era when diagnosis of HIV had little impact on prognosis. The activism that led to its exceptional status can also be credited with encouraging greater

respect for autonomy, informed consent, and confidentiality within medical establishments (De Cock & Johnson, 1998).

Normalisation refers to the process of treating HIV more like other infectious diseases for which early diagnosis is essential for appropriate therapeutic and preventive measures (De Cock et al., 1998). It encapsulates the notion that all doctors should be confident and competent at HIV testing and diagnosis. It should still incorporate the need for confidentiality and informed consent.

The national strategy for sexual health and HIV (Department of Health, 2001) set specific targets to improve HIV testing uptake and reduce undiagnosed HIV infection. 'By the end of 2004 all GUM clinic attendees should be offered an HIV test' with a view to increasing uptake of the test to 40% (70% by 2007), and reducing by 50% the number of previously undiagnosed HIV infected people attending GUM clinics by 2007 (Department of Health, 2001). The strategy also draws attention to health inequalities noting that sexual ill health is not equally distributed among the population and black and minority ethnic groups are acknowledged as bearing some of the highest burdens of sexual ill health and HIV in particular. Similarly it highlights that service provision, including HIV prevention services, is inequitable across the country. New models of working are envisaged which increase the role of GPs. HIV testing and counselling is considered a level one service that should be available through primary care. The strategy does not stipulate how these changes are to be achieved and no financial incentives to ensure they occur are provided. However the strategy does mark an important cultural shift towards normalising the provision of HIV testing.

An audit at the Mortimer Market Centre, a large central London sexual health clinic, in 2001 showed that, despite a universal offering policy, only 47% of new attendees had an HIV test (Arthur, Burns, Mercer, & Mercey, 2002). Since then this clinic has

attempted to further normalise the process of HIV testing. A pre test discussion still occurs but there has been a move away from in-depth counselling. In a more recent audit at the same clinic, 98% of 2368 new attendees over a three-month period were offered an HIV test (Arthur, 2005). Every one of these patients was made explicitly aware of HIV testing. Patients identified as high-risk were offered detailed VCT however this was not a prerequisite for testing. 77% of all patients had a HIV test. These results occurred in the context of a busy GUM service where most appointment slots are for 15 minutes.

Unsurprisingly a direct offer of an HIV test significantly increases uptake of HIV testing. However the method by which this offer is delivered, be it minimal or comprehensive discussion about all blood tests, or minimal or comprehensive HIV specific discussion, does not appear to influence uptake of the test or the anxiety associated with the test, at least in the antenatal setting (Simpson et al., 1998). HIV specific knowledge was significantly increased followed comprehensive discussion.

Universal offering of HIV testing, sometimes referred to as an opt-out policy, should now be routine practice in most GUM clinics and antenatal settings (NHS Executive, 1999; Department of Health, 2001). Compulsory HIV testing also occurs with all blood donations. These policies represent significant progress in 'normalising' HIV testing within these particular services. The benefits of these changes however are limited to those individuals who access these specialist services. Whilst we know that the majority of Africans in the UK are registered with a GP (McMunn, Mwanje, Paine, & Pozniak, 1998), the proportion of the UK African population who access GUM services is not currently known. Most Africans would not be eligible for blood donation as they are identified as a higher risk population (NHS Blood and Transplant, 2009). It remains to

be seen if the national strategy for sexual health and HIV is able to motivate change in primary care services towards HIV testing.

2.6 Conclusion

The findings of this literature review reflect the complex interplay of factors influencing HIV testing. Migrant Africans are comprised of diverse and possibly fragmented populations. Whilst the interplay of external and internal factors, that determines health and health-seeking behaviour, operates for all migrant Africans the weight of various issues will be influenced by personal circumstances.

In order to tackle the problems of HIV for migrant Africans, it is necessary to address both the internal and external factors influencing health care access, be they social, political or cultural. The complexity of the forces and interrelationships impacting on the 'healthcare system' means time; financial commitment; and a multi-sectorial approach will be necessary. The Social Exclusion Unit, designed to use joined-up-government to tackle social problems (Social Exclusion Unit, 1999), may provide a suitable starting point for initiating non-health care sector, holistic systems modification.

Efforts aimed at reducing undiagnosed HIV infection through the promotion of HIV testing remain a key component of primary and secondary HIV prevention strategies. Currently HIV testing, which effectively is the gateway to accessing HIV services, resides almost exclusively within the domain of the specialist professional sector. Adopting more innovative approaches to testing that encourage overlap with the popular and folk sectors may improve acceptability and help reduce the stigma attached to HIV. This could include adoption of community-based voluntary counselling and testing like that successfully implemented in Kenya (The Voluntary HIV Counselling and Testing

Efficacy Study Group, 2000). In this model lay people are trained as counsellors and rapid HIV assays are performed in community settings. In so doing accessing HIV services may gain the implicit approval of the milieu in which it is placed.

Chapter 3:HIV testing among Africans in Britain

Abstract

Objective: To describe the factors associated with HIV testing amongst heterosexual black Africans aged 16-44 years living in Britain.

Design: Data from the main and ethnic minority boost samples of the second British National Survey of Sexual Attitudes and Lifestyles (Natsal 2000), a stratified national probability sample survey conducted between 1999-2001, were analysed. Multivariate analysis was performed using complex survey functions to account for the clustered, stratified and differential selection probabilities inherent within the survey.

Results: A total of 385 (216 women and 169 men) black African respondents were included in the study. 44.0% women and 36.4% men reported ever having had an HIV test. In univariate analysis, HIV testing was associated with being born abroad (OR 3.63), having a new partner(s) from abroad in past five years (OR 2.88), and attending a GUM clinic (OR 3.27), among men; and higher educational attainment (OR 3.50), perception of 'not very much' personal risk of HIV (OR 2.75), and attending a GUM clinic (OR 2.91) among women. After adjusting for potential confounders, an increased likelihood of HIV testing was associated with being in the UK less than 5 years relative to being UK born (adj. OR 9.49), and ever attending a GUM clinic (adj. OR 5.53), for men; and educational attainment (adj. OR 4.13), and low perception of HIV risk (adj. OR 2.77) for women.

Conclusions: Black Africans appear to have relatively high rates of HIV testing compared to the general UK population reflecting, at least partially, awareness of risk behaviours and potential exposure to HIV. Nevertheless, there remains substantial potential for health gain and innovative approaches are required to further increase timely HIV testing.

The findings within this chapter are published in: *Sexually Transmitted Infections (2005)*; Factors associated with HIV testing amongst black Africans in Britain. F. Burns *et al*., v.81:pp 494-500.

3.0 Introduction

Reducing the level of undiagnosed HIV infection through the promotion of HIV testing is an important component of primary and secondary HIV prevention strategies (Department of Health, 2001). To date, there have been no population-based studies of HIV testing behaviours of black Africans in Britain.

The first national probability sample survey of sexual attitudes and lifestyles (Natsal) conducted in 1990/91 was designed to identify demographic and sexual behaviour characteristics that would help with understanding the reproductive and sexual health needs, as well as transmission patterns of HIV and other STIs, in Britain (Johnson, Wadsworth, Wellings, & Field, 1994). The second national survey of sexual attitudes and lifestyles (Natsal 2000) was designed to examine the changes over time and provide up-to-date estimates of sexual behaviour in Britain, as well as provide a boost sample of people from four ethnic minority groups (black Caribbean, black African, Indian and Pakistani) to allow exploration of ethnic variations in behavioural risk and outcomes.

This chapter explores uptake of HIV testing by black Africans in Britain.

3.0.1 Aims and objectives

To describe the factors associated with HIV testing among heterosexual Africans aged 16-44 years living in Britain. Specific objectives were to:

1. Describe the socio-demographic and sexual behavioural risk factors, and health service utilisation history associated with HIV testing among Africans in Natsal 2000
2. Determine the factors associated with the uptake of HIV testing.
3. Describe the association between reason for having an HIV test and where tested among Africans.

3.1 Methods

3.1.1 Natsal 2000

Data for this study came from the Natsal 2000 survey. Natsal 2000 is a stratified probability sample survey of sexual attitudes and lifestyles among 11,161 British

residents aged 16-44 years undertaken between 1999 and 2001. In order to increase the number of respondents from Britain's largest ethnic minorities further sampling of 949 black African, black Caribbean, Pakistani and Indian adults were interviewed as part of the ethnic minority boost (EMB) sample over a 9-month period at the end of the main survey.

The project was funded by the Medical Research Council and the Department of Health, and run collaboratively between the London School of Hygiene and Tropical Medicine, the National Centre for Social Research, and the Royal Free and University College Medical School.[7]

3.1.2 Sampling frame

The core sample involved a multi-stage stratified probability design. Postcode sectors were selected as the primary sampling units (PSUs). Prior to selection PSUs with fewer than a 1000 addresses were combined with neighbouring sectors to avoid tight clustering of sampling addresses. Using data from the 1991 census the PSUs were also stratified according to region, population density, age of population, and socio-economic status. 466 sectors were then selected systematically. The second stage involved selection of addresses within the PSUs from the small user postcode address file (PAF), and finally one eligible adult was randomly selected. Addresses in London were over-sampled as Natsal showed the prevalence of many HIV risk behaviours, such as homosexuality and intravenous drug, was higher in London than elsewhere in Britain.(Erens et al., 2001)

The 'boost' sampling frame was also multi-stage and very similar to the core sample. The first stage involved randomly selecting postcode sectors; secondly, addresses within

[7] Ethical approval for Natsal 2000 was obtained from the North Thames Region Multicentre Research Ethics Committee and local research ethics committees throughout Britain.

these sectors were randomly selected using the PAF; and thirdly, one adult was randomly selected. Prior to selection of PSUs for the boost sample, all postcode sectors were assigned to one of three strata based on the proportion of residents of ethnic minority origin determined by 1991 census data. The number of sectors selected for the boost sample, and the screening method, varied by stratum. In the stratum with highest density (>12%) 72 sectors were selected and full household screening occurred. Interviewers contacted every address to determine whether there were eligible residents. In the second stratum 78 sectors were selected and focused enumeration was used to screen and identify eligible residents. Focused enumeration is a cost-effective method for screening large numbers of addresses; sampled addresses were asked to identify members of ethnic minority groups in adjacent addresses, if any adjacent addresses were identified as including residents of the relevant ethnic groups the interviewers also visited those properties. Respondents living in the stratum of lowest density (<6%) were obtained in the main Natsal 2000 sample. Only addresses with at least one adult from the target ethnic minority groups were eligible for inclusion in the survey (Erens et al., 2001).

To obtain the total ethnic minority sample respondents from eligible groups identified in the core sample were included with those from the boost sample.

3.1.3 Data collection

A combination of interviewer administered computer-assisted personal interviews (CAPI), and self-completed computer-assisted self-interviews (CASI) were conducted. All respondents undertook the CAPI but only those meeting certain criteria were offered the CASI. People with no sexual experience of any kind, and 16 to 17 year olds with no heterosexual intercourse or homosexual experience, were not eligible for the CASI module. The CASI component allowed respondents to key in responses to more

sensitive questions directly on to a laptop computer. The questionnaire used for the ethnic minority boost sample was the same as that for the general population sample, with additional questions on country of origin and languages spoken. Questionnaires were available in Urdu and Punjabi for the boost sample, and trained interviewers fluent in these languages as well as English were used. Chlamydia-testing was excluded from the EMB component (Erens et al., 2001).

3.1.4 Present Study

Inclusion in the current study was limited to heterosexual Africans. For the purposes of this study black African was defined by self-classification as black or mixed ethnic group with a black African cultural background. A heterosexual was defined as any person who had ever had heterosexual intercourse and had no homosexual experience in the past five years. The study was limited to heterosexuals as people with homosexual or bisexual experience were likely to differ in terms of sexual attitudes, practices and awareness from those who were solely heterosexual. The small numbers of bisexual and homosexual Africans prevented separate analysis for these groups. People who had never had sexual intercourse were excluded, as it was unlikely that they would be testing for HIV infection.

3.1.5 Data Preparation and software

The Natsal 2000 investigators performed initial data editing, coding and consistency checks. Further checking was performed following reduction of the full data set to those meeting the eligibility criteria for this study. All the analysis for this study was conducted by myself and performed using STATA 8.0.

3.1.5.1 Rationale for using specialist survey commands

Survey commands were used in all analyses unless otherwise specified to account for the clustered, stratified and differential selection probabilities inherent within the Natsal 2000 design. For example, individuals in the same strata, or cluster, are more likely to be similar to each other than to individuals in other clusters, resulting in inaccurate estimates of effect if not accounted for. Thus stratification and over-sampling in the study design need to be incorporated into all analysis. Individuals in single-occupancy dwellings were more likely to be selected than those in multi-occupancy dwellings, those living in London were more likely to be sampled compared to the rest of Britain, and the probability of selection into the boost sample depended on the proportion of residents of ethnic minority origin in both the household and strata. To adjust for these differential selection probabilities both within and between the core and ethnic boost, the data was weighted proportional to the number of eligible residents per household, the number of eligible ethnic minority adults by household and strata, and by region. Finally to correct for differences in gender, age group and government office region between the achieved sample and population estimates, a non-response/post-stratification weight was applied. Weighting thus helps ensure the sample is broadly representative of Africans living in standard residential type accommodation in Britain.[8]

3.1.6 Data Analysis Strategy

The conceptual framework for analysis used 'ever had an HIV test' as the outcome of interest. The outcome excluded those people who had a test for HIV as part of blood donation. This was to ensure HIV testing was part of an active decision making process

[8] The weighting was set by the National Centre for Social Research.

as many people donating blood are unaware that HIV tests are conducted routinely on all blood donations.

The choice of explanatory variables was limited by the Natsal 2000 data set. For example accessing of general practitioner (GP) care would have been included if such information had been collected in the Natsal 2000 survey. The explanatory variables were grouped into distal (socio-demographics) and more immediate factors (indicators of sexual risk and general health). The more distal factors may affect more immediate factors but also may affect HIV testing independently.

3.1.6.1 Data editing and reduction

Individuals with missing data for HIV testing were excluded from analysis. All other unavailable data was coded as missing. Data on HIV testing was not available for 10 (3.6%) African men and 20 (10.4%) African women. Missing data for the explanatory variables was less than 3% in all cases except concurrency, which was 10% for men and 7% for women.

Continuous variables such as age were categorised into groups that would have statistical efficacy whilst maintaining relevance. Similarly explanatory variables were re-categorised if numbers were too small for analysis and merger of categories was not felt to lead to loss of information. The binary measure of perception of health was dropped as insufficient numbers of respondents perceived their health as poor (5 men and 6 women).

3.1.6.2 Statistical analysis

As gender differences in sexual practices, awareness and attitudes were likely to exist, men and women were analysed separately. Univariate analysis was conducted by weighted cross-tabulations and calculating the odds ratio (OR). Chi-squared tests of

association and corresponding p values were calculated to give a measure of the strength of association unless numbers were small, when Fisher's exact test was used.

As the analysis took into account clustering and weighting, classical methods and maximum likelihood theory were unable to be used. Logistic regression was used for both univariate and multivariate analysis to obtain crude and adjusted odds ratios (AOR). Significance was determined using Wald and adjusted Wald tests. A significance level of 0.05 was used, although those below 0.1 (in either the male or female analysis) were retained for multivariate analysis.

All the variables in the distal determinant group that satisfied inclusion criteria were fitted into a multivariate logistic model. Backward elimination was used to exclude variables not contributing significantly to the model ($p>0.1$) or altering the OR for variables already in the model. For the final model the more immediate factors were added to the model with backward elimination at each stage being used to obtain the most parsimonious model. The more immediate factors were added in a step-wise fashion with those related to high risk sexual practices added first, followed by perception of HIV risk, GUM clinic attendance, health care and finally health perception (see Figure 3.1 below).

Figure 3.1 Schematic representation of derivation of final multivariate model

Distal determinants → Model 1

Model 1 + high risk sexual practices → Model 2

Model 2 + perception of HIV risk → Model 3

Model 3 + GUM clinic attendance → Model 4

Model 4 + health care use → Model 5

Model 5 + health perception → Model 6=final model.

3.1.7 Confounders and effect modifiers

Age was assumed to be an *a priori* confounder and was retained in the model regardless of significance levels. All other variables were treated as potential confounders and mediators. At each stage of analysis it was assessed whether the OR for the distal determinants changed, which would imply the new variables were acting as mediators. If the OR for the newly added variables changed, either from the crude OR or when added to the model, this would suggest confounding by the variables already in the model. Effect modification was investigated once the final model had been determined. To ensure adequate numbers for statistical purposes each parameter in the final model was recoded into a binary variable. Possible interactions were tested using adjusted Wald tests.

3.2 Results

One hundred and sixty nine heterosexual black African men and 216 black African women were interviewed for Natsal 2000. The majority of respondents came from former British colonies (table 3.1), especially Nigeria (35%) and Ghana (22%).

Table 3.1 Country of origin of study respondents

Country of origin	n	%
Nigeria	134	34.8
Ghana	84	21.8
Somalia	15	3.9
Uganda	14	3.6
Zimbabwe	13	3.4
Kenya	9	2.3
South Africa	8	2.1
Sierra Leone	8	2.1
Other/not answered	100	26.0

Table 3.2 summarises the demographic and behavioural characteristics of respondents. There were significant differences in the socio-demographic characteristics of men and women. Women tended to be older, less likely to have higher education, of lower social class[9], and more likely to be married or previously married, than men. Men were more likely to report high-risk sexual practices (number of partners in past five years, new partner from abroad in past five years, early age at first sex, and concurrent partnerships in past five years) than women. Approximately 17.5% of men and women had ever being diagnosed with a sexually transmitted infection, and 23.6% of men and 17.9% (p=0.36) of women reported ever attending a GUM clinic. Self-perception of HIV risk differed (p=0.10) between men and women. 71.0% of women perceived themselves at no risk of HIV compared to 48.9% of men; and 8.5% of men and 7.6% of women perceived themselves at 'quite a lot' or 'great' risk of HIV. Men and women appeared equally likely to use tertiary NHS health services (other than antenatal services) in the previous year with 71.5% and 61.4% (p=0.184) using services respectively.

Overall, 36.4% (95%CI 26.5-47.6) black African men and 44.0%(95%CI 34.6-53.9) black African women reported having ever tested for HIV. Differences in the reasons for and site of HIV testing were observed by gender (p<0.001) (Table 3.3). 34.3% of men who tested had their last HIV test in a GUM clinic, and a further 25.8% in a GP surgery. The majority (54.6%) of men who tested had their last HIV test as part of a general health check-up. In contrast, 35.9% of women who tested listed 'elsewhere' as the site of their last HIV test. A further 22.7% tested at a GP surgery and 21.1% at family planning clinics (FPC). The majority of women (62.7%) tested due to pregnancy. Testing as part of a general health check-up tended to occur in GUM clinics (41.9%) for

[9] Registrar Generals grading system of social class: I professional/managerial, II managerial/technical, III skilled non-manual and manual, IV partly skilled, V unskilled. 'Unclassifiable' includes caring for home, military, in education, or not employed.

men, and in GP surgeries (39.6%) for women (data not shown). HIV testing for pregnancy occurred mainly 'elsewhere' for women possibly reflecting testing in antenatal clinics. 25.8% of pregnancy motivated tests apparently occurred in FPCs (data not shown).

Table 3.2 Characteristics of study respondents

Characteristic	Men (Base[1] 169UW 57WT) %	Women (Base[1] 216UW 54WT) %	p-value[2]
Age (years):			0.049
16-24	23.3 (15.4-33.6)	9.6 (6.4-15.2)	
25-34	35.5 (25.8-46.7)	43.6 (34.1-53.6)	
35-44	41.2 (30.7-52.5)	46.5	
Education:			0.006
Degree	50.0 (39.0-60.9)	31.3 (23.3-40.7)	
Higher education (<degree)	28.1 (19.8-38.2)	27.5 (20.9-35.3)	
GCSE/O-level/Other/none	21.9 (14.3-32.1)	41.2 (32.1-50.9)	
Social class			0.007
I or II	43.3 (32.5-54.8)	22.0 (15.6-30.0)	
III (manual or non-manual)	28.6 (21.1-37.5)	36.1 (28.0-45.1)	
IV or V	15.6 (9.3-25.0)	20.1 (14.1-27.9)	
Unclassified	12.5 (8.1-18.8)	21.8 (14.3-31.8)	
Index of multiple deprivation			0.446
1st -4th	35.9 (24.4-49.3)	41.6 (31.4-52.6)	
5th (most deprived)	64.1 (50.7-75.6)	58.4 (47.4-68.6)	
Marital status			0.007
Married	41.2 (30.5-52.7)	49.9 (39.8-60.1)	
Cohabiting	13.0 (6.5-24.3)	7.8 (4.4-13.4)	
Previously married	6.9 (3.8-12.2)	19.1 (12.4-28.2)	
Single, never married	38.9 (29.1-49.8)	23.3 (17.0-31.0)	
Religion			0.410
Christian – non RC	49.9 (39.2-60.7)	59.1 (49.7-67.9)	
Roman catholic	16.1 (9.2-26.7)	15.1 (10.6-21.0)	
Other /none	34.0 (24.8-44.5)	25.8 (17.5-36.3)	
Region of residence			0.081
Greater London	73.4 (62.5-82.0)	87.4 (76.1-93.8)	
Elsewhere in Britain	26.6 (18.0-37.6)	12.6 (6.2-23.9)	
Time spent in UK			0.826
Born in UK	27.4 (9.9-40.4)	26.0 (19.4-34.0)	
Born abroad	72.6 (62.6-80.8)	74.0 (66.0-80.6)	
Time in UK if migrant (years, median, range)	9.5 (0-37)	10.0 (0-35)	0.442
Region of birth			0.147
Europe	29.1 (20.7-39.1)	27.3 (20.4-35.4)	
Central/East Africa	17.9 (11.8-26.2)	29.2 (20.4-39.9)	
West Africa	44.6 (33.9-55.8)	39.9(31.2-35.3)	
Other	8.4 (3.4-19.4)	3.6 (1.7-7.5)	
Previous STI diagnosis	17.5 (11.3-26.1)	17.7 (11.0-27.4)	0.158
Sex[4] in past year without a condom			0.619
No	26.0 (18.0-36.2)	23.5 (16.6-32.2)	
Yes	63.9 (52.7-73.8)	61.3 (51.3-70.4)	
Not answered correctly	10.0 (4.6-20.7)	15.2 (8.1-26.7)	
Number of partners in past 5 yrs			<0.001
0-1	28.4 (19.9-38.8)	75.4 (66.3-82.7)	
2-5	48.0 (37.9-58.3)	22.6 (15.6-31.5)	
6+	23.6 (16.6-32.5)	2.1 (0.8-5.6)	
Median (range)	3 (0-130)	1 (0-11)	
New partner from abroad in past 5 years	37.9 (28.2-48.8)	6.4 (3.6-11.2)	<0.001

Table 3.1 continued

Characteristic	Men (Base[1] 169UW 57WT) %	Women (Base[1] 216UW 54WT) %	p-value[2]
Age at first sex[3] (years)			<0.001
16+	67.5 (57.0-76.5)	88.3 (81.1-92.9)	
<16	32.5 (23.5-43.0)	11.7 (7.1-18.9)	
Ever paid for sex[3]	14.9 (9.7-22.2)	NA	---
Had concurrent partnerships in past five years	35.6 (24.8-48.1)	7.0 (4.1-11.7)	<0.001
Perception of HIV risk for self			0.010
Not at all	48.9 (37.6-60.4)	71.0 (62.6-78.2)	
Not very much	42.5 (31.5-54.4)	23.6 (16.9-31.9)	
Quite a lot or Great	8.5 (4.1-16.8)	5.4 (3.0-9.6)	
Ever attended GUM clinic	23.6 (15.8-33.6)	17.9 (11.8-26.3)	0.360
Antenatal care (past 5 yrs)	NA	57.5 (48.3-66.2)	---
User of tertiary NHS services[4]	71.5 (60.0-80.7)	61.4 (52.2-69.9)	0.184
EVER HAD AN HIV TEST	36.4 (26.5-47.6)	44.0 (34.6-53.9)	0.303

[1] Base varies due to item non-response Wt =Weighted and UW= Unweighted Bases

[2] Comparing men and women

[3] Anal or vaginal intercourse

[4] In past year other than antenatal service

Table 3.3 Where and why had last HIV test; proportions by gender

Characteristic	Male %[1] *(Base 53UW, 20WT)*	Female %[1] *(Base 94UW, 21WT)*	p-Value
Where had last HIV test			0.076
GP surgery	25.8	22.7	
GUM clinic	34.3	17.0	
NHS Family planning clinic	11.1	21.1	
Privately	12.8	3.3	
Elsewhere	15.9	35.9	
Why had last HIV test			<0.001
Pregnancy related	14.0	62.7	
Part of insurance, travel or mortgage requirements	13.2	6.5	
Part of general health check	54.6	16.8	
Concerned about risk of HIV/AIDS to self or partner	4.6	9.6	
Other reason	13.7	4.4	

[1] Weighted percentages Wt =Weighted and UW= Unweighted Bases

Table 3.4 shows the frequency, odds ratio and adjusted odds ratio of factors associated with HIV testing. No significant associations were found between HIV testing and age, social class, index of multiple deprivation[10], marital status, religion, or region of residence. Among black African men, being born abroad was significantly associated with higher odds of HIV testing than UK born men (OR 3.63 95%CI 1.12-11.7) (data not shown). Men who had new partner(s) from abroad (including those who had sex in Britain with partners from abroad, and those who had sex abroad) in past five years were more likely to have tested for HIV than men who had not (OR 2.88 95%CI 1.03-8.05), as were men who reported attending a GUM clinic compared to men who did not (OR 3.27 95%CI 1.20-8.90). In multivariate analysis, time spent in the UK (men in UK five or more years adj. OR 5.10 95%CI 1.40-18.86; men in UK less than 5years adj. OR 9.49 95%CI 2.30-39.14) and attending a GUM clinic (AOR 5.53 95%CI 1.98-15.42) remained independently associated with higher odds of HIV testing in men. No evidence of any interactions was found in the final model.

In univariate analysis black African women with higher education but less than a degree were more likely to test for HIV than women with a degree (OR 3.50 95%CI 1.29-9.51) (Table 3.4). Women who perceived themselves at 'not very much' risk were more likely to have tested for HIV compared to women perceiving themselves at no risk (OR 2.75, 95% CI 1.06-7.13) and attending a GUM clinic meant women were more likely to have tested compared to those who had not attended (OR 2.91 95%CI 1.10-7.72). No high-risk sexual practices were significantly associated with HIV testing in women. Antenatal care in the past five years was not significantly associated with HIV testing (OR 1.25 95%CI 0.59-2.65).

[10] A ward level measure developed by the Department of Environment, Transport and the Regions, dependent on six factors: income, employment, health & disability, education, housing, and geographical area. The index consists of five levels, the higher the score the more deprived.

Table 3.4 The frequency and odds ratios (95% confidence limits) of factors associated with HIV testing in black African men & women.

	Men *(Base 159UW 55WT)*			Women *(Base 196UW 48WT)*		
	%	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**	**%**	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**
Age (years):		P=0.472	P=188		P=0.491	P=0.675
16-24	22.8 (8.3-49.2)	1.00	1.00	34.1 (16.4-57.7)	1.00	1.00
25-34	39.8 (22.5-60.1)	2.24 (0.49-10.26)	4.04 (0.90-18.08)	41.1 (27.1-56.6)	1.35 (0.43-4.26)	1.05 (0.32-3.47)
35-44	40.8 (25.1-58.7)	2.34 (0.58-9.36)	2.27 (0.57-9.08)	48.8 (35.7-62.2)	1.85 (0.61-5.55)	1.52 (0.44-5.20)
Education:		P=0.317			P=0.003	P=0.001
Degree	28.0 (15.1-46.0)	1.00		39.2 (22.5-58.9)	1.00	1.00
Higher education (<degree)	43.7 (27.5-61.3)	1.99 (0.68-5.84)		69.3 (53.3-81.7)	3.50 (1.29-9.51)	4.13 (1.43-11.88)
GCSE/O-level/Other/none	47.0 (26.8-68.2)	2.28 (0.69-7.53)		28.8 (17.5-43.4)	0.63 (0.22-1.78)	0.72 (0.27-1.93)
Social class		P=0.045			P=0.347	
I or II	27.7 (13.1-49.3)	1.00		37.3 (22.2-55.5)	1.00	
III (manual or non-manual)	51.5 (34.0-68.6)	2.77 (0.83-9.16)		55.7 (40.2-70.2)	2.11 (0.84-5.61)	
IV or V	56.9 (30.9-79.6)	3.45 (0.83-14.27)		40.7 (23.4-60.7)	1.15 (0.36-3.71)	
Unclassified	18.3 (7.7-37.7)	0.59 (0.15-2.31)		35.6 (17.2-59.5)	0.93 (0.28-3.04)	
Index of multiple deprivation		P=0.484			P=0.838	
1^{st} -4^{th}	30.9 (14.8-53.7)	1.00		42.8 (26.8-60.5)	1.00	
5^{th} (most deprived)	39.6 (28.3-52.2)	1.46 (0.50-4.29)		44.8 (34.8-55.2)	1.08 (0.50-2.32)	
Marital status		P=0.117			P=0.259	
Married	43.9 (27.2-62.1)	1.00		43.1 (28.9-58.6)	1.00	
Cohabiting	58.5 (24.7-85.9)	1.81 (0.36-9.10)		42.7 (18.2-71.5)	0.98 (0.28-3.44)	
Previously married	23.0 (9.0-47.3)	0.38 (0.10-1.44)		57.1 (40.8-72.0)	1.76 (0.75-4.12)	
Single, never married	22.7 (12.0-38.8)	0.38 (0.17-1.12)		35.1 (23.5-49.6)	0.73 (0.31-1.68)	
Religion		P=0.623			P=0.141	
Christian – non RC	31.6 (19.0-47.8)	1.00		44.1 (32.1-56.8)	1.00	
Roman catholic	48.9 (20.0-78.5)	2.07 (0.46-9.37)		61.7 (42.3-78.0)	2.04 (0.80-5.24)	
Other /none	37.5 (21.9-56.3)	1.30 (0.47-3.61)		32.7 (15.7-56.6)	0.62 (0.20-1.89)	
Region of residence		P=0.657			P=0.601	
Elsewhere in Britain	41.5 (16.9-71.3)	1.00		34.1 (8.1-75.2)	1.00	
Greater London	34.5 (25.4-45.0)	0.74 (0.20-2.80)		45.5 (36.3-55.1)	1.61 (0.26-9.84)	

	Men *(Base 159UW 55WT)*			Women *(Base 196UW 48WT)*		
	%	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**	**%**	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**
Time spent in UK		P=0.096	P=0.008		P=0.801	
Born in UK	17.5 (7.2-36.8)	1.00	1.00	40.8 (25.3-58.5)	1.00	
5+ years	40.8 (27.1-56.1)	3.25 (0.99-10.70)	5.1 (1.40-18.86)	43.8 (31.2-57.2)	1.12 (0.47-2.72)	
<5 years	50.4 (23.9-76.7)	4.78 (0.98-23.32)	9.49 (2.30-39.14)	50.5 (29.4-71.4)	1.48 (0.45-4.82)	
Region of birth		P=0.192			P=0.821	
Europe	20.9 (9.7-39.5)	1.00		40.4 (25.0-57.9)	1.00	
Central/East Africa	38.7 (21.5-59.3)	2.38 (0.70-8.16)		35.2 (20.2-53.8)	0.80 (0.29-2.18)	
West Africa	43.8 (27.1-62.1)	2.94 (0.89-9.78)		46.9 (30.5-64.0)	1.30 (0.46-3.67)	
Other	47.3 (10.8-86.9)	3.38 (0.39-29.45)		43.7 (13.8-78.9)	1.14 (0.23-5.65)	
Antenatal care (past five yrs)					P=0.559	
No	NA	NA		40.8 (29.3-53.4)	1.00	
Yes	NA	NA		46.2 (32.3-60.7)	1.25 (0.59-2.65)	
User of tertiary NHS services[1]		P=0.249			P=0.121	
No	48.6 (24.3-73.6)	1.00		34.7 (21.2-51.2)	1.00	
Yes	31.8 (22.0-43.6)	0.49 (0.15-1.66)		49.5 (38.5-60.6)	1.87 (0.85-4.02)	
Ever attended GUM clinic		P=0.021	P=0.001		P=0.032	
No	29.7 (18.8-43.4)	1.00	1.00	38.9 (28.7-50.1)	1.00	
Yes	58.0 (38.9-74.9)	3.27 (1.20-8.90)	5.53 (1.98-15.42)	64.9 (43.3-81.8)	2.91 (1.10-7.72)	
Previous STI diagnosis		P=0.261			P=0.267	
No	33.9 (22.7-47.2)	1.00		37.4 (25.7-50.7)	1.00	
Yes	48.4 (28.2-69.1)	1.83 (0.63-5.29)		53.5 (28.8-76.6)	1.93(0.60-6.17)	
Sex[2] in past year without a condom		P=0.906			P=0.701	
No	31.9 (14.3-56.8)	1.00		44.7 (29.8-60.7)	1.00	
Yes	37.8 (25.2-52.3)	1.30 (0.39-4.35)		46.4 (35.2-62.3)	1.07 (0.47-2.43)	
Not answered correctly	38.9 (11.3-76.0)	1.36 (0.20-9.37)		32.0 (10.5-65.4)	0.58 (0.14-2.51)	
Number of partners in past 5 yrs		P=0.750			P=0.792	
0-1	32.4 (18.2-50.9)	1.00		42.8 (30.7-55.8)	1.00	
2-5	41.0 (24.5-59.8)	1.45 (0.50-4.19)		48.7 (35.2-62.3)	1.27 (0.60-2.70)	
6+	32.7 (17.5-52.6)	1.01 (0.33-4.19)		37.3 (7.5-81.3)	0.80 (0.10-6.28)	

	Men *(Base 159UW 55WT)*			Women *(Base 196UW 48WT)*		
	%	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**	**%**	**Crude OR (95%CI)**	**Adjusted OR (95%CI)**
New partner from abroad in past 5 years		P=0.044			P=0.414	
No	27.3 (16.2-42.1)	1.00		45.1 (34.6-56.4)	1.00	
Yes	52.0 (34.2-69.3)	2.88 (1.03-8.05)		33.1 (13.4-61.1)	0.60 (0.18-2.05)	
Age at first sex (years)		P=0.401			P=0.071	
16+ years	33.4 (21.3-48.2)	1.00		41.2 (31.2-52.0)	1.00	
<16	35.5 (26.9-60.1)	1.20 (0.41-2.97)		65.6 (41.1-83.9)	2.72 (0.92-8.10)	
Ever paid for sex		P=0.100				
No	33.2 (22.5-45.9)	1.00		NA	NA	
Yes	55.3 (32.3-76.2)	2.49 (0.84-7.41)		NA	NA	
Had concurrent partnerships in past 5 years		P=0.517			P=0.178	
No	38.3 (24.3-54.4)	1.00		43.6 (32.6-55.2)	1.00	
Yes	30.7 (16.9-49.0)	0.71 (0.26-2.00)		66.6 (36.4-86.4)	2.47 (0.66-9.24)	
Perception of HIV risk for self		P=0.574			P=0.036	P=0.026
Not at all	36.6 (24.0-51.3)	1.00		39.1 (27.5-52.0)	1.00	1.00
Not very much	33.0 (18.3-51.8)	0.85 (0.32-2.31)		63.9 (44.9-79.3)	2.75 (1.06-7.13)	2.77 (1.00-7.81)
Quite a lot or Great	52.8 (21.0-82.4)	1.94 (0.40-9.34)		26.4 (11.1-50.7)	0.56 (0.17-1.80)	0.50 (0.17-1.44)

[1] In past year other than antenatal services

[2] Heterosexual anal or vaginal intercourse

When incorporated into a multivariate model education level (AOR 4.13 95%CI 1.43-11.88) and perception of HIV risk (AOR 2.77 95% CI 1.00-7.81) continued to be independently associated with HIV testing. No evidence of significant confounding, mediation or effect modification was found in the final model.

3.3 Discussion

In 2000, Black Africans appear to have relatively high rates of HIV testing potentially reflecting awareness of risk behaviours and potential exposure to HIV. Approximately 40% of black Africans had ever had an HIV test, compared with 12-13% having tested in the general UK population once blood donation as the reason for testing was excluded (McGarrigle et al., 2005). The inability of this study to demonstrate association between HIV testing and self-perception of risk may relate to the study's design. Although no association between testing and risk perception was found it is concerning that almost half (48.9%) of the men and 71% of the women perceived themselves 'not at all at risk of HIV'. This may reflect the high proportion of respondents from West Africa, an area with lower prevalence of HIV compared to Southern and Eastern Africa (UNAIDS, 2004).

Important heterogeneity in the factors associated with HIV testing existed between black African men and women in Britain. Higher odds of HIV testing were associated with recent arrival in the UK, and attending a GUM clinic, for men; and higher education level, and low perception of HIV risk for women.

Perhaps surprising is the lack of association between antenatal care in the past five years and HIV testing. Knowledge of the ability to reduce mother-to-child transmission has been available since 1994 (Connor et al., 1994) and universal antenatal HIV testing was introduced in the UK in 1999 (NHS Executive, 1999). This may indicate missed

opportunities to uptake HIV testing, however the study lacked power to investigate possible interactions fully. A relatively high number of people reported having their last HIV test at a NHS family planning clinic (FPC). This was selected from a range of options that consisted of GUM clinic, GP surgery, privately or elsewhere. In 2000/01 FPCs did not routinely offer HIV testing and tended to refer people to other services for testing. It may be that people misunderstood this to mean NHS antenatal testing, or NHS services generally, including GUM clinics that are not infrequently confused as FPCs.

3.3.1 Comparison with previous research

The MAYISHA study, a sexual behavioural survey of five African communities in London, (Chinouya, Davidson, & Fenton, 2000) found similar rates of HIV testing to this study (34% vs. 36% for men; and 30% vs. 44% for women). In MAYISHA, HIV testing was associated with a previous STI diagnosis in men and women, and perceived risk of acquiring HIV in men. MAYISHA, which surveyed migrant and not British born Africans in social venues, found more people reported a previous STI diagnosis. STI rates are known to be higher in migrant populations (Low, Sterne, & Barlow, 2001). Fewer men but more women did not consider themselves at risk of HIV in this study. The lower risk perception amongst women may reflect the higher proportion of women who were either born or spent over five years in Britain and/or the higher proportion having had a HIV test and therefore aware of their serostatus. Natsal 2000, which was more likely to capture both older and second generation migrants than MAYISHA, found men were more likely to test if they were recently arrived in Britain. MAYISHA found no association with time in Britain. This may reflect changing attitudes, greater visibility and increased treatment awareness of HIV within African countries, especially compared to more established African communities within Britain. Perception of HIV

risk and education level, factors found to be associated with HIV testing in women in this study, could all be influenced by time spent in Britain or age of migration. The small numbers involved meant this study lacked power to investigate possible interactions fully.

3.3.2 Limitations

This study has some limitations. Natsal 2000 was a cross-sectional survey so causality is unable to be determined. The association between GUM attendance and HIV testing may reflect individuals accessing these services for the expressed intention of obtaining an HIV test, or reflect the offering of an HIV test as a result of their attendance. Similarly perception of HIV risk will be influenced by knowledge of their result (HIV status) at some point. This may account for the finding of low perception of HIV risk being associated with HIV testing for women. Data on those who tested HIV positive is not available. Women perceiving themselves at high risk of HIV appeared less likely to test for HIV; given the small sample size in the current study this should be investigated further in future studies.

Survey participants did not include the homeless or those living in institutions such as hostels. A substantial proportion of the African population in Britain may be students, refugees, asylum seekers, or living in tied accommodation and thus more likely to be housed in institutions or even homeless. 6% of men and 5% of women in the ethnic boost sample refused CASI, compared to 1% of the core sample. The CASI component included all the questions on sexual behaviour and HIV testing. These factors may have influenced those who felt able to complete the questionnaire. A number of potential confounders were not included in the survey questions and therefore unable to be included in the analysis for example, GP utilisation, residency status, fears and concerns around HIV testing, and perceptions of health services. Finally 'black Africans'

comprise a heterogeneous aggregation of population sub-groups and includes individuals both born in the UK and in Africa. The broad ethnicity categorisation may obscure important cultural, religious, and temporal diversities that may impact on sexual attitudes and lifestyles (Fenton et al., 2002; Fenton et al., 2005).

3.3.3 Implications for future policy and research

A high proportion of men had sex with a partner from abroad; most are likely to be with people of the same ethnic background as the respondent (Fenton et al., 2001). This assortative sexual mixing contributes to perpetuating the cycle of high HIV risk amongst Africans in Britain. Maintaining surveillance within Britain and globally of migration patterns, ethnic variations and STI epidemiology is fundamental to planning effective health interventions.

The national strategy for sexual health and HIV sets specific targets to improve HIV testing uptake and reduce undiagnosed HIV infection (Department of Health, 2001). Results from this study will therefore help identify where HIV testing promotion interventions should be targeted. For example the low level of risk-perception in African women, suggests a need for enhanced gender specific education programmes.

This study also provides baseline data to help evaluate the effectiveness of HIV testing promotion campaigns and provides a useful adjunct to interpreting data derived from other community and clinic based surveys. Encouragingly, black Africans appear to have relatively high rates of HIV testing compared to the general population (McGarrigle et al., 2005). GUM and antenatal services, where the majority of HIV testing in the UK occurs, are also well accessed by this population. These findings suggest prior prevention interventions with these communities have been successful. Nevertheless, there remains significant potential for health gain as the proportion of

undiagnosed HIV infection remains high and diagnoses continue to be made late in this group (The United Kingdom Collaborative Group for HIV and STI Surveillance, 2004). Innovative approaches are needed to improve opportunities for, and uptake of, HIV testing.

3.3.4 Summary

This chapter suggests that British black Africans do access health services and have a relatively high uptake of HIV testing. However as stated above Africans continue to present to HIV services with advanced disease. Greater understanding of the factors associated with when and why Africans access HIV services in the UK is required, and this is the focus of the study presented in chapter 4.

Chapter 4: Key informant understandings of factors contributing to late presentation

Abstract

Objective: To identify the key issues affecting utilisation of HIV services for Africans in Britain.

Design: Employing purposive sampling techniques, semi-structured interviews were conducted with key informants with extensive experience working with African communities, HIV and sexual health.

Results: Eleven interviews were conducted. Respondents felt there was high HIV awareness within African communities in Britain but this did not translate into perception of individual risk. Home country experience and community mobilisation was highly influential on HIV awareness, appreciation of risk, and attitudes to health services. All informants identified confidentiality, stigma and migration issues as major influences on uptake of HIV services. Many institutional barriers to care exist; these include lack of cultural understanding, lack of open access or community clinics, failure to integrate care with support organisations, and the inability of GPs to address HIV effectively.

Conclusion: Considerable agreement about the major issues influencing uptake of HIV services existed amongst the key informants. Community involvement is paramount to effectively tackle health issues for these communities and should include input to ensure there is: better cultural understanding within the NHS; normalisation of the HIV testing process; and a clear message on the effectiveness of therapy. This would enable greater openness and visibility; vital to breaking down barriers to care and stigma.

The findings within this chapter are published in *AIDS care* (2007): Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilisation of HIV health and social services by African migrants in Britain. F. Burns *et al*., v.19: pp 102-8.

4.0 Introduction

Work presented in chapter 3 shows around 40% of black Africans in Britain having ever knowingly tested for HIV, compared to just 13% of the general British population (excludes those testing as part of blood donation) (McGarrigle et al., 2005; Burns et al., 2005). This suggests relatively high awareness of HIV within British African

communities however compared to non-Africans HIV positive Africans in the UK access HIV services at a later stage of disease (Burns et al., 2001; Del Amo, Goh, & Forster, 1996; Sinka et al., 2003). Late diagnosis of HIV disease (CD4<200) significantly increases the risk of death within one year of diagnosis (OR 13.9, p<0.01) compared to those not diagnosed late (Chadborn, Delpech, Sinka, Rice, & Evans, 2005). Whilst the proportion diagnosed late is decreasing amongst men who have sex with men, it remains stable at between 40 and 50% among heterosexuals (The UK Collaborative Group for HIV and STI Surveillance, 2005).

Given this significant health inequity in accessing of HIV services it is important to identify factors impeding more timely access. Review of the literature can be limited in its ability to identify local issues and, due to the inherent time involved in undertaking and writing up research, may not address topical issues. Interviews with local key informants could help identify the current key issues influencing service uptake by HIV positive Africans living in London. This knowledge would help inform development of the questionnaire and topic guide to be used in SONHIA. The interviews would also provide an opportunity for exploration of the acceptability and appropriateness of the proposed methodology.

4.0.1 Aim

To undertake key informant interviews to identify key issues influencing service uptake by HIV positive Africans in Britain and to map out the pathways to HIV care for African migrants.

4.1 Methods

4.1.1 Sampling frame

Purposive sampling based around a sampling frame was used to ensure diversity of knowledge and experience. The sampling frame was defined according to key constituencies in the field of HIV service provision; these comprised of clinicians, public health consultants and epidemiologists, policy makers, health service researchers, health promotion specialists, and those involved in the voluntary sector. People living with HIV were not specifically identified for this study. Once the key constituencies were defined it was possible to identify key organisations within each constituency (Table 4.1). By focusing down to the organisational level key people became identifiable, as the field of HIV and African communities in the UK is comparatively small.

Table 4.1 Sampling Frame used for identifying key informants

Key Constituency	Organisation
Clinical	District general hospital Academic teaching hospital
Public Health/Epidemiology	Health Protection Agency - National Health Protection Agency - Local
Health service access researchers	Universities Hospitals/NHS
Voluntary sector	Terrence Higgins Trust (National HIV NGO) African community NGOs
Health promotion	Terrence Higgins Trust Camden & Islington Health Promotion Health First
Policy	National AIDS Trust African HIV Policy Network

4.1.2 Recruitment

All prospective informants were approached by letter and then phone. If the individual agreed an informal face-to-face interview was arranged and conducted at the venue of their choice. At least one individual from each constituency was interviewed. In order to

reduce selection bias the key informants were also asked if they could recommend anyone to speak to. The HIV status of informants was not ascertained at any time.

4.1.2 The interviews

The interviews were interactive and exploratory in form based on a topic guide (Box 4.1 and appendix 2). The key areas for exploration included: influences on community attitudes towards HIV and health care; perception of health services and the barriers to accessing care; HIV treatments; and how to improve services and information. Informants were also asked to map out the pathways into HIV care. Clinical practice, other than how policy and structure of health services affect it, was not discussed thus avoiding potential ethical dilemmas pertaining to individual clinical practice.

Box 4.1 Topic guide – summary of key areas for investigation

Key informant particulars
Community attitudes –
- Influences on learning about and attitudes towards HIV
- Influences on learning about and attitudes towards health care access

Health Services & service history
- Barriers to health care access
- Successes in improving access to health services
- Map out pathways to HIV care

HIV treatment options
- Influence on presentation to services
- Belief & utilisation of other forms of therapy
- Treatment migration as a phenomenon

Improvements to services & information
- Effective forms of encouragement and information
- Who should be targeted

Research process of proposed study
- Views on proposed methodology

4.1.3 Data collection and analysis

All interviews were electronically recorded where possible. Recording was not possible for four interviews, in these cases extensive field notes were taken during the interview and subsequently written up. The recorded interviews were independently transcribed

verbatim. Analysis was undertaken using 'Framework'(Ritchie & Spencer, 1994). This is a method of qualitative data analysis that involves ordering and synthesising verbatim data within a thematic matrix. The themes are developed both from the research question and from the accounts of the research participants. 'Framework' is seen as particularly good for applied health service research (Ritchie et al., 1994). I conducted all the interviews, was responsible for identifying a thematic framework (based on the recurrent issues which emerged as important to the informants themselves), indexing, charting and interpretation of the data.

4.1.4 Ethical approval

Ethical approval for this study was obtained from the London Multi-centre research ethics committee (MREC 03/2/001) and informed consent obtained from all participants.

4.2 Results

4.2.1 Overview of sample

Eleven interviews were conducted between July and September 2003. The informants had a total of 122 years (average 11 years) experience of working with African communities affected by HIV. The key informants included three clinical doctors, one public health consultant/epidemiologist, two health service researchers, two health promotion specialists, and five individuals who worked in the voluntary sector. Ten of the individuals were or had been directly involved in research into HIV within African communities in the UK. Six informants had lived and/or worked in Africa, and five were Black Africans. Several individuals were involved in multiple roles such that all

constituencies and organisations identified in the sampling frame were represented in the sample. Interviews took on average one hour (range 45 to 90 minutes).

4.2.2 Influences on knowledge and attitudes

4.2.2.1 The community

All informants identified an individual's national and ethnic identification as a key determinant of HIV awareness and that the level of awareness was proportional to the HIV prevalence in the country of origin. This was modified by the extent of political will and community mobilisation that was occurring in African countries to highlight the problem of HIV. Ugandans were regarded as a community that acknowledged HIV as a major problem and mobilised accordingly, both in Uganda and in the UK. Conversely West African communities were identified as not yet acknowledging HIV as a major issue and there was a corresponding lack of community mobilisation and awareness.

Compared to non-Africans, UK African communities were thought to have a higher degree of HIV awareness. However, most informants did not think this awareness translated into an appreciation of individual HIV risk, and that overall perception of personal risk remained low among most Africans resident in the UK. This was attributed to a combination of denial and beliefs that sexual practices outside the norm were required to enable HIV transmission.

> 'There is dissonance between fact and expectation, … a separation of awareness from risk, and community from self.'
>
> Health promotion, male

4.2.2.2 Stigma

HIV remains a much-stigmatised disease within African communities in the UK, and all informants acknowledged this as a major barrier to accessing HIV testing and other HIV services. Why this continues to exist despite high HIV prevalence in Africa and often shared-common experience of the disease was not fully understood. The lack of openness about HIV, especially by those in positions of power and influence (for example religious leaders and community elders) was identified as a causative factor. That HIV is predominantly a sexually transmitted infection, and thus carries connotations about personal character, was also identified as an important factor increasing HIV-associated stigma. This association impacted on the accessing of services. People were fearful of presenting for an HIV test as the testing process itself carried an implication of blame; one only testing if they considered themselves susceptible because of their behaviour.

However the perception of HIV as a deadly disease, directly resulting from home country experience, was seen as the principal cause of fear and stigma; as one informant stated:

> 'There is a set of assumptions that an HIV diagnosis is an immediate death sentence because that's the experience that they've come from…. So there is a vision of what HIV means which I think colours a lot of stuff.'
>
> Female clinician

It was generally felt that there was now less stigma and discrimination attached to HIV in Africa. However many Africans in the UK were not aware of a cultural shift towards greater openness and acceptance of HIV in Africa. The HIV-related stigma and fear of discrimination coming from within African communities was seen to have impeded

development of an effective community response, such as that seen within the gay community in the 1980s.

4.2.2.3 Confidentiality

Confidentiality was another barrier to accessing care that all informants identified. Limited freedom of movement as a consequence of prolonged immigration processes amplified individuals' personal fears about disclosure and their ability to 'contain' the information about their HIV status from others, particularly people 'at home'. An example given was the fear that knowledge of HIV status may get back to the home country without them having any ability to modify the impact of this news for friends, family or acquaintances. Several informants referred to Africans actively trying to avoid 'burdening' those back in Africa with knowledge of their HIV status, especially given the context of HIV diagnosis and association with death. Due to the isolation experienced as a consequence of migration, support networks in Britain tend to be small and based on kinship rather than direct or extended family. The common perception was that people would face social isolation, and even violence, if their HIV status were disclosed.

Confidentiality concerns also involved the accessing of particular services being associated with being HIV positive:

> 'There were special wards for people everywhere so people started fearing to go to any hospital. They would rather go where they don't know them or where there's no special ward'
>
> Voluntary sector, female

Several informants believed this attitude was changing and that there was now a greater acceptance of the need for specialist services. Nevertheless, most felt UK Africans with HIV would prefer their HIV services to be located within a general medical context, to

avoid the possibility of indirect disclosure that comes with attending specialist services. Similarly there was perceived reluctance of Africans to access HIV services run by people from within their own communities due to increased likelihood of indirect disclosure.

Fears around disclosure were intimately linked to the immigration process. Informants believed that many people either thought an HIV diagnosis would adversely affect their application for permanent residence, or that accessing health services would identify them to the immigration services. Several informants spoke of lay fears of a 'Big Brother' like computer network operating between government departments that routinely exchanged such information.

4.2.2.4 Cultural norms

Experiences people brought with them when they migrate were thought fundamental to how they subsequently viewed HIV and UK health services. In many African settings health services are accessed only when there is a specific need, and then, only when it is perceived to be serious. As a result the philosophy of health promotion and preventive medicine are not well established in most African communities.

> 'As I understand it, in that society you wouldn't go to hospital unless you were ill and therefore I've seen people present late, get an HIV diagnosis and are really dead pretty quickly afterwards so I think that people come with that, that lens, if you like. And so to then come to a society where you might just go to hospital feeling completely well and walk in and take an HIV test is not necessarily what people think of as standard behaviour.'
>
> Female Clinician

As a result most Africans would be unfamiliar with a sexual health clinic that is 'open-access' from the street, where one might go routinely, and certainly not expect it to be a place one would routinely go for an HIV test. Thus they would be unlikely to either

identify it as a place to go or know what to expect when they attend. Informants felt that many people did not know where to go for an HIV test, how long it would take, or that the result would be confidential. Similarly informants believed a high proportion of African immigrants did not appreciate that the National Health Service (NHS) is free at the point of delivery.

The importance of the oral tradition within African societies was acknowledged by all informants as fundamentally important for imparting of knowledge, forming social attitudes, and for perpetuating ignorance around HIV transmission, fear and stigma. The informants felt there was a lack of accessible information on health services that reinforced the reliance on word-of-mouth, thus hindering individuals from acting independently.

4.2.2.5 Migration

The difficulties encountered by migrants generally were identified as a key factor impacting on HIV service uptake. Health is only a priority when one is unwell; otherwise issues around immigration, housing, employment, and childcare take precedence. English being a second language means health messages get lost or distorted in translation. Disempowerment experienced by asylum seekers in particular was considered as a major factor impacting on health. Uncertainty about entitlement to care under the National Health Service (NHS) was believed to limit utilisation of health services and although many people knew about treatments, many believed they would not be eligible for them or would have to pay for them.

Although the migration experience and corresponding economic hardship was seen as a unifying factor, there remained significant diversity in the British 'African community'. Informants felt these differences, not only in terms of country of origin but also gender

or religion, were not being acknowledged or addressed in services or information targeting 'Africans'. 'Treatment migration', where individuals specifically migrate to Britain to access HIV services, was acknowledged to occur but was not felt to be significant.

4.2.2.6 Institutional issues

Informants described numerous structural and cultural institutional barriers to accessing health care. They felt the NHS's institutional culture did little to help 'break the silence' around HIV in African communities. This was not perceived as institutional racism but institutional inertia. Failure of clinicians to understand cultural factors, social exclusion or poverty was felt to contribute to making the population of HIV infected Africans in Britain 'invisible'. The lack of advocacy for Africans with HIV in Britain was compounded by the adverse advocacy frequently expressed in the media; HIV amongst migrants was still perceived by society as something we shouldn't be spending money on. All informants raised the negative impact of the media. It contributed to sense of general mistrust of people and institutions, specifically helped create mistrust of the NHS, and generally fuelled fear of stigma and discrimination.

> 'Africans are seen as vectors of infection. Testing in this environment just reinforces prejudices'
>
> Voluntary sector, male

To balance this perspective the informants believed requires money, political will, and advocacy, resources that are often lacking for British African communities.

Structural barriers to health care included appointment systems, which were viewed as especially intimidating for people unfamiliar with the system, or with English as a second language. Language barriers still exist although this is being addressed with the rise in interpreter and advocacy services. Lack of family facilities made access for those

with children difficult, as the HIV clinic environment is inappropriate for children. The overcrowding of many sexual health clinics amplified the fear of disclosure.

Many of the informants identified problems within primary care. Many General Practitioners (GPs) were perceived to be failing to address HIV with their service users, whether this reflected a lack of knowledge or a lack of confidence on the part of GPs was unknown. Some felt people had lost trust in their GPs because despite testing HIV positive elsewhere the GP asked questions which were perceived to reflect ignorance, e.g. 'how did you get it?' or failed to even mention HIV. This prevents patients disclosing their HIV status to them. Several informants identified GP receptionists as being associated with breaches of confidentiality.

To develop new initiatives to improve access for Africans affected by HIV, staff, time and money would be required; as health services were identified as already struggling to cope with current workload this was recognised as difficult.

4.2.2.7 Treatment

Effective treatments for HIV had impacted tremendously on people with diagnosed HIV infection; they had lifted morale and enabled patients to plan for the future. However the availability of treatment was not yet felt to have influenced attitudes or behaviours amongst those people who were not accessing HIV services. Only one informant felt the benefit of effective therapies was feeding back into the community and changing people's perceptions of and reactions to HIV. The uncertainty over entitlement to care was felt by some to be a limiting factor in the impact of antiretroviral therapies.

Belief in and utilisation of other forms of therapies for HIV was thought to occur although other than the use of faith none of the informants had knowledge as to how common this may be. Faith was felt to be widely used, as most African societies are

faith based; whilst there was acknowledgement that occasionally faith was used in lieu of medical interventions this was not felt to be common.

4.2.3 Pathways to HIV care

In Britain the majority of HIV testing occurs within open-access sexual health settings however informants felt migrant Africans rarely accessed these services directly. Instead indirect pathways exist encompassing social contacts, primary care, and hospital services. The failure of GPs to address HIV directly often means multiple exposures to health services before an HIV test is undertaken.

> 'One of the biggest barriers to HIV testing is how poorly accessible health services are in the UK. Its only when you're very, very sick that you're persistent. So people who access [HIV services] normally will have been to four or five different health facilities before they actually end up [here] - time and time again that's what you see.'
>
> Male Clinician

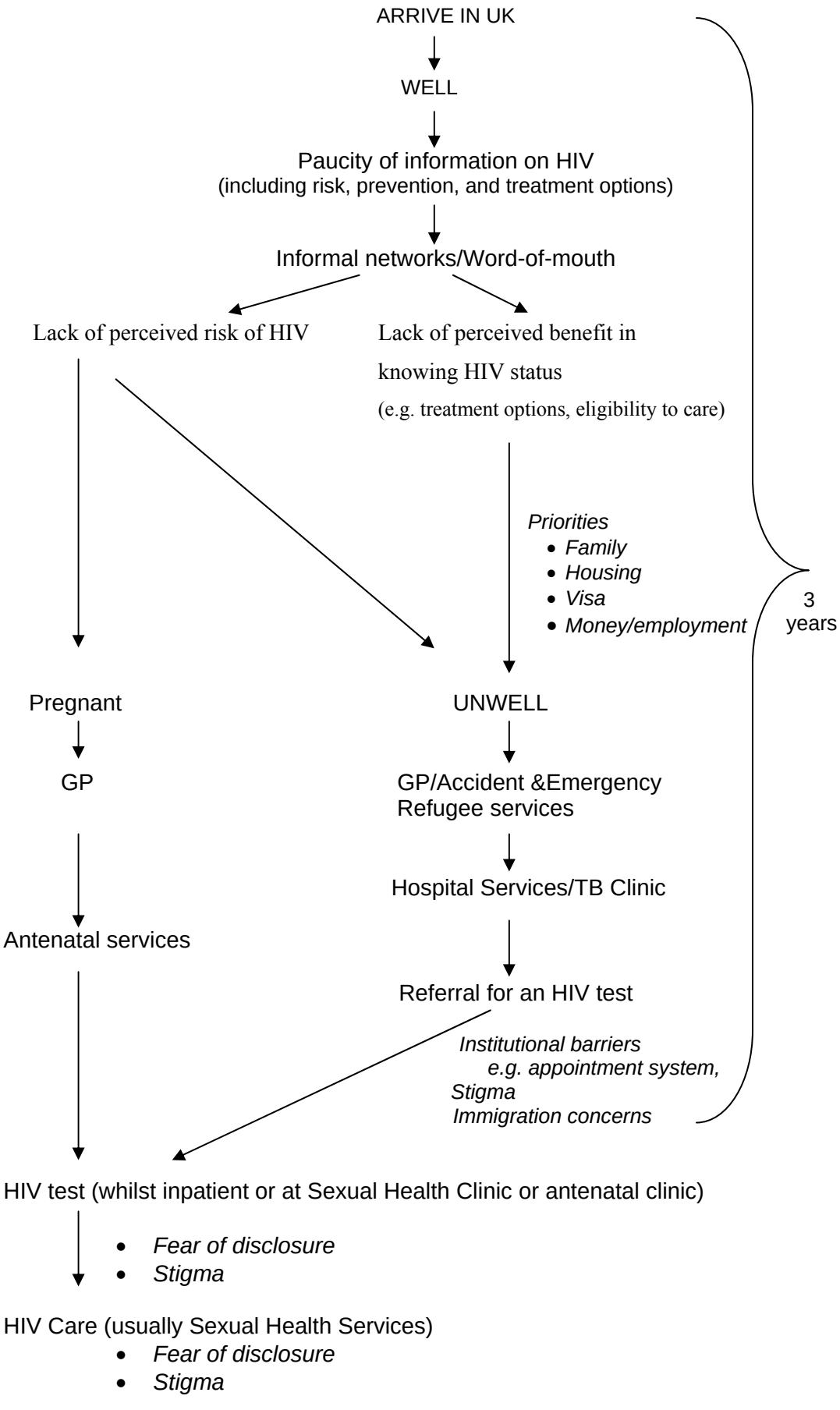
Entrance into HIV care for migrant Africans was perceived to be predominantly via hospital based services, e.g. antenatal and TB services, although social services (including the National Asylum Support Service), student health and community based organisations also provided important access points (figure 4.1). Services were not accessed unless driven by illness, which informants felt to be typically two to three years after arrival in the UK.

4.2.3 Improving access to HIV services

4.2.3.1 Community involvement

As peer-led interventions were perceived as best practice, all informants felt more community involvement was fundamental to improving information and services for Africans affected by HIV. Community participation was required at all stages of service provision from inception to implementation and evaluation. Greater

Figure 4.1 Schematic of Pathways to HIV Care



community involvement incorporated the idea of more community clinics and testing opportunities.

Community involvement would enable greater openness and visibility, which was vital to breaking down barriers to care and stigma. In particular informants identified a need for community leaders (faith leaders, traditional leaders, big business people) to be involved. Greater openness would in turn enable more positive advocacy. It was hoped Africans would become more involved with organisations that are already well established with political clout (e.g. the Terrence Higgins Trust).

4.2.3.2 Cultural understanding of health and disease

Better training of health professionals around the cultural meanings of health and disease was identified as an area that would improve services and help with development of appropriate prevention interventions. Clinicians need to understand the assumptions made and the impact on the social environment of testing HIV positive.

> 'Some of the literature that comes out I think is not very appropriate, it's very Western medical model, this is HIV and it's a virus, it doesn't really take into account people's cultures and understanding about illness and what it means'
>
> Male clinician

The importance of community prescribed norms in influencing behaviours must not be overlooked. The difficulty for prevention interventions was in adopting messages that actually support African culture and cultural needs, such as reproductive drive.

4.2.3.3 Gender

All the informants spoke of the need to engage more with African men. There is evidence that African men access HIV services later than African women (SOPHID, 2003). Men lack a 'front door' to services (compared to women who access health services for pregnancy and childcare issues), are greater risk takers (more sexual

partners, more time and social space than women are likely to have), and are less willing to seek help unless absolutely necessary. These issues exist for all men however the processes involved in migration (see above) have the potential to amplify these barriers for African men living in the UK. Men were also felt to have more difficulty accepting their diagnosis.

4.2.3.4 Broaden health message

The informants felt HIV information needs to broaden its remit. Currently most HIV information for African communities is targeted at those already positive rather than focusing on prevention and health promotion. Similarly the messages should incorporate all aspects of sexual health. The message of 'probably acquired in Africa' was felt to be counterproductive to HIV prevention work within Britain. Africans do not embrace imagery targeted at Africans per se, as this is perceived to fuel stigma and discrimination. Providing different universal messages that include Africans was preferred. Health promotion needed to become incorporated into everyday life, as people will not attend HIV talks as this implies 'bad behaviour'.

However clinicians when working with patients should try to personalise the message, i.e. focus on the individual not the population.

> 'It's important for <u>you</u> to use a condom because of this…'
>
> Health promotion, man

Other ideas included utilising the Internet and provision of information on how to access health services outside of health services. Several informants felt that acknowledging modes other than sexual transmission would enable more people to access HIV services.

4.2.3.5 Successful interventions

Examples of successful interventions involving HIV services were limited. All informants referred to the antenatal HIV testing programme. Whilst there was acknowledgement of the difficulties and controversies associated with diagnosis at this time it was felt to have proved successful in reducing vertical transmission of HIV and in getting women appropriate care. The combination of political will and community mobilisation was thought crucial to the success of this programme.

Otherwise informants referred to the increase in community mobilisation generally, this incorporated the rise in HIV positive support organisations and trained HIV positive speakers doing outreach and general advocacy. 'Awaredressers' in Birmingham was identified as a successful intervention in which hairdressers are trained in health promotion around HIV and sexual health. Optimism was expressed about the integrated HIV testing service with Lighthouse Kings where health professionals and community organisations worked in unison. Finally the health packs provided by the Refugee Council were identified as helping get people into services.

4.2.4 Views on proposed methodology

A detailed overview of the proposed methodology for SONHIA was provided to the informants for feedback on during the interview. The aims and objectives, recruitment process, and utilising dual methodologies were discussed. Few informants had specific comments about the proposed methodology for SONHIA. Most anticipated that the study population would be reluctant to participate due to the concerns around disclosure and mistrust of 'the system'. The informants felt recruitment to the interviews, and of men in particular, would be especially problematic. The proposed 'token of appreciation' was felt to be important for acknowledging the time involved and in its

ability to act as an incentive to facilitate recruitment. They agreed that providing the survey in French and English should suffice, the use of interpreters being sufficient for those not covered by those languages.

Several informants recognised that the in-depth interviews to be conducted in SONHIA would allow comparison of issues identified by the service users with those of service providers, enhancing the applicability of these findings.

The strongest message was the need for acknowledgment and dissemination of the research findings back into the communities affected by the research. The need for participants to see the results of research and how they impact on their community and health care experiences was perceived to be currently lacking from most research. Community involvement was felt paramount to effectively tackle the health issues for this immigrant population. Whilst the involvement of a community advisory group was always anticipated, feedback from the interviews reinforced the importance of community involvement from inception right through to dissemination of findings. Proposed outputs were modified to include more extensive dissemination to the communities following these interviews.

Being a white New Zealander was not seen as barrier to me conducting the research.

4.3 Discussion

Considerable agreement about the major issues influencing uptake of HIV services, regardless of professional background, existed among these key informants. Respondents felt there was high HIV awareness within African communities in the UK but this did not translate into perception of individual risk or effective use of services. Home country experience and community mobilisation was hugely influential on HIV awareness, appreciation of risk, and attitudes to health services. All informants

identified stigma, confidentiality and migration issues as major influences on uptake of HIV services. Many institutional barriers to care were thought to exist. These include lack of cultural understanding amongst staff, lack of open access clinics and child-care facilities, failure to integrate care with support organisations, few community clinics, and the inability of many GPs to address HIV effectively.

The issues identified by the key informants support previous work that has been done in this area. UK African communities still need basic information on how and where to access appropriate health services, what these services entail, that they are confidential and that they are not linked to the Home Office or Immigration Services (Erwin et al., 1999; Maharaj et al., 1996; Ndofor-Tah et al., 2000). HIV-related stigma and the fear of discrimination, which are intimately tied into issues of poverty and migration, continue to exert a disproportionate influence on health and health service access (Doyal & Anderson, 2005; Erwin et al., 1999).

Effective antiretroviral regimes have been widely available within the NHS since 1996. Despite this, there has been no decline in the proportion of Africans in Britain presenting to HIV services with advanced disease (The UK Collaborative Group for HIV and STI Surveillance, 2005). This study suggests poor understanding of the benefits of early intervention, fear of the consequences of testing positive in relation to immigration, ignorance around entitlement to care and unfamiliarity with the NHS combine to hinder service access.

This study highlights the institutional role played by NHS service structures in perpetuating poor access for migrant Africans. Several informants, as well as recent literature (Manavi & Welsby, 2005), suggested that the emphasis placed on detailed voluntary counselling and testing has created a barrier for many clinicians to offering HIV tests. Clinicians outside sexual health clinics and antenatal settings appear

reluctant to offer an HIV test themselves, even when they suspect HIV infection, and prefer instead to recommend attendance at a sexual health clinic.

The process of onward referral inevitably creates a barrier to HIV testing, and complicates the pathway into care. Referral to a sexual health clinic in particular, may create its own barrier for African communities given the stigma associated with HIV and unfamiliarity with sexual health services. The informants all spoke of the indirect pathway into HIV care experienced by many Africans.

Although the sample size of this study was small, utilising purposive sampling techniques ensured it encompassed a broad cross-section of experts involved with African communities and HIV care in Britain. Even with the diverse sample, there was consistency in expert views about what were the key issues, suggesting that some degree of 'saturation' of view about the problem had been reached. Emergent themes such as community involvement could potentially be influenced by the sample selected, for example many of the informants were directly involved with community organisations. Care was taken to ensure that when views that may reflect a vested interest or bias were expressed that these views were either also expressed by other informants or were acknowledged as such.

The lack of service users among the informants is a major limitation of the current study. Involvement of service users would enhance the applicability of these findings and allow comparison of their identified issues with those of service providers; a study of this nature is presented in chapter 9.

4.3.1 Summary

Socio-cultural factors are key determinants of the HIV epidemic. For many, migration is a difficult uncertain process and HIV in this scenario can have greater social

consequences than it does for others in the UK general population. Community involvement is paramount to effectively tackle health issues for immigrant populations. To address HIV in African communities this should include input to ensure there is better cultural understanding within the NHS and other government organisations; normalisation of the HIV testing process; and a clear message of the effectiveness of therapy.

This study provides some insight into how people working in the field perceive factors impacting on utilisation of HIV services by migrant Africans. These views need to be considered in conjunction with those of service users and the rest of this thesis will be a presentation and discussion of the Study of newly diagnosed HIV infection among Africans in London (the SONHIA study).

Chapter 5: Study of newly diagnosed HIV infection in Africans in London: Methodology

Abstract

This chapter describes the design of a study to determine and explore the factors influencing access and utilisation of HIV treatment services, and to determine the extent of UK acquisition of HIV, among Africans resident in London. Methodology was to combine quantitative and qualitative methods in a multi-centre study of newly diagnosed HIV positive Africans.

A study of newly diagnosed HIV positive Africans attending 15 HIV treatment centres across London was conducted between April 2004 and February 2006. The study consisted of two components: i. a quantitative cross-sectional survey and ii. in depth interviews with a purposively selected sub sample. The survey consisted of a confidential self-completed questionnaire linked to clinician completed clinical records. All HIV positive Africans attending the participating centres i) diagnosed HIV positive for the first time within twelve months of recruitment and ii) aged 18 years or older were eligible for recruitment to this study. For the purposes of this study 'Africans' were defined as persons born or raised (up to and including 16 years of age) in Africa. Whilst uptake amongst those approached was higher than anticipated, the referral of eligible patients to the study team for recruitment was lower, necessitating extension of the recruitment period.

Exploring factors associated with late presentation to HIV services and UK acquisition of HIV with newly diagnosed HIV positive Africans was both feasible and acceptable to staff and study population alike. Continual monitoring of study instruments and procedures ensured problems were identified early and addressed appropriately.

5.0 Introduction

The literature review presented in chapter 2, the analysis of factors associated with HIV testing among Africans residing in Britain (chapter 3), and the key informant interviews (chapter 4) were critical components of the preparatory work towards the study of newly diagnosed HIV infection in Africans in London (the SONHIA study). This chapter describes the methodology employed, the development and validation of the

study instruments (questionnaire, clinical data form and topic guide), and the principles behind the study design. The chapter concludes with the challenges of implementation of this study, and the strategies to address them.

5.1 SONHIA

The study of newly diagnosed HIV positive Africans in London (SONHIA) consisted of two inter-linked components implemented over two years: i) A survey of newly diagnosed HIV positive Africans presenting to specialist HIV services in London linked to clinical data; and ii) A qualitative study amongst a purposively selected sub sample of newly diagnosed HIV positive Africans employing in-depth interviewing techniques.

5.1.1 Why use dual methodologies?

Quantitative and qualitative approaches differ conceptually and methodologically yielding different types of information; it is this very difference that makes them complementary. To quantify patients' experiences of a disease would only tell half the story without also identifying the ways in which the disease impacts on their lives, or indeed how their lives impacts on the disease.

Quantitative research focuses on revealing causal relationships through quantification and hypothesis testing. Surveys can provide valuable data on the 'how much' and 'what' but are limited in their ability to answer complex questions such as exploring the 'how' and 'why'. Qualitative research, whilst also examining causation, focuses on discovering the nature of phenomena as humanly experienced (Minichiello, Sullivan, Greenwood, & Axford, 1999). Particular aspects of culture, such as health seeking behaviours, can only be understood by placing them in a broader context.

By using mixed methodology a more holistic or critical understanding of the issues affecting accessing of HIV services is acquired. The quantitative component provides

data on distribution and associations with outcomes, whilst the qualitative component provides in-depth understanding of meaning and context. Qualitative methods will help highlight the contradictions and ambivalence in what may at first seem a simple reality. Simply put, the combining of quantitative and qualitative methodologies allows for both detailed measurement and explanation.

Development of the questionnaire, clinical data form and topic guide did not occur until completion of all phases of preparatory work; including the key informants interviews, analysis of Natsal 2000 dataset and the literature review. This enabled questions to be incorporated that explored the major issues identified in the background work. To facilitate future comparative analysis questions were taken from other large-scale surveys of health service utilisation, and sexual attitudes and lifestyles, e.g. Natsal 2000 (Erens et al., 2001) and the MAYISHA study (Chinouya, Davidson, Fenton, & on behalf of the MAYISHA Team, 2000), whenever possible. The underlying principles that informed development of the study instruments are provided in box 5.2 below.

Box 5.2

Key principles that informed development of the questionnaire and topic guide

- Format and content to be acceptable to study population
- Ensure ethically and culturally appropriate
- Keep questions simple (questionnaire to be self-completed by pen on paper)
- To use validated questions whenever possible
- To incorporate findings from literature review, Natsal analysis and key informant interviews.
- Focus limited to study objectives
- Facilitate comparison with other large-scale behavioural surveys (MAYISHA, Natsal) where possible
- Enable in-depth exploration to maximise output potential
- Facilitate recruitment by minimising work for clinic staff

5.1.2 Developing the quantitative component

5.1.2.1 Designing the questionnaire

In order to design the quantitative questionnaire and clinical data form it was important to first identify specific survey objectives.

The measurement objectives of the study were defined as follows:

1. To measure the frequency and event experience of HIV testing.
2. To measure utilisation of health and social services in the UK prior to HIV diagnosis.
3. To measure attitudes towards and knowledge of HIV and HIV services, and to examine their relationship with behaviour.
4. To assess the proportion of HIV infections amongst Africans acquired within the UK
5. To determine the probability of onward transmission of HIV infection related to undiagnosed HIV infection.
6. To determine the demographic, social and behavioural characteristics of those who present with advanced HIV disease.

Defining the measurement objectives enabled identification of the research variables needed to meet these objectives.

Research variables

Utilisation of services: Frequency and cause of use; Perception of health services; Knowledge and awareness of sexual health services.

Sexual health: Knowledge and awareness of HIV; Attitudes towards HIV; History of STIs; Sources of information on HIV; HIV testing.

Sexual partners: Numbers and gender of sexual partners in different time intervals; Experience of paying or being paid for sex.

*Migration histo*ry: Time in the UK; Travel back to Africa; Country of birth and adolescence; Residency status.

Clinical (at diagnosis and 6 months post diagnosis): CD4 count; HIV viral load; AIDS defining illnesses; CDC stage; Probable seroconversion; Treatment history.

Demographic variables for subgroup analysis: gender, age, marital status, education level, religion, ethnic identity, area of residence, children, employment, country of birth, language, residency status.

All these variables were captured within the questionnaire.

5.1.2.2 Method of data collection

The decision about the methods of data collection revolved around the study population, the nature of the information to be collected, cost and practicality. Computer-assisted self-interview (CASI) has been shown to aid in the disclosure of sensitive information (Johnson et al., 2001) however some concern was expressed by key informants about this modality for this particular study population. Computers were identified as a source of mistrust by some informants and linked into fears of information sharing and disclosure between government agencies. In Natsal 2000 6% of men and 5% of women in the ethnic boost sample refused CASI, compared to 1% of the core sample (Erens et al., 2001). There was also no budget for the multiple laptops CASI would require given the number of study sites, nor a budget for the staff time that would be required to administer the questionnaire in this way. Thus although pen and paper limited the nature, breadth and depth of questions, this was the chosen modus operandi. The

questionnaire was designed to be self-completed to facilitate disclosure to sensitive questions.

5.1.2.3 Questionnaire format

The questionnaire was structured to provide a sequence of questions that would provide clarity and facilitate reliable responses. Relatively neutral questions (for example requests on demographics and general health) led on to more sensitive ones. The questionnaire was presented in a booklet divided into chronological sections designed to provide a contextual framework to place events, order thoughts, and aid recall.

5.1.2.4 Language

As the questionnaire was designed to be self-completed, it was very important that all respondents interpreted terminology the same way. Thus the self-completion booklet was prefaced with a glossary of key terms. To enable cross study comparison the same definitions used in the Natsal 2000 survey (Erens et al., 2001) were employed in this study. The language used throughout the questionnaire was neutral but formal.

The questionnaire was made available in both an English and French version. HIV/AIDS surveillance data from the Public Health Laboratory Service[11] at the time of study development suggested that for the ten most common countries of origin for newly diagnosed Africans (accounting for over 75% of newly diagnosed infections), the overwhelming majority were from English speaking Commonwealth African countries. This reflects our historical ties with the countries of origin and current migratory patterns. Most other non-English speaking countries represented within the surveillance data were francophone, with Congo being the largest contributor.

[11] The Public Health Laboratory Service was the predecessor of the Health Protection Agency. It ceased to exist on 1/4/2003.

Experience with research among African communities also supported this approach. After extensive field-research, the MRC-funded ethnic minority boost for the National Survey for Sexual Attitudes and Lifestyles (Natsal 2000) felt that provision for languages other than English were not required. Whilst MAYISHA, a study of over 700 Black Africans from the highest prevalence countries in Britain, utilised English and French questionnaires for respondents (Chinouya et al., 2000).

The SONHIA questionnaire was only available in English and French versions, however advocates and translators were used for those participants who spoke other languages; the numbers requiring this service being small. In addition the key worker was available to assist with the questionnaire should this have been required.

5.1.2.5 Reliability and validity

A study of this nature, although linked to clinical information, essentially relies on self-reports. Disclosing honest information related to sexual behaviour in the context of HIV infection could be problematic for some. Guarantees of confidentiality were given on the front cover and throughout the booklet to help maximise veracity. This was reinforced by the provision of a sealable envelope to put the completed questionnaire in. 'Permissive' questions, i.e. questions that by their wording imply acceptance of the behaviour in question, were sometimes employed to aid disclosure. The questionnaire consisted largely of tick boxes to facilitate the answering of sensitive questions.

Whenever possible questions were taken from other large-scale surveys of health service utilisation, and sexual attitudes and lifestyles, e.g. Natsal 2000 (Erens et al., 2001) and the MAYISHA study (Chinouya et al., 2000), as these questions had already undergone thorough validation and reliability testing. An eligibility criterion from the time of initial HIV diagnosis was specifically set up to minimise recall bias. As the

study's principal aim was to understand the factors associated with initiating access to HIV care it was important that respondents completed the questionnaire as close as possible to their initial diagnosis.

5.1.2.6 The survey instruments

The survey instruments (questionnaire and clinical data form (appendices 4 and 5)) were designed to obtain data related to patient's health beliefs and utilisation of health services; the demographic, behavioural and social factors associated with delayed presentation to treatment services; and the extent to which acquisition of their infection may have occurred within the UK. They also obtained information on patient's demographic characteristics, HIV history, sexual health and sexual behaviour, antiretroviral drug history, and service access. Finally, the questionnaire was designed to assess knowledge, attitudes and beliefs around HIV/AIDS.

Each confidential self-completed pen and paper questionnaire (available in English and French) was linked to relevant clinical information obtained from the patient's medical notes. Clinical data from the time of diagnosis and six-months post diagnosis was collected by members of the research team. Data collected included: CD4 and viral load, clinical staging including seroconversion and AIDS defining conditions, exposure to antiretroviral medication, viral subtypes and resistance patterns.

The questionnaire was designed to take between 30 and 60 minutes to complete. All participants completing the questionnaire were reimbursed £10 to cover time and travel expenses. A list of relevant helplines was provided to each respondent. All respondents undertook this component of the study.

5.1.2.7 Sample size

Previous research suggest that between 35 and 50% of Africans who are diagnosed with HIV in London already have advanced disease at the time of diagnosis (Burns et al., 2001; Gupta, Gilbert, Brady, Livingstone, & Evans, 2000; Saul, Erwin, Bruce, & Peters, 2000). Along with AIDS, a CD4 count below 200 cells/μL is a marker of advanced HIV disease. As CD4 can be viewed as a more solid marker of late presentation given that tuberculosis (TB), an AIDS defining illnesses especially prevalent among Africans (Sinka et al., 2003), can occur early in the course of HIV infection. Late presentation was defined according to CD4 criteria alone. Late presentation (CD4 count below 200 cells/μL at time of HIV diagnosis) was the principal outcome for the survey.

It was assumed that a measure of late presentation would have a population prevalence of roughly 40%. The aim was to have 80% power to detect significant associations of moderate risk, e.g. relative risk (RR) 1.5, necessitating a sample size of 330. Assuming a response rate to the questionnaire part of the study of 70% then approximately 470 eligible patients would be required. Sample size was calculated using Epi info.

5.1.3 The qualitative component

5.1.3.1 Sample design

The population for this qualitative sub study comprised of English speaking African people aged over 18 diagnosed recently with HIV infection. African communities contain an aggregation of heterogeneous population sub-groups, which vary geographically and over time. For a sample of this kind purposive sampling using quota criterion was appropriate to ensure maximum diversity of key socio-demographic variables thought to be associated with late presentation. The quota matrix (appendix 7) consisted of primary and secondary criteria. The primary criteria comprised of age,

gender and length of residence in the UK. The secondary criteria consisted of partnership status, region of origin (divided according to a low, high or increasing HIV prevalence), and recruitment site. The selection criteria were informed by the key informants interviews.

Because of the screening procedure employed it was not possible to link selection criteria with clinical stage. The initial plan was for forty purposively selected participants were to be interviewed, as this number should allow for data saturation (when no new concepts are emerging). The interviews were limited to those proficient in English as all interviews were conducted by myself.

5.1.3.2 Development of the topic guide

As with the survey instruments the topic guide was not developed until all phases of preparatory work were completed; thus enabling inclusion of the key issues that emerged. Refinement of the topic guide (appendix 8) was an ongoing process grounded in the information obtained from the interviews themselves.

The key areas for investigation were: personal circumstances, e.g. partnership status, migration history; personal and community attitudes and influences, e.g. stigma, role of religion; learning about and the awareness of HIV – both personally and within the community; perceptions and experiences of health services; detailed sexual health history; awareness and beliefs on HIV treatment options; and means of improvement to services and information.

It was estimated that the interviews would take approximately 90 minutes to complete. All participants were reimbursed £20 to cover time and travel expenses. A list of relevant helplines was offered to each participant, as was the opportunity to discuss further any issues raised with an appropriate trained professional.

5.2 Validation

An African community reference group (ACRG) was set-up to approve, review and oversee all stages of the study. The steering committee for the African HIV Research Forum (AHRF) was chosen for the role of ACRG. The AHRF is an umbrella organisation that's main aim is to bring together individuals and organisations to focus on all aspects of HIV research relating to the various African communities within the United Kingdom. The AHRF steering committee is drawn from key stakeholders working in community-based organisations, the statutory and voluntary sectors. Although individuals changed the steering committee was essentially always comprised of people with knowledge and interest in the field of HIV and African communities, they were already formally linked and meet regularly.

Once the Topic Guide and Questionnaire were developed they were presented both to the key informants and to members of the ACRG for review. This was done in order to try and ensure that the content, construct and context of the instruments were appropriate. The London Multi-centre research ethics committee (MREC) also suggested some minor changes to wording of certain questions and further explanation on certain terminologies that were duly incorporated. At this stage the questionnaire and topic guide were piloted.

5.2.1 Piloting of questionnaire

Piloting was undertaken before embarking upon full-scale recruitment in order to test the feasibility of survey procedures and their acceptability to patients. The pilots explored patients' understanding of the questionnaire's items and constructs and involved: i) recruitment of 13 respondents; ii) monitored administration of questionnaires (timing, questions asked by respondent); iii) in-depth cognitive

interviewing with respondents to explore understanding of key words and constructs; and iv) review of questionnaire completion and item non-response rates.

Two small-scale pilots, including cognitive interviews, were conducted on African patients attending the Mortimer Market Centre. The second pilot (n=8) was conducted following modification of the questionnaire to incorporate feedback from the initial pilot (n=5). All people participating in the pilot were reimbursed £10. Following the initial pilot construction and/or terminology of several questions was modified, one question was dropped and several open-ended questions were changed to tick boxes options. Piloting of the modified questionnaire led to inclusion of more statements about confidentiality of the study. The average time to complete the questionnaire was 40 minutes (range 20 to 65 minutes).

5.2.2 Feedback from pilots and presentation to ACRG

Response to the questionnaire from both the pilots and ACRG was overwhelmingly positive. The research was seen as worthwhile with 'relevant', 'valid' and 'important' being frequently used to describe the aims of the study by both the ACRG and pilot participants.

The questionnaire bordered on being too long however the reimbursement provided helped compensate for this. Despite the length and use of jumps the questionnaire was 'informative, straightforward and to the point' and 'not complicated'. One patient felt unable to answer the question about the belief that HIV was created by white people because she knew she was going to talk to me after completing the questionnaire and I am a white person. Otherwise all patients piloting the questionnaire felt able to answer all questions honestly with the stems making the very sensitive questions acceptable. Respondents described getting a sense of purpose from the questionnaire.

5.2.3 Pilot of in-depth interviews

A pilot was undertaken to test survey procedures and their acceptability to patients before embarking upon full-scale recruitment. The pilot was used to explore patients understanding of the items and constructs included in the topic guide. The pilot involved: i) recruitment of three respondents; ii) monitored in-depth interview to explore understanding of key words and constructs, timing, questions asked by respondent; iv) review of topic guide; and v) feedback on interviewing technique by my supervisors.

The pilot interviews were all conducted at Newham University Hospital in a private room. Two women and one man were interviewed, and the interviews lasted between 60 and 90 minutes. The interviews were tape-recorded although for the first interview the recording mechanism failed. This was discovered immediately after the interview at which stage extensive notes were written. At completion of the interviews the interviewees were all asked how they found the interview, and whether they had difficulty with any of the questions. One of the interviewees had recounted very traumatic experiences and had expressed a lot of grief during the interview, despite this all said they would be involved in further interviews should these be required and expressed a sense of pride that they had in some way contributed to research into HIV and African communities. One of the respondents had indefinite rights to remain in the UK, one was an asylum seeker and the other was 'illegal'; yet they felt secure discussing immigration issues and being tape-recorded. It was important to them to know that the tape recording could be stopped whilst they answered certain questions although none used this option. The interviewees received £20 for participating in the pilots.

The tape-recordings/transcripts and field notes of the pilot interviews were all reviewed by one of my supervisors. The content and conduct of the interviews were felt appropriate. Guidance on allowing space within an interview and exploring emerging themes in more depth was also provided.

5.3 Study setting

The study was undertaken in 15 London HIV treatment centres providing in- or out-patient services: Archway Sexual Health Clinic, Central Middlesex Hospital, Charing Cross Hospital, The Chelsea and Westminster Hospital, Homerton University Hospital, the Mortimer Market Centre, the North Middlesex Hospital, Newham University Hospital, the Royal London Hospital, St. Bartholomew's Hospital, St. George's Hospital, St. Mary's Hospital, University College Hospital, Watford General Hospital, and the Victoria Clinic for Sexual Health.

Initially 11 HIV treatment centres were approached to participate in SONHIA however after 10 months of recruitment it was evident that to obtain adequate numbers further sites would be needed; at this stage four further sites became involved (table 5.1).

5.4 Study population

All HIV positive Africans attending the participating centres i) diagnosed HIV positive for the first time within twelve months of recruitment and ii) aged 18 years or older were eligible for recruitment to this study. For the purposes of this study 'Africans' were defined as persons born or raised (up to and including 16 years of age) in Africa. Africans of all racial and ethnic backgrounds were included in the study. Patients diagnosed HIV positive for longer than twelve months but transferring to the study centres during the recruitment period were not eligible for inclusion.

Initially recruitment was restricted to those patients within six months of initial HIV diagnosis; this was in order to reduce measurement error associated with recall bias, and to limit loss to follow-up. It became apparent that such a short time span missed too many eligible patients, in particular pregnant women. The period of eligibility for recruitment was increased to twelve months in May 2005. The time extension provided greater opportunities to approach patients at 'appropriate' times without substantially altering the potential for recall bias.

5.4.1 Patient identification and recruitment

The same recruitment procedure was used for both study components: Each of the 15 study centres nominated a key worker (for example a research nurse) who was responsible for identifying eligible patients. Key workers identified eligible patients via electronic databases and HIV positive case note review. The case notes of all eligible patients were then 'flagged', thereby alerting the physician for study recruitment at an appropriate time. This 'appropriate' time was at the discretion of the attending physician. Recruitment could be undertaken by the physician but was usually conducted by the key worker.

At recruitment, patients received information sheets summarising the study and its key objectives (appendix 5). Written informed consent was required prior to participation in the study (appendix 6). For patients declining to participate in the study collection of anonymised minimal information (ethnicity, country of origin, CD4) to enable assessment of potential selection and participation biases was desired. Despite an appeal, the ethics committee approving this study expressly stipulated that written consent must be obtained to collect this data. If consent was not obtained only data on gender and age could be collected. Once recruited, the key worker arranged for the patient to complete the questionnaire at a convenient time and place.

Once the quantitative component was completed patients were also invited to consider participation in the interviews and if agreeable provided their contact details. Contact was established by telephone and a short screening questionnaire was completed to assess eligibility according to the quota system developed. If the respondent was eligible arrangements were made to conduct the interview at a mutually convenient time and location.

An opportunity to discuss any sensitive issues raised as a result of participating in the interviews or questionnaire (with an appropriate trained professional) was offered to all participants.

5.4.2 Monitoring of recruitment

Monitoring of recruitment procedures occurred throughout the study period. All eligible patients were recorded onto a clinic log. The log included data on age, gender and date of HIV diagnosis. If a patient failed to be approached within the eligibility period this was recorded on the log; as were details and outcome of any approach made within the eligibility period. Copies of the clinic logs were collected on a quarterly basis. In addition for every respondent approached a response sheet was completed. If consent was obtained the response sheets collected data on site of recruitment, age, gender, ethnicity, country of birth, time in UK, and CD4 count and CDC stage at HIV diagnosis. If consent to supply baseline information by those declining to participate was not obtained then only data on clinic site, age and gender was obtained. These sheets were collected regularly and provided a means of monitoring whether systematic bias was occurring in the recruitment process.

I obtained an honorary contract as a clinical researcher at every study site. This enabled me to check data handling methods, review procedures for patient identification, and assist the key workers in data collection, flagging notes and recruitment.

5.5 Ethical approval

Agreement to collaborate was granted from the Lead HIV Consultant in all participating treatment centres. The questionnaire, topic guide, information sheets, consent forms and protocol were granted approval from the London Multicentre Research Ethics Committee (MREC/03/2/105). The study was awarded a no local investigator status, which meant approval from all the appropriate Local Research Ethics Committees was not required although they were all notified about the project. In addition the ACRG approved, reviewed and oversaw all stages of the study.

5.6 Timetable

The quantitative component was initially designed to run for 18 months, with recruitment to the qualitative component to occur in the final 6 months of this 18-month period. In reality the quantitative component ran for 22 months, with recruitment to the in-depth interviews occurring over the final 10-month period. The first study sites commenced recruitment to SONHIA in April 2004. A rollout of subsequent sites followed until March 2005. All sites stopped recruiting on 28 February 2006.

5.7 The challenges of implementation

5.7.1 Recruitment

The principal difficulty with SONHIA was recruitment. Although intended otherwise recruitment was effectively suspended during my maternity leave. In addition the

numbers of Africans diagnosed HIV positive at nearly all the study centres was substantially fewer than those anticipated (table 5.1).

Table 5.1 Study sites recruitment tally

Site	Site #	Start date	Anticipated Total[1]	Actual Total eligible	Approach rate %	Uptake rate % (of those approached)
Archway Sexual Health Clinic	1	06/05/04	57 (19x3)	43	44.2	63.2
Charing Cross Hospital	2	22/4/04	76 (19x4)	12	75.0	100
Chelsea & Westminster Hospital	3	3/8/04	96 (16x6)	78	67.9	43.4
Homerton University Hospital	4	18/05/04	111 (18.5x6)	72	41.7	90.0
Mortimer Market Centre	5	7/4/04	140 (20x7)	58	67.2	87.2
Newham University Hospital	6	01/08/04	160 (16x10)	130	56.9	87.8
North Middlesex Hospital	7	12/5/04	171 (19x9)	108	25.9	96.4
Royal London Hospital	8	15/3/05	102 (8.5x12)	38	36.8	92.9
St. Bartholomew's Hospital	9	17/03/05	17 (8.5x2)	20	80.0	81.3
Victoria Clinic	10	01/08/04	32 (16x2)	3	100	100
University College Hospital	11	01/09/04	30 (15x2)	6	83.3	83.3
Central Middlesex	12	15/12/04	48 (12x4)	7	85.7	83.3
Watford General Hospital	13	30/03/05	32 (8x4)	26	57.7	80.0
St. Georges Hospital	14	18/02/05	28 (9.5x3)	51	35.3	94.4
St. Mary's Hospital	15	9/03/05	36 (9x4)	59	40.7	70.8

[1]Based on 2002-2003 figures of expected eligible patients per month provided by local lead clinician multiplied by number of months in study (ending 31/12/05).

Whilst uptake amongst those approached was higher than anticipated the initial approach was lower. Recruitment opportunities were reduced by the delay inherent in obtaining research and development approval and honorary contracts at each site. Table 5.1 shows the start dates for each study site.

To address these difficulties the period for recruitment was extended and new study sites included. In addition the sample size was reduced from 330 to 250 as power calculations demonstrated minimal effect on the ability to detect associations of interest (table 5.2). MREC was notified of, and approved, these changes.

Table 5.2 Sample size and relative risk

Ability to detect significant associations[1] with outcome measure:	
Sample size	Late presentation
200	RR 1.67
250	RR 1.58
330	RR 1.5

[1]Assuming explanatory factor is binary with a prevalence of 50%, 80% power and significance of 0.05

There was no budget to financially reimburse any of the study sites and involvement in the study was undertaken on a basis of goodwill. Protected time for key workers to work on SONHIA did not exist at most sites and clinical and other research priorities often took precedence. Strategies to support clinic staff, and the key workers, included regular newsletters, emails and phone calls. Collaborative meetings enabled key workers to be kept up to date, and provided a forum for problem solving. In addition I became more directly involved with recruiting at various sites. Clinic presentations were conducted to inform clinic staff about the study, and how they could facilitate recruitment.

5.7.2 Data

Data related issues arose on several fronts. Early on several completed anonymous questionnaires were posted via Royal Mail but never arrived. As a consequence all questionnaires had to be completed on site (given the financial reimbursement), and

completed questionnaires and clinical data sheets remain on site to be collected in person.

To facilitate determination of country of HIV acquisition a revised questionnaire that incorporated additional variables was distributed in August 2005 (appendix 3). These questions included: 'Does your partner currently live in the UK?'; the start and end dates and country of origin of the past two sexual partners; and 'how many people have you had sex with since moving to the UK?'. MREC was notified about, and approved, these changes.

As anticipated those individuals declining to participate also declined to consent to baseline data collection. This was principally due to concerns about disclosure; the consent form was the only place persons could be identified as it included both name and signature. Several persons had been happy to participate until the consent form was presented. A request to obtain the same baseline data on those who were eligible but not approached (the rate limiting step in recruitment) was approved by MREC (substantial amendment 3, December 2005).

The initial plan was that an interim analysis of the quantitative component would have been undertaken prior to the in-depth interviews - thus allowing exploration of factors of interest identified in the survey. This did not occur due to time constraints.

5.8 Further work

Further methodology specific to analysis of the survey is presented along with the results in chapters 6 and 7; in particular chapter 6 explores factors associated with missed opportunities for earlier HIV diagnosis, and chapter 7 with late presentation. The methodology used to determine likely acquisition of HIV in the UK is presented

along with the results in chapter 8. Finally the methodology and findings specific to the qualitative component, the in depth interviews, is found in chapter 9.

Chapter 6: Survey of newly diagnosed HIV positive Africans in London: Results

Abstract

Objective: To describe the socio-demographic and sexual health profile of Africans with newly diagnosed HIV infection living in London.

Methods: A survey of newly diagnosed HIV positive Africans attending 15 HIV treatment centres across London was conducted between April 2004 and February 2006. The survey consisted of a confidential self-completed questionnaire linked to clinician completed clinical records.

Results: 263 questionnaires were completed, representing an uptake rate of 79.5% of patients approached. 49.8% (131/263) of participants presented with advanced HIV disease (CD4 <200x10^6/l at diagnosis). In the year prior to HIV diagnosis 76.4% (181/237) had seen their GP, 38.3% (98/256) had attended outpatient services, and 15.2% (39/257) inpatient services, representing missed opportunities for earlier HIV diagnosis. Of those attending GP services the issue of HIV and/or HIV testing was raised for 17.6% (31/176). 37.1% (78/210) had a previous negative HIV test, 32.5% of these within the UK. Despite the population predominantly coming from countries of high HIV prevalence personal appreciation of risk was comparatively low and knowledge of benefits of testing lacking.

Conclusion: Africans are accessing health services but clinicians are failing to use these opportunities effectively for preventive and diagnostic purposes with regards to HIV infection. Comparatively low appreciation of personal risk and lack of perceived ill health within this community means clinicians need to be more proactive in addressing HIV.

The findings within this chapter are published in *AIDS* (2008) Missed opportunities for earlier HIV diagnosis within primary and secondary health care settings in the UK. F Burns *et al*., v.22: pp.115-122.

6.0 Introduction

Africans with HIV infection in the UK access HIV services at a later stage of HIV disease than non-Africans (Sinka et al., 2003; Del Amo et al., 1998; Burns et al., 2001), this denies them optimal therapeutic options and may hinder prevention efforts.

However the extent of missed opportunities within primary and secondary health care[12] settings for earlier diagnosis within Britain is not known.

This chapter seeks to describe the characteristics of the study population, identify opportunities for earlier HIV diagnosis within primary and secondary care settings in the UK, and to identify factors related to these missed opportunities, in Africans with newly diagnosed HIV infection. Data management, response rates and item non-response are discussed, followed by the descriptive analysis.

6.0.1 Aims and objectives

This chapter aims to describe the health beliefs, heath care utilisation and clinical presentation patterns of newly diagnosed HIV positive Africans in London. Specific objectives are:

a) To describe the demographic characteristics, migration history, HIV/sexual health history, patterns of service utilisation and levels of psycho-social support among this group.

b) To determine opportunities for earlier diagnosis of HIV disease within the UK.

6.1 Methods

As previously described in chapter 5.

6.1.1 Data Preparation and software

Data was entered onto a secure database and systematically checked. Access to the database was limited to the research team and password protected. No identifying data, such as name or hospital number was entered into the database. The questionnaires and

[12] Secondary care: Services provided by medical specialists who generally do not have first contact with patients (e.g., cardiologist, urologists, dermatologists). In the UK patients must first seek care from primary care providers (General practitioners) and are then referred to secondary and/or tertiary providers, as needed.

master sheet are stored in a locked cupboard with access limited to the research team. Data editing, coding and consistency checks were performed prior to any statistical analysis. Analysis was performed using STATA 8.0 (Stata Corporation, College Station, Texas, USA) and SPSSv.12.0 (SPSS Inc.).

6.1.2 Data editing and reduction

All unavailable data was coded as missing.

When necessary continuous variables such as age were categorised into groups that would have statistical efficacy whilst maintaining relevance.

6.1.3 Statistical analysis

Frequency tables and summary statistics with confidence intervals were used to describe the sample population in terms of the various demographic, behavioural, and health service utilisation information of interest.

Two-way associations were examined using cross tabulations and χ^2 tests, unless numbers were small when Fishers exact test was used. Logistic regression was used for univariate analysis to obtain crude odds ratios (OR) with 95% confidence intervals (95%CI). Significance was set at $p<0.05$.

6.2 Results

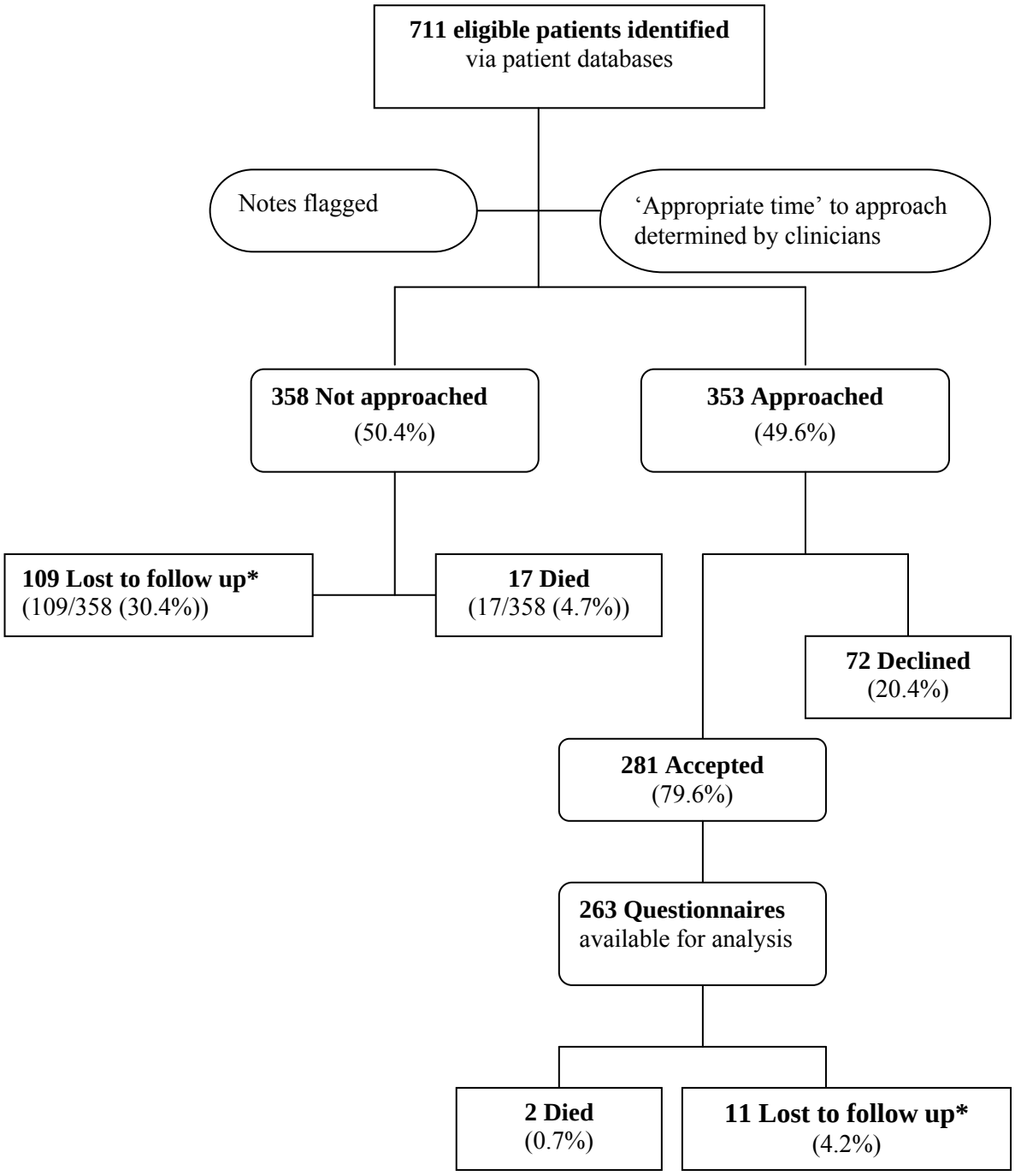
6.2.1 Response rate and missing values

6.2.1.1 Response rate

Of 711 potentially eligible patients 109 (15.3%) were lost to follow-up and 17 (2.4%) had died before they could be approached regarding the study (figure 6.1). Sixty percent (353/585) of remaining patients were approached. The approach rate varied (25.9-100%, $p<0.001$)) between study sites (table 6.1). The uptake rate was 79.6%

(281/353) and 263 questionnaires were available for analysis. A total of 18 questionnaires were lost in the postal system and not available for analysis.

Figure 6.1 Recruitment flow chart



* Not re attended within the 12-month eligibility period after receiving HIV diagnosis, or if recruited no longer attending site for follow-up by six months post diagnosis.

Table 6.1 Characteristics of those approached and not approached regarding study participation

Characteristic	Approached[1] % (r/n)	p-value[2]
Gender		0.165
Male	53.1 (139/262)	
Female	47.7 (214/449)	
Age (years):		0.272
18-24	50.0 (30/60)	
25-34	45.8 (143/312)	
35-44	53.5 (130/243)	
45+	53.9 (48/89)	
Median (range)	35.0 (18-64)	
Site:		<0.001
Archway sexual health clinic	44.2 (19/43)	
Chelsea & Westminster group[3]	69.9 (65/93)	
Homerton Hospital	41.7 (30/72)	
MMC & UCH[4]	68.8 (44/64)	
Newham Hospital	56.9 (74/130)	
North Middlesex Hospital	25.9 (28/108)	
St. Bartholomew's & The Royal London	51.7 (30/58)	
St. Georges Hospital	35.3 (18/51)	
St. Mary's Hospital	40.7 (24/59)	
Watford & Central Middlesex Hospitals	63.6 (21/33)	

[1] [2] Includes those accepting and declining to participate

[2] Comparing those approached with not approached

[3] Chelsea & Westminster hospital, West London Centre for Sexual Health & the Victoria Clinic for Sexual Health

[4] The Mortimer Market Centre & University College Hospital

Data on country of birth and CD4 at diagnosis was collected on those not approached but not for those approached but who declined to participate (see previous chapter, section 5.4.1).

Patients not approached did not differ significantly from those approached in terms of gender or age (table 6.1). Patients that agreed to participate were more likely to come from Southern & Eastern Africa (73.0% vs. 57.9%, p<0.001) than patients not approached (table 6.2). The median CD4 of those accepting to participate was 182

whilst for those not approached it was 260. The patients that were lost to follow up before they could be approached did not differ significantly in terms of gender, age, region of birth, or CD4 at diagnosis from others not approached (data not shown). The proportions of eligible patients approached varied substantially according to site attended (table 6.1).

Table 6.2 Characteristics of those accepting to participate and those not approached

Characteristic	% (r/n)[1]		p-value[2]
	Accepting to participate[3]	Not approached	
Region of birth:			0.001
Central Africa	6.4 (18/281)	8.1 (26/321)	
Southern & Eastern Africa	73.0 (205/281)	57.9 (186/321)	
West Africa	18.1 (51/281)	29.9 (96/321)	
Other (including North Africa)	2.5 (7/281)	4.1 (13/321)	
HIV prevalence in country of birth[4]			0.007
High (>15%)	44.4 (122/275)	33.1 (106/320)	
Medium (5-15%)	39.6 (109/275)	42.8 (137/320)	
Low (<5%)	16.0 (44/275)	24.1 (77/320)	
CD4 count at diagnosis (x10^6/l)			<0.001
0-49	18.9 (53/281)	9.3 (28/300)	
50-199	33.8 (95/281)	26.3 (79/300)	
200-349	23.1 (65/281)	29.0 (87/300)	
350+	24.2 (68/281)	35.3 (106/300)	
Median (range)	182 (0-1333)	260 (1-1160)	
Late presentation (CD4<200)	52.7 (148/281)	35.7 (107/300)	<0.001
Lost to follow up (excludes those known to have died)	4.2 (11/261)	32.0 (109/341)	<0.001
Died within six months of HIV diagnosis	0.8 (2/252)	6.7 (17/248)	<0.001

[1] Base varies due to missing data

[2] Comparing those approached with not approached

[3] Excludes those approached but declining to participate

[4] According to UNAIDS 2003 data (adults aged 15-45)

6.2.1.2 Missing Data

The variables: partner currently living in the UK, country of birth of last two sexual partners, commencement and termination dates of last two sexual relationships, number of (both new and total) sexual partners in UK, and what participants would like more information on, were added at a later date (see previous chapter, section 5.7.2) and so only available to answer for 80 participants.

Item non-response was less than 5% except for those variables shown in table 6.3.

Table 6.3 Questionnaire item non-response

Variable	Item non-response
Postcode	11.0%
Number of sexual partners in UK prior to HIV diagnosis	12.2%
Condom use in UK prior to HIV diagnosis	8.4%
Ever been paid for sex	5.3%
STI diagnosis prior to UK	9.1%
STI diagnosis in the UK	18.6%[1]
Previous negative HIV test	20.2%
Number of people participant knew to have HIV prior to their diagnosis	12.2%
Main source of HIV information prior to diagnosis	18.2%
Influence of advertising on HIV testing	10.6%
Perceived time of infection	20.5%
Perceived reason for HIV infection	24.3%
Factors that would have made participant test earlier	6.1%
Accessing of HIV support groups	12.2%

[1] Typing error routed participants away from this question – amended half way through recruitment period.

Questions presented in the form of a Likert scale were more poorly answered than other question formats. For the Likert scales exploring beliefs around HIV and HIV services, and people's reactions and attitudes to HIV, missing responses were 4.2-7.2%. Missing responses for the Likert scales exploring factors preventing participants testing earlier ranged between 14.8-18.6%.

6.2.2 Descriptive analysis:

One hundred and four men and 159 women completed the questionnaire. The median time between HIV diagnosis and questionnaire completion was 3.5 months. 83.6% of participants came from countries with HIV prevalence greater than 5% (table 6.4), and the median time in the UK prior to diagnosis was 3.9 years.

Table 6.4 Country of birth of study participants (n=263)

Country of birth	N (%)
High (>15%) HIV prevalence countries[1]	
Zimbabwe	68 (25.9)
Zambia	27 (10.3)
South Africa	23 (8.7)
Swaziland	1 (0.4)
Medium (5-15%) HIV prevalence[1]	
Uganda	33 (12.5)
Nigeria	20 (7.6)
Kenya	12 (4.6)
Malawi	8 (3.0)
Cameroon	7 (2.7)
Congo (Democratic republic of)	6 (2.3)
Rwanda	5 (1.9)
Burundi	5 (1.9)
Cote d'Ivorie	4 (1.5)
Tanzania	1 (0.4)
Low (<5%) HIV prevalence[1]	
Ghana	22 (8.4)
Ethiopia	5 (1.9)
UK	5 (1.9)
Somalia[2]	5 (1.9)
Angola	2 (0.8)
Eritrea	1 (0.4)
Algeria	1 (0.4)
Italy	1 (0.4)
Sierra Leone[2]	1 (0.4)

[1] According to UNAIDS 2003 data (adults aged 15-49)

[2] Data unavailable – assumed to be <5% prevalence

Socio-Demographics (table 6.5)

The median age of respondents was 34 years, 62.5% were women, 98.1% were born in Africa, and 93.5% described their ethnicity as black African. Almost half (48.3%) of respondents had migrated from Southern or South-eastern Africa, and 17.9% (47/263) from West Africa. The majority (92.5%) defined themselves as heterosexual and most (66.5%) had children. Respondents were well educated, 43.8% having undertaken higher education, however 31.3% were unemployed when completing the survey.

A substantial minority (21.7%) were dependent on friends or relatives for housing and 6.1% were homeless living in hostels or bed and breakfasts. 48.1% of respondents had secure permanent residency rights within the UK, this included citizenship, indefinite leave to remain, and refugee status. A further 33.5% were on time-limited visas, and 18.5% had uncertain rights to remain in the UK as they were awaiting decisions on asylum applications, applying for visas or illegally in the country.

Several significant differences in the socio-demographic characteristics existed between men and women. Men tended to be older (median age 37 vs. 33, p=0.001), more likely to define themselves as homosexual or bisexual, more likely to be married, to be in full time employment, and of occupational class 1 or 2 (12.9% vs. 4%, p=0.002) than women. Women were more likely to be of black ethnicity, to have been previously married, to be in full time study, to attend religious services once a week or more (60.4% vs. 35.9%, p=0.002) and to report their faith as very important (94.3 vs. 85.4, p=0.027) compared to men.

Table 6.5 Socio-demographic profile of study participants

Characteristic	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Gender	100 (263/263)	39.5 (104/263)	60.5 (159/263)	---
Age (years):				0.001
18-24	7.6 (20/263)	2.9 (3/104)	10.8 (17/159)	
25-34	43.0 (113/263)	33.7 (35/104)	48.7 (78/159)	
35-44	35.7 (94/263)	49.0 (51/104)	27.2 (43/159)	
45+	13.7 (36/263)	14.4 (15/104)	13.3 (21/159)	
Median (range)	34 (18-62)	37 (22-57)	33 (18-62)	
Ethnicity:				---
Black African	93.5 (246/263)	88.5 (92/104)	96.9 (154/159)	
Black other (including black British and mixed)	3.4 (9/263)	3.8 (4/104)	3.1 (5/159)	
Other (White, Asian, Arab)	3.0 (8/263)	7.7 (8/104)	0	
Sexuality:				<0.001
Heterosexual	92.5 (234/253)	84.8 (84/99)	97.4 (150/154)	
Bi or Homosexual	7.5 (19/253)	15.2 (15/99)	2.6 (4/154)	
Education				0.134
Degree	27.3 (71/260)	35.0 (36/103)	22.3 (35/157)	
Diploma/NVQ or equivalent	16.5 (43/260)	11.7 (12/103)	19.7 (31/157)	
A-levels or equivalent	21.2 (55/260)	22.3 (23/103)	20.4 (32/157)	
GCSE/O-level equivalent	23.5 (61/260)	21.4 (22/103)	24.8 (39/157)	
Other/none	11.5 (30/260)	9.7 (10/103)	12.7 (20/157)	
Marital Status:				0.003
Married/cohabiting	38.0 (98/258)	46.2 (48/104)	32.5 (50/154)	
Previously married	18.6 (48/258)	8.7 (9/104)	25.3 (39/154)	
Partner but living apart	20.9 (54/258)	25.0 (26/104)	18.2 (28/154)	
Single, never married	22.5 (58/258)	20.2 (21/104)	24.0 (37/154)	
Have children	66.5 (173/260)	62.7 (64/102)	69.0 (109/158)	0.298
At least one child born in UK since 1998[4]	13.6 (35/257)	17.0 (17/100)	12.8 (20/156)	0.353
Region of birth:				0.304
Central & Western Africa	23.6 (62/263)	26.9 (28/104)	21.4 (34/159)	
East Africa	25.5 (67/263)	20.2 (21/104)	28.9 (46/159)	
Southern & South-eastern Africa	48.3 (127/263)	49.0 (51/104)	47.8 (76/159)	
Other (Northern Africa & Europe)	2.7 (7/263)	3.8 (4/104)	1.9 (3/159)	
HIV prevalence[3] of country of birth				0.148
High (>15%)	45.2 (119/263)	48.1 (50/104)	43.4 (69/159)	
Medium (5-15%)	38.4 (101/263)	30.8 (32/104)	43.4 (69/159)	
Low (<5%)	16.4 (43/263)	21.2 (21/104)	13.2 (21/159)	
Currently:				0.497
Living in the UK	76.8 (202/263)	81.7 (85/104)	73.6 (117/159)	
Visiting the UK	4.9 (13/263)	3.8 (4/104)	5.7 (9/159)	
Studying in the UK	12.5 (33/263)	9.6 (10/104)	14.5 (23/159)	
Other (e.g. short term-work contract)	5.7 (15/263)	4.8 (5/104)	6.3 (10/159)	

Characteristic	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Residency status in the UK				0.185
Indefinite leave to remain (British citizen, EEC member, Permanent resident, refugee)	48.1 (125/260)	54.8 (57/104)	43.6 (68/156)	
Visa entry	33.5 (87/260)	27.9 (29/104)	37.2 (58/156)	
Uncertain right to remain (e.g. Asylum seeker, applying for visa, illegal)	18.5 (48/260)	17.3 (18/104)	19.2 (30/156)	
Accommodation				0.164
Own	9.9 (26/262)	14.4 (15/104)	6.9 (11/158)	
Rent	62.4 (164/262)	60.6 (63/104)	63.5(101/158)	
Live with friends or relatives	21.7 (57/262)	21.2 (22/104)	22.0 (35/158)	
Other (incl. Hostel, B&B)	6.1 (16/262)	3.8 (4/104)	7.5 (12/159)	
Employment status				0.007
Employed fulltime	35.9 (93/259)	48.1 (50/104)	27.7 (43/155)	
Employed part time	14.3 (37/259)	12.5 (13/104)	15.5 (24/155)	
Student (Full time)	18.5 (48/259)	12.5 (13/104)	22.6 (35/155)	
Unemployed	31.3 (81/259)	26.9 (28/104)	34.2 (53/155)	
Unemployed – not registered for benefits	43.2 (35/81)	50.0 (14/28)	39.6 (21/53)	
Age on arrival in the UK				0.187
0-29 years	55.9 (146/261)	51.0 (53/104)	59.2 (93/157)	
30+ years	44.1 (115/261)	49.0 (51/104)	40.8 (64/157)	
Time in UK before HIV diagnosis:				0.265
3 or more years	63.2 (165/261)	67.3 (70/104)	60.5 (95/157)	
<3 years	36.8 (96/261)	32.7(34/104)	39.5 (62/157)	
Median in years (range)	3.94(-0.7–34.6)	4.22 (0.1-31.8)	3.85 (-0.7-36.4)	
English spoken comfortably	88.2 (232/262)	94.2 (97/103)	84.9(135/159)	0.021
Preferred language to read in				0.074
English	89.0 (234/263)	95.2 (99/104)	84.9 (135/159)	
French	5.3 (14/263)	1.9 (2/104)	7.5(12/159)	
Other (includes illiterate)	5.7 (15/263)	3.0 (3/104)	7.5 (12/159)	
Religion:				0.569
Roman catholic	35.2 (92/261)	34.6 (36/104)	35.7 (56/157)	
Christian – non Roman Catholic	54.0 (141/261)	51.9 (54/104)	55.4 (87/157)	
Muslim	6.9 (18/261)	7.7 (8/104)	6.4 (10/157)	
Other	3.8 (10/261)	5.8 (6/104)	2.5 (4/157)	

[1] Base varies due to item non-response

[2] Comparing men and women (Pearson Chi-square or Fishers Exact Test where appropriate)

[3] HIV prevalence (%) adults aged 15-49 at end of 2003 according to UNAIDS

[4] Universal HIV testing introduced in antenatal clinics in UK in 1999.

Sexual health and behaviour (table 6.6)

Of the 190 respondents in a relationship when completing the questionnaire 37.4% did not know the HIV status of their partner, and 24.7% had HIV negative partners. Consistent condom use whilst in the UK was reported by 21.2% of respondents, and 39.4% of all respondents reported two or more sexual partners in the UK prior to HIV diagnosis. Respondents were asked to provide details about their last two sexual partnerships in the UK: 69.2% (72/104) of partnerships were with African nationals, and 36.0% of these partnerships were concurrent.

Travel back to Africa was reported by 38.5% of respondents. Of those travelling to Africa sexual intercourse with a new partner was reported to occur on their last journey in 25.0% (25/100) of cases, with 68% (17/25) reporting no, or inconsistent, condom use.

Almost a quarter (23.3%) of men reported paying for sex, and 3.4% (5/147) of women had been paid for sex. Past history of a STI diagnosis was high with 27.2% (65/239) (47.7% of men & 15.2% of women, $p<0.001$) reporting a STI prior to moving to the UK.

Significant differences between men and women existed for all the sexual health variables except reported condom use. Men appear more likely to know the HIV status of their partners, to have had more sexual partners since moving to the UK, to have sexual partners from Britain, and to have concurrent partners, than women. Women were more likely not to have had sex in the past two years, and for their last two sexual partners to come from Africa, than men.

Table 6.6 Sexual health and risk of study participants

Characteristic	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Partner				0.004
HIV positive	28.1 (72/256)	36.9 (38/103))	22.2 (34/153))	
HIV negative	18.4 (47/256))	24.3 (25/103)	14.4 (22/153)	
Untested for HIV	7.4 (19/256)	3.9 (4/103)	9.8 (15/153)	
Did not know	20.3 (52/256)	14.6 (15/103)	24.2 (37/153)	
Did not have a partner	25.8 (66/256)	20.4 (21/103)	29.4 (45/153)	
In the last 2 years have had sex with:				<0.001
Opposite sex only	79.1 (200/253)	78.8 (78/99))	79.2 (122/154)	
Same or both sexes	5.9 (15/253)	14.1 (14/99)	0.6 (1/154)	
Not had sex in last 2 years	15.0 (38/253)	7.1 (7/99)	20.1 (31/154)	
Median number of sexual partners since moving to UK[3] (range)	2 (0-250) n=73	3.0 n=28	2.0 n=45	
Median number of new sexual partners since moving to UK[3] (range)	1 (0-250) n=68	2.5 (0-250) n=26	1.0 (0-3) n=42	
Number of sexual partners in UK prior to HIV diagnosis				<0.001
0	21.2 (49/231)	15.1 (13/86)	24.8 (36/145)	
1	39.4 (91/231)	33.7 (29/86)	42.8 (62/145)	
2-3	22.1 (51/231)	18.6 (16/86)	24.1 (35/145)	
4 or more	17.3 (40/231)	32.6 (28/86)	8.3 (12/145)	
Median number (range)	1 (0-247)	2.0 (0-247)	1.0 (0-30)	
Mean (standard deviation)	5.76 (25.88)	12.64 (41.14)	1.59 (2.83)	
Condom use in UK prior to HIV diagnosis				0.159
Yes, every occasion	21.2 (51/241)	27.1 (26/96)	17.2 (25/145)	
Yes, some occasions	39.0 (94/241)	41.7 (40/96)	37.2 (54/145)	
No, not used	18.7 (45/241)	13.5 (13/96)	22.1 (32/145)	
Unsure	1.7 (4/241)	2.1 (2/96)	1.4 (2/145)	
Not had sex in UK	19.5 (47/241)	15.6 (15/96)	22.1 (32/145)	
Proportion of past 2 sexual partners from Africa[3,4]	69.2 (72/104)	51.2 (22/43)	82.0 (50/61)	
Proportion of past 2 sexual partners from Britain[3,4]	17.3 (18/104)	25.6 (11/43)	11.5 (7/61)	
Last two sexual partners concurrent[3]	36.0 (18/50)	58.8 (10/17)	24.2 (8/33)	0.016
Number of sexual partners in past year				<0.001
0	21.4 (52/243)	15.1 (14/93)	25.3 (38/150)	
1	53.5 (130/243)	44.1 (41/93)	59.3 (89/150)	
2-3	16.0 (39/243)	24.7 (23/93)	10.7 (16/150)	
4 or more	8.4 (22/243)	16.1 (15/93)	4.7 (7/150)	
Median number (range)	1.83 (0-50)	.0 (0-30)	1.0 (0-50)	
Condom use in past year				0.192
Yes, every occasion	19.1 (48/251)	23.0 (23/100)	16.6 (25/151)	
Yes, some occasions	31.9 (80/251)	35.0 (35/100)	29.8 (45/151)	
No, not used	26.3 (66/251)	25.0 (25/100)	27.2 (41/151)	
Unsure	1.2 (3/251)	2.0 (2/100)	0.7 (1/151)	
Not had sex in past year	21.5 (54/251)	15.0 (15/100)	25.8 (39/151)	

Characteristic	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Travelled back to Africa	38.5 (100/260)	38.5 (40/104)	38.5 (60/156)	0.971
Median time in years since last visit (range)	2.0 (0.4-19.6)	2.2 (0.6-19.6)	1.9 (0.4-13.5)	
Sexual intercourse with new partners on last visit	25.0 (25/100)	47.5 (19/40)	10.0 (6/60)	<0.001
Condom use with new partner(s) when last visiting Africa				0.798
Yes, every occasion	32.0 (8/25)	36.8 (7/19)	16.7 (1/6)	
Yes, some occasions	36.0 (9/25)	31.6 (6/19)	50.0 (3/6)	
No, not used	16.0 (4/25)	15.8 (3/19)	16.7 (1/6)	
Unsure	16.0 (4/25)	15.8(3/19)	16.7 (1/6)	
Ever paid for sex	10.6 (27/254)	23.3 (24/103)	2.0 (3/151)	---
Where paid for sex:				
In Africa	50.0 (13/26)	52.2 (12/23)	33.3 (1/3)	
In UK	34.6 (9/26)	39.1 (9/23)	0	
In UK & Africa	11.5 (3/26)	8.7 (2/23)	33.3 (1/3)	
Ever been paid for sex	2.8 (7/249)	2.0 (2/102)	3.4 (5/147)	---
Where been paid for sex:				
In Africa	33.3 (2/6)	0	25.0 (1/4)	
In UK	50.0 (3/6)	100.0 (2/2)	50.0 (2/4)	
In UK & Africa	16.7 (1/6)	0	25.0 (1/4)	
Previous STI diagnosis				
Prior to moving to UK	27.2 (65/239)	47.7 (42/88)	15.2 (23/151)	<0.001
Herpes	7.6 (18/238)	12.5 (11/88)	4.7 (7/150)	0.027
Trichomonas vaginalis (TV)	0	0	0	-
Syphilis	4.2 (10/238)	10.2 (9/88)	0.7 (1/150)	<0.001
Gonorrhoea	9.2 (22/238)	22.7 (20/88)	1.3 (2/150)	<0.001
Genital warts	5.9 (14/238)	9.1 (8/88)	4.0 (6/150)	0.107
Non-specific urethritis	0.4 (1/238)	1.1 (1/88)	0	-
Chlamydia	2.1 (5/238)	2.3 (2/88)	2.0 (3/150)	0.887
STI of unknown name	5.0 (12/238)	5.7 (5/88)	4.7 (7/150)	0.715
Pelvic inflammatory disease (PID) (women only)	-	-	0.7 (1/150)	
Since moving to UK	29.9 (64/214)	35.3 (30/85)	26.4 (34/129)	0.145
Herpes	8.4 (18/214)	10.6 (9/85)	7.0 (9/129)	0.352
TV	0	0	0	-
Syphilis	6.1 (13/214)	10.6 (9/85)	3.1 (4/129)	0.025
Gonorrhoea	0.9 (2/214)	2.4 (2/85)	0	-
Genital warts	5.6 (12/214)	5.9 (5/85)	5.4 (7/129)	0.887
Chlamydia	5.6 (12/214)	7.1 (6/85)	4.7 (6/129)	0.454
Non-specific urethritis	0.9 (2/214)	2.4 (2/85)	0	-
STI of unknown name	2.8 (6/214)	3.6 (3/85)	2.3 (3/129)	0.591
BV (women only)	-	-	6.2 (8/129)	
PID (women only)	-	-	3.1 (4/129)	

[1] Base varies due to item non-response

[2] Comparing men and women

[3] Maximum base of 80

[4] Excludes those who have not had sex in the UK

Health service utilisation (tables 6.7 and 6.8)

Primary care use was high with 84.6% (220/260) being registered with a general practitioner (GP) for a median of 3 years. In the year prior to HIV diagnosis 76.4% (181/237) had seen their GP, 38.3% (98/256) had attended outpatient services, and 15.2% (39/257) inpatient services. The reasons for seeking medical attention are presented in table 6.8. Whilst accessing of health services was high the majority (64.8% (169/261)) of participants rated their health status as excellent or very good 12 months prior to completion of the questionnaire. Of those attending GP services the issue of HIV and/or HIV testing was raised for 17.6% (31/176).

Other than differences pertaining to pregnancy there were no significant differences in health and social service use prior to HIV diagnosis by gender.

HIV awareness (table 6.9)

Thirty seven percent (78/210) of respondents had a previous negative HIV test, of these 32.5% (25/77) occurred within the UK. Five percent (14/263) of participants were diagnosed with HIV within two years of a negative HIV test. The median time between last negative HIV test and testing HIV positive was 2.8 years for those who been previously tested. Neither the type of health service nor the number of different services attended was associated with either the site of (e.g. in hospital), or reason for (e.g. advised to by Doctor), last HIV test (data not shown).

While most (68.4%) participants knew about medical confidentiality a lower proportion (28.3%) was aware that HIV testing could be freely obtained, and half of respondents had lived in the UK for two years or more before they knew where to obtain an HIV test. The most common (30.1%) source of HIV testing site information was whilst an inpatient, 24.7% reported being influenced by advertising in deciding to test.

Table 6.7 Health & social service use prior to HIV diagnosis of study participants

Services	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Registered with GP	84.6 (220/260)	82.7 (86/104)	85.9 (134/156)	0.483
Median time with GP (years)	3	3.5	3	
Inpatient use in past year	15.2 (39/257)	12.9 (13/101)	16.7 (26/156)	0.408
In UK	74.4 (29/39)	84.6 (11/13)	69.2 (18/26)	0.528
Outpatient use in past year	38.3 (98/256)	35.0 (36/103)	40.5 (62/153)	0.368
In UK	86.6 (84/97)	83.3 (30/36)	88.5 (54/61)	0.468
Number of GP visits in year before HIV diagnosis:				0.607
None	33.3 (79/237)	36.4 (36/99)	31.2 (43/138)	
1	11.8 (28/237)	15.2 (15/99)	9.4 (13/138)	
2-4	43.0 (102/237)	36.4 (36/99)	47.8 (66/138)	
5 or more	11.8 (28/237)	12.0 (12/99)	11.6 (16/138)	
Median (range)	2 (0-18)	1 (0-12)	2 (0-18)	
Attended GP in 2 years before HIV diagnosis	75.1 (193/257)	74.5 (76/102)	75.5 (117/155)	0.860
HIV testing mentioned by GP in past year	17.1 (31/176)	16.2 (11/68)	18.5 (20/108)	0.839
Illness or accident that has affected health for at least 3 months in the last 5 years (apart from HIV)	24.5 (63/257)	20.6 (21/102)	27.1 (42/155)	0.235
Attended antenatal care in UK in past 5 years	15.9 (25/157)	--	15.9 (25/157)	na
Mean number of pregnancies	1.23	---	1.3	
Attends HIV services within own Strategic Health Authority	72.6 (170/234)	69.0 (69/100)	75.4 (101/134)	0.279
Health 12 months ago				0.883
Excellent or very good	64.8 (169/261)	66.3 (69/104)	63.7 (100/157)	
Fair	20.7 (54/261)	19.2 (20/104)	21.7 (34/157)	
Poor or terrible	14.6 (38/261)	14.4 (15/104)	14.6 (23/157)	
Health now				0.084
Excellent or very good	51.5 (135/262)	57.7 (60/104)	47.5 (75/158)	
Fair	34.4 (90/262)	33.7 (35/104)	34.8 (55/158)	
Poor or terrible	14.1 (37/262)	8.7 (9/104)	17.7 (28/158)	
Length of poor health				0.539
Not at all	56.5 (148/262)	53.8 (56/104)	58.2 (92/158)	
12 months or less	38.2 (100/262)	41.3 (43/104	36.1 (57/158)	
More than 1 year	5.3 (14/262)	4.8 (5/104)	5.7 (9/158)	

[1] Base varies due to item non-response

[2] Comparing men & women [3] Prior to HIV diagnosis

Table 6.8 Summary of medical care prior to HIV diagnosis. Values are numbers (percentages).

	Attended GP in the two years prior to HIV diagnosis[1]	Attended outpatients in the year prior to HIVdiagnosis[1]	Inpatient stay in the year prior to HIVdiagnosis[1]
Total	193/257 (75.1)	98/256 (38.3)	39/257 (15.2)
Reason for seeking care[2]	n=183	n=92	n=31
Dermatology	42 (23.0)	6 (6.5)	-
Gastroenterology	3 (1.6)	3 (3.3)	1 (3.2)
Hypertension & Diabetes	6 (3.3)	6 (6.5)	-
Infectious causes			
Fever ?cause	3 (1.6)	-	4 (12.9)
Flu or chest infection[3]	84 (45.9)	17 (18.5)	2 (6.5)
TB	-	0.5 (1)	-
Varicella Zoster	3 (1.6)	1 (0.5)	1 (3.2)
Other (e.g. hepatitis, meningitis, sinusitis, syphilis)	3 (1.6)	11 (11.9)	3 (9.7)
Malaise	4 (2.2)	7 (7.6)	-
Neurological	7 (3.8)	1 (1.1)	-
Obstetrics, gynaecology & family planning	38 (20.8)	5 (5.4)	3 (9.7)
Psychiatric/depression	-	4 (4.3)	3 (9.7)
Surgical	3 (1.6)	6 (6.5)	9 (29.0)
Trauma/minor injury	12 (6.6)	4 (4.3)	-
Other	31 (16.9)	21 (22.8)	4 (12.9)

[1] Total greater than 100% as more than one reason could be listed

[2] Percentages are the proportion of those accessing that service with reason given

[3] Including pneumonia

HIV awareness prior to HIV diagnosis appeared similar between men and women. Most (72.4%) knew someone with HIV prior to their own diagnosis, and many knew more than one (41.2% knowing 5 or more people). A difference did exist in the perception prior to diagnosis of the type of person who got HIV. Men were more likely to think ‘anybody’ could get it (72.1% vs. 57.1%, p=0.018) than women; and women were more likely to believe that only ‘people who sleep with lots of people’ got HIV (46.8% vs. 28.8%, p=0.004) than men.

Table 6.9 HIV awareness prior to HIV diagnosis of study participants

HIV awareness prior to diagnosis	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Previous negative HIV test[3]	37.1 (78/210)	36.9 (31/84)	37.3 (47/126)	0.954
Number of previous tests				0.018
1	53.4 (39/73)	71.4 (20/28)	42.2 (19/45)	
2-4	46.6 (34/73)	28.6 (8/28)	57.8 (26/45)	
Median duration from last negative HIV test to positive test (years)	2.8 n=44	2.4 n=19	3.2 n=25	
HIV diagnosis within 2 years of a negative HIV test	31.8 (14/44)	47.4 (9/19)	20.0 (5/25)	0.101
Site of last negative test				0.115
In Africa	63.6 (49/77)	54.8 (17/31)	69.6 (32/46)	
In UK GUM or antenatal clinic	23.4 (18/77)	35.5 (11/31)	15.2 (7/46)	
Elsewhere in UK	13.0 (10/77)	9.7 (3/31)	15.2 (7/46)	
HIV mentioned in context of previous sexual health consultation[4]				
In Africa	15.9 (14/88)	16.3 (7/43)	15.6 (7/45)	1.000
In UK	51.8 (43/83)	63.6 (21/33)	44.0 (22/50)	0.116
Time in UK before knowledge of where to have HIV test:				0.388
Less than 12 months	33.1 (83/251)	27.2 (28/103)	37.2 (55/148)	
1-2 years	17.1 (43/251)	19.4 (20/103)	15.5 (23/148)	
2-5 years	28.3 (71/251)	29.1 (30/103)	27.7 (41/148)	
>5 years	21.5 (54/251)	24.3 (25/103)	19.6 (29/148)	
How found out where to have HIV test:				0.008
From a GP surgery	20.9 (52/249)	14.7 (15/102)	25.2 (37/147)	
Friends or family	17.7 (44/249)	19.6 (20/102)	16.3 (24/147)	
The media	6.0 (15/249)	9.8 (10/102)	3.4 (5/147)	
Internet	2.4 (6/249)	4.9 (5/102)	0.7 (1/147)	
Offered whilst in hospital	30.1 (75/249)	29.4 (30/102)	30.6 (45/147)	
Partner	5.6 (14/249)	8.8 (9/102)	3.4 (5/147)	
Other	17.3 (43/249)	12.7 (13/102)	20.4 (30/147)	
Ever try but unable to have an HIV test	11.0 (28/255)	6.9 (7/102)	13.7 (21/153)	0.103
Reason unable to have test:				0.888
Not offered by clinician	25.9 (7/27)	28.6 (2/7)	25.0 (5/20)	
Didn't know where to go	29.6 (8/27)	28.6 (2/7)	30.0 (6/20)	
Other (no appointments, no childcare, etc)	44.4 (12/27)	42.9 (3/7)	45.0 (9/20)	
Discussed HIV with someone prior to diagnosis	76.8 (199/259)	78.8 (82/104)	75.5 (117/155)	0.552
If yes who with:				
Partner	47.7 (95/199)	48.8 (40/82)	47.0 (55/117)	0.886
Friends	63.8 (127/199)	64.6 (53/82)	63.2 (74/117)	0.882
Health care professional	14.6 (29/199)	13.4 (11/82)	15.4 (18/117)	0.839
Other				
Influenced to have HIV test by advertising	24.7 (58/235)	20.2 (18/89)	27.4 (40/146)	0.275
Knowledge that HIV testing would be free when arrived in UK	28.3 (73/258)	32.7 (34/104)	25.3 (39/154)	0.208
Knowledge of medical confidentiality prior to HIV diagnosis	68.4 (175/256)	71.6 (73/102)	66.2 (102/154)	0.411

HIV awareness prior to diagnosis	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Perception of type of person who got HIV prior to HIV diagnosis[5]				
Anybody	62.7 (163/260)	72.1 (75/104)	57.1 (89/156)	0.018
Only people who have sex with lots of people	39.6 (103/260)	28.8 (30/104)	46.8 (73/156)	0.004
Only people who have sex in Africa	2.7 (7/260)	1.9 (2/104)	3.2 (5/156)	0.706
Drug addicts	11.9 (31/260)	10.6 (11/104)	12.8 (20/156)	0.697
Gay men	13.1 (34/260)	11.5 (12/104)	14.1 (22/156)	0.579
People who do not believe in God	2.3 (6/260)	2.9 (3/104)	1.9 (3/156)	0.686
Other	3.5 (9/260)	4.8 (5/104)	2.6 (4/156)	0.491
Number of people participant knew to have HIV prior to their diagnosis (excludes don't knows):				0.457
No one	27.6 (63/228)	26.9 (25/93)	28.1 (38/135)	
1	10.1 (23/228)	12.9 (12/93)	8.1 (11/135)	
2-4	21.1 (48/228)	23.7 (22/93)	19.3 (26/135)	
5 or more	41.2 (94/228)	36.6 (34/93)	44.4 (60/135)	
Main source of HIV information prior to diagnosis				0.385
Health care workers	23.3 (50/215)	17.0 (15/88)	27.6 (35/127)	
HIV positive people or organisations	10.2 (22/215)	10.2 (9/88)	10.2 (13/127)	
Friends or partner	20.0 (43/215)	22.7 (20/88)	18.1 (23/127)	
The media	34.0 (73/215)	38.6 (34/88)	30.7 (39/127)	
Other	12.6 (27/215)	11.4 (10/88)	13.4 (17/127)	

[1] Base varies due to item non-response

[2] Comparing men and women

[3] Excludes those who do not know if they have ever tested (n=37)

[4] Where a diagnosis of a previous STI, Candida or BV infection has been established.

[5] Respondents had option of more than one response so total >100%

HIV testing and diagnosis (table 6.10)

The majority of participants were diagnosed with HIV in a sexual health clinic (50.6%) or in hospital (34%). Only 4% (10/250) reported that they were diagnosed HIV positive in Africa. Advice by a hospital or clinic doctor was the main reason for the HIV test (33.7%). 11.9% had the test as part of a routine check up. Only 14.9% (37/258) were expecting the positive result whilst a further 21.3% did not know what to expect. No significant differences in site, of, reason for, or expectation of, HIV test were found by gender.

Table 6.10 Experiences of testing HIV positive for study participants

HIV Testing	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Diagnosed HIV positive in Africa	4.0 (10/250)	5.1 (5/99)	3.3 (5/151)	0.523
Site of HIV diagnosis in the UK				---
Sexual Health Clinic	50.6 (131/259)	53.4 (55/103)	48.7 (76/156)	
GP surgery	6.2 (16/259)	4.9 (5/103)	7.1 (11/156)	
In hospital (ward or outpatients)	34.0 (88/259)	39.8 (41/103)	30.1 (47/156)	
Ante-natal clinic	6.9 (18/259)	0	11.5 (18/156)	
Other	2.3 (6/259)	1.9 (2/103)	2.9 (4/156)	
Main reason for last HIV test				0.438
Advised to by hospital or clinic doctor	33.7 (88/261)	37.5 (39/104)	31.2 (49/157)	
Advised to by GP	6.5 (17/261)	4.8 (5/104)	7.6 (12/157)	
Health complaints thought may be related to HIV	18.4 (48/261)	17.3 (18/104)	19.1 (30/157)	
Sexual contact with someone known or thought to have HIV	9.6 (25/261)	12.5 (13/104)	7.6 (12/157)	
Child tested positive	3.1 (8/261)	2.9 (3/104)	3.2 (5/157)	
Related to pregnancy of partner or self	10.0 (26/261)	5.8 (6/104)	12.7 (20/157)	
Routine check up	11.9 (31/261)	13.5 (14/104)	10.8 (17/157)	
Other	6.8 (18/261)	5.8 (6/104)	7.6 (12/157)	
Expecting positive result	14.3 (37/258)	16.5 (17/103)	12.9 (20/155)	0.634
Do not know	21.3 (55/258)	22.3 (23/103)	20.6 (32/155)	
Perceived reason for time of infection				---
Sex with someone now known to have HIV	15.6 (31/199)	20.5 (17/83)	12.1 (14/116)	
Sex with someone at high risk of HIV	22.6 (45/199)	30.1 (25/83)	17.2 (20/116)	
Sexual assault/rape	6.5 (13/199)	0	11.2 (13/116)	
Became unwell	21.1 (42/199)	18.1 (15/83)	23.3 (27/116)	
Blood transfusion or injection	6.5 (13/199)	6.0 (5/83)	6.9 (8/116)	
Other/don't know	27.6 (55/199)	25.3 (21/83)	29.3 (34/116)	

[1] Base varies due to item non-response

[2] Comparing men and women

[3] Participants could select more than one reason hence total more than 100%

Influencing factors on HIV testing (table 6.11)

Approximately 70% (179/256) of the participants had not considered the possibility that they may be HIV positive. Similarly 59.1% (146/247) felt that if someone had told them they were at risk it would have made them test earlier. 17.8% were unaware that HIV could be treated and 11.7% unaware that the risk of mother to child transmission (MTCT) could be reduced, both factors that would have made participants test earlier.

Table 6.11 Factors influencing study participants timing of HIV test[1]

	Factor[2]	Main Factor[2]
Factors stopping participants testing for HIV earlier	n=256	n=208
Had not considered possibility that may be HIV+	69.9%	54.3%
Well so no need	51.2%	20.2%
Afraid of the result	28.1%	11.1%
Afraid of the stigma associated with HIV	28.9%	5.8%
Other[3]	33.1%	8.6%
Factors that would have made participants test for HIV earlier	n=247	n=213
If someone had told me that I was at risk	59.1%	49.3%
If felt would be supported if I tested HIV positive	31.2%	8.0%
If there was no stigma associated with HIV	36.8%	16.4%
If HIV was not so linked to sex	21.9%	6.6%
If knew medication for HIV was available	17.8%	6.6%
If knew could reduce vertical transmission	11.7%	4.2%
Other factor	10.9%	8.9%

[1] Participants were asked to tick all factors that applied and to identify the single most important factor.
[2] Base varies due to item non-response

[3] Other includes not wanting to go to a Genitourinary medicine clinic, not knowing where to go, fear of losing a relationship, fear of influencing immigration process, the fact that some had previously tested for HIV so felt not applicable.

The factors potentially influencing the timing of an HIV test did not significantly differ between men and women.

Clinical presentation (table 6.12)

Half (131/263) of all participants presented with late stage disease, with 20% (52/263) being severely immuno-compromised (CD4 counts below $50x10^6$/l). In keeping with the immunology 46.2% (121/262) had symptomatic disease (CDC B or C) at diagnosis: Tuberculosis (29/74) accounted for 39.2% of all AIDS defining illnesses. Mutations conferring medium or high-level primary antiretroviral drug resistance were found in 9.5% (9/95) of samples tested. Within six months of diagnosis 63.1% (169/252) of participants were commenced on ART and 66.9% (113/169) had an undetectable viral load (<50 copies/ml).

Table 6.12 Clinical characteristics of study population

Clinical Characteristics	Total	% (r/n)[1] Male	Female	p-value[2]
Proportion with late disease at diagnosis (CD4<200)	49.8 (131/263)	52.9 (55/104)	47.8 (76/159)	0.420
CD4 count at diagnosis (x10^6/l)				0.733
0-49	19.8 (52/263)	23.1 (24/104)	17.6 (28/159)	
50-199	30.0 (79/263)	29.8 (31/104)	30.2 (48/159)	
200-349	24.3 (64/263)	23.1 (24/104)	25.2 (40/159)	
350+	25.9 (68/263)	24.0 (25/104)	27.0 (43/159)	
Median (range)	200 (0-1333)	170 (0-1020)	202 (0-1333)	
HIV viral load at diagnosis (copies/ml)				<0.001
<10,000	25.5 (63/246)	11.6 (11/95)	34.4 (52/151)	
10,000-<100,000	44.1 (109/246)	51.6 (49/95)	39.1 (59/151)	
100,000+	30.4 (75/246)	36.8 (35/95)	26.5 (40/151)	
Median	36650	51000	25864	
Proportion with symptomatic disease at diagnosis (CDC[3] B or C)	46.2 (121/262)	51.9 (54/104)	42.4 (67/158)	0.131
Proportion with AIDS within 6 months of diagnosis	28.8(74/257)	33.3 (34/102)	25.8 (40/155)	0.192
Principal AIDS defining illnesses				
TB pulmonary	39.2 (29/74)	38.2 (13/34)	40.0 (16/40)	
Pneumocystis carinii pneumonia	14.9 (11/74)	11.8 (4/34)	17.5 (7/40)	
Oesophageal candidiasis	14.9 (11/74)	8.8 (3/34)	20.0 (8/40)	
Viral subtype (clade)				---
A	4.3 (3/69)	3.3 (1/30)	5.1 (2/39)	
B	7.2 (5/69)	16.7 (5/30)	0	
C	52.2 (36/69)	43.3 (13/30)	60.0 (23/39)	
D	4.3 (3/69)	0	7.7 (3/39)	
F	2.9 (2/69)	6.6 (2/30)	0	
G	4.3 (3/69)	3.3 (1/30)	5.1 (2/39)	
Recombinant	23.2 (16/69)	26.7 (8/30)	20.5 (8/39)	
Multiple	1.4 (1/69)	0	2.6 (1/39)	
Primary resistance found[4]	9.5 (9/95)	20.0 (7/35)	3.3 (2/60)	0.011
Antiretrovirals within 6 months of diagnosis	63.1(169/252)	60.6 (60/99)	71.2 (109/153)	0.079
Proportion on therapy with undetectable viral load (<50copies/ml)	66.9 (113/169)	66.7 (43/60)	64.2 (70/109)	0.106
CD4 count six months post diagnosis (x10^6/l)				0.478
0-49	5.0 (13/258)	5.9 (6/102)	4.5 (7/156)	
50-199	26.7 (69/258)	30.4 (31/102)	24.4 (38/156)	
200-349	31.4 (81/258)	32.4 (33/102)	30.8 (48/156)	
350+	36.8 (95/258)	31.4 (32/102)	40.4 (63/156)	
Median (range)	270 (1-1062)	257 (10-850)	277 (1-1062)	

[1] Base varies due to item non-response

[2] Comparing men & women

[3] Centers for disease control and prevention classification: A=documented HIV infection, asymptomatic; B=symptomatic conditions not in category C; C=AIDS defining conditions; 1=CD4 >=500; 2=CD4 200-499; 3= CD4<200.

[4] Only mutations conferring medium or high-level resistance included.

Data on time on ART in relation to viral load was not collected. Very few differences existed by gender: men were likely to have a higher viral load at diagnosis (median of 51,000 copies/ml vs. 25,864 copies/ml, p<0.001) and more likely to have primary resistance (20.0% (7/35) vs. 3.3% (2/60), p=0.011) than women.

Post-diagnosis (table 6.13 & 6.14)

Whilst 89.6% (233/260) trusted the staff at their HIV clinics, 39.6% (97/245) trusted the staff at their GP surgery. Principal concerns were lack of confidentiality (54.1%), behaviour and attitudes of reception staff (53.2%), discrimination (33.0%) and lack of knowledge about HIV (30.3%). Thirty six percent (78/214) of respondents had disclosed their HIV status to their GP.

Disclosure of HIV status to current partners was reported by 58.6% (129/220), 12.6% had disclosed to some or all of their ex-partners, and 25.3% to a least one friend. Approximately half of the respondents knew people who had also HIV tested and 32.8% believed most people would test if they thought they were at risk of HIV.

A belief that faith alone can cure HIV was reported by 30.6%, and 4.7% believed taking ART implies a lack of faith in God. These beliefs were as likely amongst people on ART and those with undetectable viral loads as those not on ART (data not shown). Very few differences existed by gender: men were more likely than women to discuss HIV with their partner (62.1% vs. 38.9%, p<0.001); women were more likely to believe that faith alone can cure HIV (37.8% vs. 19.6%, p =0.008). Fewer than 10% reported use of traditional or herbal medicines. More information on having a family and disclosing status to partners was wanted by 44.3% and 45.5% respectively.

Table 6.13 Post HIV diagnosis

Since diagnosis	% (r/n)[1]			p-value[2]
	Total	Male	Female	
Disclosed HIV status to someone	89.1 (228/256)	87.1 (88/101)	90.3 (140/155)	0.424
Who disclosed to[3]:				
Partner	58.6 (129/220)	65.6 (59/90)	53.8 (70/130)	0.083
GP	36.4 (78/214)	35.7 (30/84)	36.9 (48/130)	0.858
Friend(s) (all or some)	25.3 (56/221)	22.1 (19/86)	27.4 (37/135)	0.376
Ex-partners (all or some)	12.6 (26/206)	9.9 (8/81)	14.4 (18/125)	0.340
Belief that faith alone can cure HIV	30.6 (79/258)	19.6 (20/102)	37.8 (59/156)	0.008
Do not know	18.2 (47/258)	20.6 (21/102)	16.7 (26/156)	
Belief that taking ART implies lack of faith in God	4.7 (12/255)	2.0 (2/101)	6.5 (10/154)	0.149
Do not know	10.2 (26/255)	12.9 (13/101)	8.4 (13/154)	
Used traditional or herbal medicines[4]	9.7 (25/258)	8.7 (9/104)	10.3 (16/155)	0.831
Trust staff at HIV clinic/hospital:				0.143
Yes	89.6 (233/260)	88.3 (91/103)	90.4 (142/157)	
Don't know	7.7 (20/260)	10.7 (11/103)	5.7 (9/157)	
Trust staff at GP surgery:				0.530
Yes	39.6 (97/245)	39.6 (38/96)	39.6 (59/149)	
Don't know	25.7 (63/245)	29.2 (28/96)	23.5 (35/149)	
Believe most people would have an HIV test if they thought they were at risk of infection	32.8 (84/256)	34.0 (35/103)	32.0 (49/153)	0.719
Don't know	43.8 (112/256)	40.8 (42/103)	45.8 (70/153)	
Number of people known who have had an HIV test				0.724
Most	6.9 (18/262)	5.8 (6/104)	7.6 (12/158)	
A few	45.4 (119/262)	42.3 (44/104)	47.5 (75/158)	
None	21.0 (55/262)	23.1 (24/104)	19.6 (31/158)	
Don' know	26.7 (70/262)	28.8 (30/104)	25.3 (40/158)	

[1] Base varies due to item non-response

[2] Comparing men and women

[3] Excludes those who do not have a partner, or GP etc. Assumes no response is equivalent to no so long as indicated had disclosed to someone (ie. addressed the question)

[4] Traditional medicine use for any reason, not necessarily HIV related use.

The principal benefits of knowing HIV positive status were: ability to take medication to remain healthy and alive (85.8%), and the ability to prevent onward transmission (76.5%), only 1.9% (5/260) reported that there were no benefits. Reasons not to know HIV status included fear (64.5%) and discrimination within the community (34.1%); despite having accessed HIV services and information 12.4% (31/251) felt nothing

could be done about HIV thus there was no point in knowing status. There were no significant differences reported in the pros or cons of knowing HIV positive status by gender.

Table 6.14 Pros and cons of knowing HIV positive status

	Factor[2]	Main Factor[2]
Benefits of knowing HIV positive status:	n=260	n=177
It's a weight off my shoulders	41.5%	6.8%
Can prevent onward transmission	76.5%	33.9%
Can reduce likelihood of vertical transmission	37.7%	7.9%
Can take medication to keep healthy and alive	85.8%	30.5%
It has helped with future planning	66.9%	11.9%
It has provided me social support	23.5%	0.6%
It provides me control over my health	68.8%	6.2%
There are no benefits	1.9%	2.3%
Reasons not to know HIV positive status:	n=261	n=185
Discrimination within community	64.1%	31.9%
Discrimination at work	43.8%	2.7%
Difficulty in planning a family	30.7%	4.9%
Increases likelihood of deportation	14.3%	3.8%
Insurance and mortgage difficulties	27.5%	1.6%
Knowing ones status makes one ill	21.5%	3.8%
There is no point as nothing can be done.	12.4%	2.2%
There is no point as God will protect me	6.8%	1.6%
Fear	64.5%	40.0%
Other	12.0%	7.6%

[1] Participants were asked to tick all factors that applied and to identify the single most important factor.
[2] Base varies due to item non-response

Beliefs regarding HIV and HIV services (table 6.15)

Beliefs around HIV and HIV services appeared similar between men and women. Whilst the majority of participants did not subscribe to conspiracy theories 3.6% (9/250) disagreed and 5.6% (14/250) were unsure that HIV causes AIDS, 8.6% (21/244) believed HIV to be created by white people (with a further 23.4% (57/244) neither agreeing or disagreeing), and 5.6% (14/250) felt medicines were less effective for black people than white people.

Table 6.15 Study participants' beliefs around HIV and HIV services

	Total	% (r/n)[1] Male	Female	p-value[2]
HIV causes AIDS				0.889
Agree or strongly agree	90.8 (227/250)	91.2 (93/102)	90.5 (134/148)	
Neither agree or disagree	5.6 (14/250)	5.9 (6/102)	5.4 (8/148)	
Disagree or strongly disagree	3.6 (9/250)	2.9 (3/102)	4.1 (6/148)	
HIV is a disease created by white people				0.525
Agree or strongly agree	8.6 (21/244)	11.0 (11/100)	6.9 (10/144)	
Neither agree or disagree	23.4 (57/244)	22.0 (22/100)	24.3 (35/144)	
Disagree or strongly disagree	68.0 (166/244)	67.0 (67/100)	68.8 (99/144)	
The medicines available work just as well on black people as white people				0.667
Agree or strongly agree	86.4 (216/250)	88.0 (88/100)	85.3 (128/150)	
Neither agree or disagree	8.0 (20/250)	8.0 (8/100)	8.0 (12/150)	
Disagree or strongly disagree	5.6 (14/250)	4.0 (4/100)	6.7 (10/150)	
The NHS meets the needs of African patients				0.956
Agree or strongly agree	81.4 (201/247)	82.0 (82/100)	81.0 (119/147)	
Neither agree or disagree	15.8 (39/247)	15.0 (15/100)	16.3 (24/147)	
Disagree or strongly disagree	2.8 (7/247)	3.0 (3/100)	2.7 (4/147)	
The NHS treats African patients as fairly as other patients				0.529
Agree or strongly agree	82.4 (206/250)	79.8 (79/99)	84.1 (127/151)	
Neither agree or disagree	13.2 (33/250)	16.2 (16/99)	11.3 (17/151)	
Disagree or strongly disagree	4.4 (11/250)	4.0 (4/99)	4.6 (7/151)	

[1] Base varies due to item non-response

[2] Comparing men and women

Reactions and attitudes to HIV (table 6.16)

The majority of participants (66.1%, 162/245) believed partners would leave if they knew about the HIV; this was more evident in the women's responses than the men's (72.4% vs. 57.0%, p=0.027). Otherwise perceptions of people's reactions and attitudes to HIV did not differ by gender. 68.3% (172/252) felt families, 26.6% (65/244) believed friends, and 35.2% (87/247) believed the church/mosque would stand by and support them if they knew about the HIV.

Table 6.16 Participants perceptions of people's reactions and attitudes to HIV

	Total	% (r/n)[1] Male	Female	p-value[2]
Most partners of people who are HIV+ would leave if they knew about the HIV				0.027
Agree or strongly agree	66.1 (162/245)	57.0 (57/100)	72.4 (105/145)	
Neither agree or disagree	19.6 (48/245)	27.0 (27/100)	14.5 (21/145)	
Disagree or strongly disagree	14.3 (35/245)	16.0 (16/100)	13.1 (19/145)	
My family would stand by and support me if they knew about my HIV				0.664
Agree or strongly agree	68.3 (172/252)	65.0 (65/100)	70.4 (107/152)	
Neither agree or disagree	17.1 (43/252)	19.0 (19/100)	15.8 (24/152)	
Disagree or strongly disagree	14.7 (37/252)	16.0 (16/100)	13.8 (21/152)	
My friends would stand by and support me if they knew about my HIV				0.302
Agree or strongly agree	26.6 (65/244)	30.9 (30/97)	23.8 (35/147)	
Neither agree or disagree	34.0 (83/244)	28.9 (28/97)	37.4 (55/147)	
Disagree or strongly disagree	39.3 (96/244)	40.2 (39/97)	38.8 (57/147)	
HIV + people are at risk of isolation if their church/mosque finds out about their diagnosis				0.686
Agree or strongly agree	39.7 (98/247)	36.7 (36/98)	41.6 (62/149)	
Neither agree or disagree	25.1 (62/247)	27.6 (27/98)	23.5 (35/149)	
Disagree or strongly disagree	35.2 (87/247)	35.7 (35/98)	34.9 (52/149)	
There is a sense of personal failure associated with being diagnosed HIV+				0.937
Agree or strongly agree	63.3 (155/245)	62.2 (61/98)	63.9 (94/147)	
Neither agree or disagree	16.3 (40/245)	17.3 (17/98)	15.6 (23/147)	
Disagree or strongly disagree	20.4 (50/245)	20.4 (20/98)	20.4 (30/147)	
Being diagnosed HIV+ is a source of shame for family in Africa				0.189
Agree or strongly agree	67.8 (166/245)	61.9 (60/97)	71.6 (106/148)	
Neither agree or disagree	9.8 (24/245)	13.4 (13/97)	7.4 (11/148)	
Disagree or strongly disagree	22.4 (55/245)	24.7 (24/97)	20.9 (31/148)	

[1] Base varies due to item non-response

[2] Comparing men and women

6.3 Discussion

In keeping with national Black and minority ethnic HIV statistics, 60% of SONHIA participants were women, 92% heterosexual, and 50% presented late to HIV services. Respondents predominantly defined themselves as black African (93.5%) and Christian

(89.2%), were well educated (43.8% having some form of tertiary education), and 48.1% had indefinite rights to remain in the UK. However 31.3% were not in paid employment or full time education, and 6.1% were homeless with a further 21.7% reliant on friends or family for accommodation.

High primary and secondary care use was found prior to HIV diagnosis representing missed opportunities for earlier HIV diagnosis. Primary care in particular was extremely well utilised however HIV testing was not broached by the GP in 82.4% (145/176) of cases. Medical attention was sought for wide ranging reasons, often not obviously connected to underlying HIV status. 37% had previously tested negative for HIV, representing a failure in HIV prevention.

Despite the population often coming from countries of high HIV prevalence, and demonstrating significant risk factors, e.g. 47.7% of men having been diagnosed with a STI whilst in Africa and 23% of men having paid for sex, personal appreciation of risk was low and knowledge lacking as to the benefits of HIV testing. Confidentiality concerns meant trust and disclosure of HIV status to GPs was low.

The HIV status of partners was reported as negative by 18.4% (47/256) of respondents, and it was unknown for a further 27.7%. Whilst it is likely that many partners with untested/unknown HIV status were HIV positive some will not have been. Thus many respondents were currently in HIV serodiscordant relationships. Of those respondents currently in a relationship 41.4% (91/220) had not disclosed their HIV positive status to their partner, and only 12.6% of respondents had informed either all or some of their ex-partners. The median time between HIV diagnosis and questionnaire completion was 3.5 months so it is possible that respondents were intending on informing their partners but had yet to do so. Assortative sexual mixing, in which people are more likely to have sex with people like themselves, was found with 69.2% (72/104) of reported

partnerships being with fellow Africans. Concurrency was also frequent, occurring in 36.0% of partnerships. 17.3% of all respondents reported 4 or more sexual partners since moving to the UK, and 21.2% reported consistent condom use in the UK prior to diagnosis. These findings demonstrate the substantial potential for onward transmission of HIV in the UK. They also show a need for more effective partner notification strategies.

6.3.1 Limitations

This study had some limitations. The study design meant only those people already accessing care were eligible. This could introduce selection bias, it is possible that this population may be more favourably disposed to and eligible for medical services than those not accessing services. The 17 people who were potentially eligible but died before being approached may have differed in their opportunities for earlier diagnosis compared to the sampled population. However all of these patients died of advanced HIV related diseases, if any missed opportunity for earlier diagnosis did exist this reflects a real failing on the part of our health services. If no such opportunity had existed then we must ask ourselves why someone who was likely to have been unwell had not been or felt able to seek medical care earlier.

Similarly of concern is the substantial proportion (15.4%) of potentially eligible patients who became lost to clinic follow-up. These people may also differ compared to the sampled population. The reasons for lost to follow up were usually not known but are likely to include people already known to be HIV positive and using the testing process as a means of disclosure to a partner, people transferring care to other centres, people returning to Africa, those unable to come to terms with their HIV diagnosis, and those who found HIV services unacceptable. Whilst getting people into HIV services earlier is the first step to improving clinical outcomes, this will only be achieved if people find

services acceptable and are able to continue to access them. The study was limited to London so was unable to assess if people moving away from their communities, as in the asylum dispersal scheme (UK Parliament, 2002), had any impact on opportunities for earlier diagnosis.

People not approached to participate in the study were more likely to come from West Africa (a region with generally lower HIV prevalence than Southern & Eastern Africa) and to have higher CD4 counts than those approached. It is possible that this selection bias may have influenced our findings.

As data were collected retrospectively recall bias may have occurred, especially for those in whom prior accessing of health services was associated with their HIV diagnosis. However any effect of this is likely to have been small given that participants were surveyed within 12 months of HIV diagnosis (the median time between diagnosis and questionnaire completion was only 3.5 months) and questions around health care were deliberately restricted to a relatively narrow time frame.

Gender differences may partially be attributable to reporting bias. Men and women may differ in what they count as 'sex', and social desirability bias may cause men to over-report and women to under-report certain behaviours.

6.3.2 Implications

The data suggests that rather than having poor access to health services, Africans report higher rates of primary and secondary care attendance and HIV testing than the general population (Burns & Mercer, 2006). That Africans continue to present to HIV services with advanced disease despite accessing health services prior to diagnosis suggests HIV is often missed as a differential diagnosis, or that clinicians are either reluctant to address HIV or are doing so ineffectively. Similarly, that many Africans test HIV

positive after a previous negative test, suggests these HIV prevention opportunities are not being used effectively.

The age and country of origin of participants alone should guide health practitioners to the possibility of HIV infection, irrespective of health status. Whilst some of the reasons for attending medical services may relate to HIV many do not. The findings suggest a proactive approach to HIV testing, as found in the antenatal setting, is required to minimise these missed opportunities for earlier diagnosis. 37.1% of respondents reported a previous negative HIV test. Whilst the majority of these occurred in Africa 32.5% had occurred in the UK. HIV infection risks are ongoing, with acquisition within the UK a real phenomenon for resident Africans. The risk of HIV acquisition within the UK is the focus of chapter 8.

The Centres for Disease Control and Prevention (CDC) now recommends that HIV screening be performed routinely in all health-care settings for 13-64 year olds (Branson et al., 2006). GP's should be the first port of call for all health issues, including HIV. The ongoing care relationship provided by primary care services should lend itself to the provision of personalised ongoing HIV information and repeat screening opportunities. Work to address the concerns of service users around HIV and primary care is required.

The National Strategy for Sexual Health and HIV (Department of Health, 2001) in 2001 set clear targets for HIV testing and reducing undiagnosed infection. In practice these recommendations have yet to be realised, probably because of the low priority of sexual health in most primary care trusts has resulted in lack of funds. Proposals to exclude overseas visitors from eligibility to free NHS primary medical service (Department of Health, 2004b), designed to align primary care with hospital care, will further reduce opportunities for earlier diagnosis. A more positive approach would be to ensure that

health services that are currently well utilised by this high risk population have both the resources and incentives to effectively address HIV.

Quantitative questionnaires of this nature provide crude measures that help focus direction, but they are unable to disentangle the complex components of a culture in enough depth, to guide HIV prevention interventions. Qualitative work is required to gain deeper understanding of these factors and the interplay between them. The findings of 26 in-depth interviews conducted to explore late presentation are presented in chapter 9.

Chapter 7: Late presentation of HIV in Africans in London

Abstract

Objective: To identify factors associated with late presentation of HIV in Africans resident in London.

Methods: Analysis of data from the survey of newly diagnosed HIV positive Africans in London (SONHIA).

Results: 263 questionnaires were completed, representing an uptake rate of 79.5% of patients approached. 49.8% (131/263) of participants presented with advanced HIV disease (CD4 <200x10^6/l at diagnosis).

Participants who defined themselves as bi or homosexual, who were French speakers, and who did not believe HIV causes AIDS, were less likely to present with advanced disease than heterosexuals (AOR 0.16, 95%CI 0.04, 0.62), non-French speakers (AOR 0.11, 95%CI 0.02, 0.58), and people who believed HIV causes AIDS (AOR 0.25, 95%CI 0.08, 0.863). Late presentation was not significantly associated with gender, age, or socio-economic factors, in this study.

Conclusion: HIV presentation patterns appear to be governed by factors linked to the characteristics of, and response to, the HIV epidemic operating within people's sociocultural networks. Further work is needed to understand these factors in order to guide HIV interventions.

7.0 Introduction

This chapter seeks to identify the demographic, behavioural and social factors associated with delayed presentation to HIV treatment services in Africans with newly diagnosed HIV infection. The first section explains the conceptual framework and statistical approaches utilised in analysing the cross sectional survey. The second explores the factors associated with late presentation, providing crude and adjusted odds ratios.

7.0.1 Aims and objectives

This chapter aims to determine the demographic, behavioural and social factors independently associated with delayed presentation (CD4<200 cells/µl at time of HIV diagnosis) to treatment services.

7.1 Methods

As previously described in chapters 5 and 6.

7.1.1 Outcome

The principal endpoint for the survey was late presentation. Late presentation was defined as a CD4 count below 200 cells/µL at time of HIV diagnosis.

7.1.2 Data editing and reduction

When necessary continuous variables such as age were categorised into groups that would have statistical efficacy whilst maintaining relevance. Similarly explanatory variables were re-categorised if numbers were too small for analysis and merger of categories was not felt to lead to loss of information. The impact of re-categorising explanatory variables was tested to ensure association with the outcome variable of late presentation was not significantly altered.

7.1.3 The conceptual framework

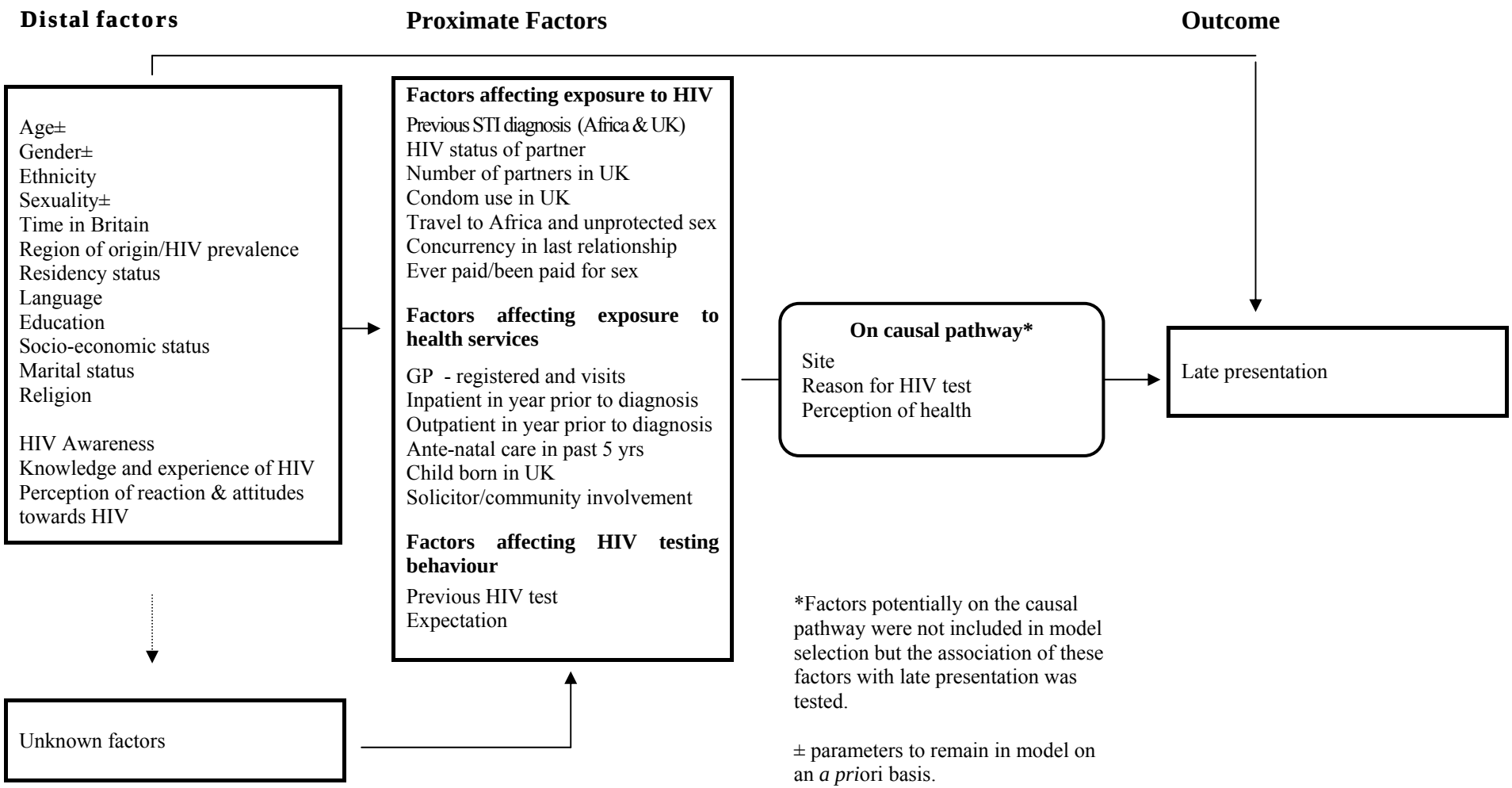
Traditionally epidemiological studies have relied predominantly on individual risk factor analysis without the application of a conceptual framework. This can make the interpretation of the relative importance of individual variables difficult. The need to understand the socioeconomic and sociocultural forces underlying population processes is increasingly being recognised. Conceptual frameworks that acknowledged the biological processes that link society to health outcomes initially developed for the

study of fertility and infant mortality (Mosley & Chen, 2003; Stover, 1998), have been adapted for HIV (Boerma & Weir, 2005; Lewis et al., 2007).

These 'proximate-determinant' frameworks explain the hierarchical and non-hierarchical associations between different variables. The frameworks have a set of variables, termed 'proximate determinants', that have behavioural and biological aspects that can be influenced by changes in contextual variables or by interventions (the 'distal' or 'underlying determinants').

Boerma and Weir's proximate-determinant model is concerned with the acquisition of HIV, thus it incorporates biological determinants that affect the reproductive number for infection (the average number of secondary cases that arise from any new case of infection (Anderson, 1992)) (Boerma et al., 2005). The focus of this study however is not HIV acquisition but HIV testing behaviour. Thus the framework (figure 6.1) does not include variables exploring efficiency of HIV transmission per contact or duration of infectivity. It does include biological factors related to exposure to HIV as these could impact on perception of HIV risk and thus testing behaviours. It also includes factors affecting exposure to health services and factors affecting HIV testing behaviour. Boerma and Weir included one feedback mechanism, prevalence of HIV infection, which is absent in this model. This is because background HIV prevalence has been viewed as an underlying contextual determinant that influences the more proximate factors. The framework is restricted to sexual transmission of HIV, the predominant mode of HIV transmission in this population.

Figure 7.1 Conceptual framework underlying analysis



7.1.4 Statistical analysis

Two-way associations were examined using cross tabulations and χ^2 tests, unless numbers were small when Fishers exact test was used.

Logistic regression was used for both univariate and multivariate analysis to obtain crude and adjusted odds ratios (OR) with 95% confidence intervals (95%CI). Significance was set at $p<0.05$, although those below 0.1 were retained for multivariate analysis.

Factors potentially on the causal pathway were excluded from the multivariate model. These included site of HIV diagnosis, reason for last HIV test, and perception of health.

Several variables that were significantly associated with late presentation in univariate analysis measured very similar behaviours or factors, thus exhibiting high degrees of co linearity: Sexuality (heterosexual or homosexual/bisexual) had substantial overlap with 'in the past two years had sex with: opposite sex, same or both sexes, and not had sex'; The ability to speak French comfortably (yes or no) was closely aligned to the preferred language to read in (English or other including illiterate); and country of birth and country of adolescence also exhibited high co linearity. To enable multivariate analysis the variables 'with whom had sex in the past two years', 'preferred language to read in', and 'country of adolescence' were dropped.

For multivariate analysis backwards-stepwise selection was used based on a simple conceptual framework (figure 7.1). First the association of the socio-cultural and economic factors with the outcome was determined. Variables were eliminated from this 'distal model' if they did not contribute significantly to the model ($p<0.055$). Gender, age and sexuality were kept in the model on *a priori* basis as all of these factors are known to be associated with late diagnosis (The UK Collaborative Group for HIV

and STI Surveillance, 2006). The proximate factors, which had been significantly associated with the outcome in bivariate analysis, were then included and the process of stepwise backward elimination repeated, preserving those factors that contributed significantly in the 'distal model'. Several variables (when think was infected with HIV, why think was infected with HIV, main source of information about HIV, and previous negative HIV test) had appreciable missing data and were excluded from the stepwise analysis. Once the most parsimonious model was found logistic regression was repeated with all eligible cases. Those variables that had been dropped from the analysis due to their small base were then sequentially added back into the model and retained if they contributed significantly, however none did.

The model selection (backwards stepwise) was then repeated without any hierarchy or *a priori* variables, i.e. treating all factors equally, to assess the influence of the conceptual framework.

7.1.5 Effect modifiers

Effect modification was investigated once the final model had been determined. To ensure adequate power each parameter in the final model was recoded into a binary variable.

Despite this it was not possible to test for interactions between French language and any of the other parameters in either the hierarchal or non-hierarchal model. This was because characteristics inherent in this population made certain combinations of variables so rare there were not adequate numbers. Whilst this means this study is unable to definitely say whether interactions between these parameters existed, the occurrence would be so rare it is unlikely to be of practical importance. No interactions were found between any of the other parameters.

7.2 Results

7.2.1 Descriptive analysis

Detailed description of response rates, item non-response and the socio-demographic, health beliefs, heath care utilisation and clinical presentation patterns of newly diagnosed HIV positive Africans in London and missed opportunities for earlier diagnosis are reported in chapter 6.

7.2.2 Factors associated with late presentation

Fifty percent of participants presented late to HIV services

7.2.2.1 Univariate analysis

Socio-demographics (Tables 7.1)

Gender, age, education, marital status, time in the UK, and residency status were not significantly associated with late presentation. Age was not associated with late presentation whether it was treated as a categorical or a continuous variable (data not shown). Participants defining themselves as bi- or homosexual were less likely to present late than heterosexuals (OR 0.25; 95%CI 0.08-0.77); French speakers were less likely to present late (OR 0.11, 95%CI 0.03-0.50) than non French speakers, and persons who preferred to read in a language other than English (including illiterate) were also less likely to present late (OR 0.41, 95%CI 0.18-0.94).

Table 7.1Univariate analysis of socio-demographic factors associated with late presentation (CD4 <200 cells/μL at diagnosis)

Characteristic	% (r/n)[1]	Crude OR	95% CI	p-value
Gender				
Male	52.9 (55/104)	1	-	-
Female	47.8 (76/159)	0.82	0.50, 1.34	0.420
Age (years):				
<35	48.1 (64/133)	1	-	-
35+	51.5 (67/130)	1.15	0.71, 1.86	0.579
Ethnicity:				
Black African	50.8 (125/246)	1	-	-
Other	35.3 (6/17)	0.53	0.19, 1.47	0.216
Sexuality:				
Heterosexual	51.7 (121/234)	1	-	-
Bi or Homosexual	21.1 (6/19)	0.25	0.08, 0.77	0.016
Education				
High school education or below	51.9 (70/135)	1	-	-
Higher education	48.8 (61/125)	0.89	0.54, 1.44	0.623
Marital Status:				
Married or cohabiting	49.0 (48/98)	1	-	-
Other	51.3 (82/160)	1.10	0.66, 1.81	0.723
Have children				
No	46.0 (40/87)	1	-	-
Yes	51.5 (89/173)	1.24	0.74, 2.09	0.405
HIV prevalence[2] of country of birth				
5% or higher	48.6 (107/220)	1	-	
Low (<5%)	55.8 (24/43)	1.33	0.69, 2.57	0.390
Time in UK before HIV diagnosis:				
3 or more years	49.7 (82/165)	1	-	-
<3 years	51.04 (49/96)	1.07	0.65, 1.77	0.798
Age on arrival in UK				
0-29 years	45.9 (67/146)	1	-	-
30+ years	55.7 (64/115)	1.50	0.92, 2.45	0.106
Currently:				
Living in the UK	48.5 (98/202)	1	-	-
Other (e.g. studying, short term-work contract, visiting)	54.1 (33/61)	1.25	0.70, 2.22	0.445
Residency status in the UK				
Indefinite right to remain (British citizen, EEC member, Permanent resident, refugee)	50.4 (63/125)	1	-	-
Other (e.g. visa entry, Asylum seeker, applying for visa, illegal)	48.9 (66/135)	0.94	0.58, 1.53	0.808
Accommodation				
Own or rent	46.8 (89/190)	1	-	-
Other	56.9 (41/72)	1.50	0.87, 2.59	0.144
Employment status				
Employed fulltime	46.2 (43/93)	1	-	-

Characteristic	% (r/n)[1]	Crude OR	95% CI	p-value
Other (e.g. employed part time, student, unemployed)	51.2 (85/166)	1.22	0.73, 2.03	0.443
Speaks English comfortably				
No	43.3 (13/30)	1	-	-
Yes	50.4 (117/232)	1.33	0.62, 2.86	0.464
Speaks French comfortably				
No	52.5 (128/244)	1	-	-
Yes	11.1 (2/18)	0.11	0.03, 0.50	0.001
Preferred language to read in				
English	52.1 (122/234)	1	-	-
Other, including illiterate	31.0 (9/29)	0.41	0.18, 0.94	0.032
Religion:				0.898
Roman catholic	48.9 (45/92)	1	-	
Christian – non Roman Catholic	48.9 (69/141)	1.00	0.59, 1.69	
Other (including Muslim)	53.6 (15/28)	1.21	0.52, 2.81	

[1] Base varies due to missing values

[2] HIV prevalence (%) adults aged 15-49 according to UNAIDS 2003 data

Sexual health & behaviour (table 7.2)

The only sexual health variable significantly associated with late presentation in univariate analysis related to sexual behaviour in the two years prior to diagnosis. Participants who had sex with the same or both sexes were less likely to present late (OR 0.27, 95%CI 0.07-0.97) than those who had sex with only the opposite sex. This would be expected given the association between sexuality and presentation (see above), this variable was included to measure actual behaviour rather than sexual identity.

Table 7.2 Univariate analysis of sexual health factors associated with late presentation (CD4 <200 cells/μL at diagnosis)

Characteristic	% (r/n)[1]	Crude OR	95% CI	p-value
Partner[2]				0.739
HIV positive	43.1 (31/72)	1	-	
HIV negative	48.9 (23/47)	1.27	0.61, 2.65	
Do not know or untested for HIV	48.7 (38/78)	1.26	0.66, 2.39	
In the last 2 years have had sex with:				0.026
Opposite sex only	48.5 (97/200)	1	-	
Same or both sexes	20.0 (3/15)	0.27	0.07, 0.97	
Not had sex in last 2 years	63.2 (24/38)	1.82	0.89, 3.72	
Number of sexual partners in UK prior to HIV diagnosis				0.149
0	61.2 (30/49)	1	-	
1	48.4 (44/91)	0.59	0.29, 1.20	
2 or more	44.0 (40/1)	0.50	0.24, 1.01	
Consistent condom use in the UK if sex prior to HIV diagnosis				
Yes	49.0 (25/51)	1	-	-
No or unsure	47.6 (68/148)	0.94	0.50, 1.79	0.857
Number of sexual partners in past year				0.061
0	63.5 (33/52)	1	-	
1	43.9 (57/130)	0.45	0.23, 0.87	
2 or more	49.2 (30/61)	0.56	0.26, 1.19	
Consistent condom use if sex in past year				
Yes	47.9 (23/48)	1	-	-
No or unsure	46.3 (69/149)	0.94	0.49, 1.80	0.846
Travelled back to Africa since moving to UK				
No	53.4 (86/141)	1	-	-
Yes	43.4 (43/99)	0.67	0.40, 1.11	0.118
Sexual intercourse with new partners on last visit to Africa				
No	46.1 (35/76)	1	-	-
Yes	37.5 (9/24)	0.70	0.27, 1.80	0.462
Ever paid for sex				
No	48.9 (111/227)	1	-	-
Yes	51.9 (14/27)	1.13	0.51, 2.50	0.772
Ever been paid for sex				
No	49.2 (119/242)	1	-	-
Yes	57.1 (4/7)	1.38	0.30, 6.29	0.678
STI prior to moving to UK				
No	48.9 (85/174)	1	-	-
Yes	50.8 (33/65)	1.08	0.61, 1.91	0.792
STI since moving to UK				
No	45.6 (68/149)	1	-	-
Yes	48.4 (31/64)	1.12	0.62, 2.01	0.707

[1] Base varies due to item non-response [2] Excludes those without a partner at present

Health & health care behaviours (table 7.3)

Use of primary and secondary care services did not significantly differ in those presenting late compared to those not presenting late (primary care OR 1.22; 95%CI 0.69-2.15; inpatient use OR 1.85; 95%CI 0.92-3.72; outpatient use OR 1.05; 95%CI 0.64-1.74)) (Table 6.13). Similarly GPs mentioning HIV was not associated with late presentation (OR1.2; 95%CI 0.55-2.61). No one reason for seeking medical care was found to be associated with late presentation.

Variables likely to reflect the impact of HIV disease on health were unsurprisingly found to be associated with late presentation. Three or more GP visits in the past year, an illness or accident affecting health for greater than three months in the last five years, and poor or terrible health 12 months ago and currently, were all associated with significantly higher odds of late presentation. Similarly testing HIV positive in a hospital or GP surgery had higher odds of late presentation than other testing sites (OR 3.17, 95%CI 1.84-5.44).

Table 7.3 Univariate analysis of health & social service use prior to HIV diagnosis associated with late presentation (CD4 <200 cells/μL at diagnosis)

Services	% (r/n)[1]	Crude OR	95% CI	p-value
Registered with GP				
No	45.0 (18/40)	1	-	-
Yes	50.5 (111/220)	1.24	0.63, 2.45	0.526
GP visits in year before HIV diagnosis:				0.025
None	44.3 (35/79)	1	-	
1-2	41.3 (33/80)	0.88	0.47, 1.66	
3 or more	61.5 (48/78)	2.01	1.06, 3.80	
Attended GP in 2 years before HIV diagnosis[2]				
No	45.3 (29/64)	1	-	-
Yes	50.3 (97/193)	1.22	0.69, 2.15	0.493
Inpatient use in year prior to HIV diagnosis				
No	46.3 (101/218)	1	-	-
Yes	61.5 (24/39)	1.85	0.92, 3.72	0.080
Outpatient use in year prior to HIV diagnosis				
No	48.7 (77/158)	1	-	-
Yes	50.0 (49/98)	1.05	0.64, 1.74	0.844
Illness or accident affecting health for at least 3 months in the last 5 years (excluding HIV)				
No	43.8 (85/194)	1	-	-
Yes	65.08 (41/63)	2.39	1.32, 4.31	0.003
Attended antenatal care in UK in past 5 years				
No	49.1 (114/232)	1	-	-
Yes	48.2 (13/27)	0.96	0.43, 2.13	0.922
Child born in the UK				
No	51.2 (105/205)	1	-	-
Yes	44.2 (23/52)	0.76	0.41, 1.39	0.368
Attends HIV services within own SHA				
No	43.8 (28/64)	1	-	-
Yes	50.6 (86/170)	1.32	0.74, 2.35	0.351
Health 12 months ago				0.004
Excellent or very good	43.2 (73/169)	1	-	
Fair	53.7 (29/54)	1.53	0.82, 2.82	
Poor or terrible	73.7 (28/38)	3.68	1.68, 8.06	
Health now				<0.001
Excellent or very good	38.5 (52/135)	1	-	
Fair	57.8 (52/90)	2.18	1.27, 3.76	
Poor or terrible	70.3 (26/37)	3.77	1.72, 8.26	
Length of poor health				
Not at all	37.2 (55/148)	1	-	-
Ill health present	65.8 (75/114)	3.25	1.95, 5.42	<0.001

[1] Base varies due to item non-response
[2] Reasons for seeing GP in the 2 years prior to HIV diagnosis not associated with late presentation

HIV awareness (table 7.4)

People who had a prior negative HIV test were less likely to present late (OR 0.55; 95%CI 0.31-0.96); this did not depend on whether the test was in the UK or abroad (OR 0.94; 95%CI 0.35-2.49).

Participants who found out where to have an HIV test by means other than being offered one whilst in hospital, and who knew about medical confidentiality prior to their HIV test were also less likely to present late.

HIV knowledge, attitudes and beliefs (tables 7.5, 7.6, & 7.7)

Participants who tested for reasons other than advice by a Doctor or being symptomatic were less likely to present to HIV service late. Participants who perceived the timing of HIV acquisition as related to high-risk sexual contact had lower odds of presenting late than those who associated HIV acquisition with becoming unwell (OR 0.37, 95%CI 0.17-0.80).

No factors related to the perception of peoples reaction and attitudes to HIV were found to impact significantly on presentation. However participants who disagreed or were ambivalent about whether HIV causes AIDS were less likely to present late (OR 0.18, 95%CI 0.06-0.56).

Table 7.4 Univariate analysis of HIV awareness factors associated with late presentation (CD4 <200 cells/µL at diagnosis)

HIV awareness prior to diagnosis	% (r/n)[1]	Crude OR	95% CI	p-value
Previous negative HIV test[2]				
No	56.1 (74/132)	1	-	-
Yes	41.0 (32/78)	0.55	0.31, 0.96	0.035
Last negative test in UK				
Yes	40.0 (10/25)	1	-	-
No	38.5 (20/52)	0.94	0.35, 2.49	0.897
HIV testing mentioned by GP in past year				
No	50.3 (73/145)	1	-	-
Yes	54.8 (17/31)	1.20	0.55, 2.61	0.650
Time in UK before knowledge of where to have HIV test:				
Less than 2 years	48.4 (61/126)	1	-	-
2 or more years	51.2 (64/125)	1.12	0.68, 1.83	0.659
How found out where to have HIV test:				<0.001
Offered whilst in hospital	69.3 (52/75)	1	-	
From a GP surgery	48.1 (25/52)	0.41	0.20, 0.85	
Other (e.g. partner, friends, media, internet)	39.3 (48/122)	0.29	0.16, 0.53	
Ever try but unable to have an HIV test				
No	48.5 (110/227)	1	-	-
Yes	57.1 (16/28)	1.42	0.64, 3.13	0.388
Perception of type of person who got HIV prior to HIV diagnosis[5]				
Anybody				
No	46.9 (45/96)	1	-	-
Yes	51.2 (84/164)	1.19	0.72, 1.97	0.499
Only people who have sex with lots of people				
No	52.23 (82/157)	1	-	-
Yes	45.6 (47/103)	0.77	0.47, 1.26	0.298
Number of people participant knew to have HIV prior to their diagnosis (excludes don't knows):				0.985
5 or more	50.0 (47/94)	1	-	
1-4	49.3 (35/71)	0.97	0.52, 1.80	
No one	50.8 (32/63)	1.03	0.55, 1.95	
Main source of HIV information prior to diagnosis				0.144
Health care workers	62.0 (31/50)	1	-	
Media	43.8 (32/73)	0.48	0.23, 1.0	
Other (e.g. friends, partner, organisations)	51.3 (60/117)	0.65	0.33, 1.27	
Knowledge that HIV testing would be free when arrived in UK				
No	47.6 (88/185)	1	-	-
Yes	56.2 (41/73)	1.41	0.82, 2.44	0.214
Knowledge of medical confidentiality				
No	59.3 (48/81)	1	-	-
Yes	44.0 (77/175)	0.54	0.32, 0.92	0.024
Influenced to have HIV test by advertising				
No	49.7 (88/177)	1	-	-
Yes	44.8 (26/58)	0.82	0.45, 1.49	0.518

[1] Base varies due to item non-response

[2] Excludes those who do not know if they have ever tested (n=37)

Table 7.5 Univariate analysis of factors associated with testing HIV positive and late presentation (CD4 <200 cells/μL at diagnosis)

HIV Testing	% (r/n)[1]	Crude OR	95% CI	p-value
Site of HIV diagnosis in UK				<0.001
Sexual Health Clinic	40.5 (53/131)	1	-	
In hospital or GP surgery	68.3 (71/104)	3.17	1.84, 5.44	
Other (e.g. Ante-natal clinic)	25.0 (6/24)	0.49	0.18, 1.32	
Main reason for last HIV test				
Advised to by Doctor or health complaints thought related to HIV	64.7 (99/153)	1	-	-
Other (e.g. pregnancy)	29.6 (32/108)	0.23	0.14, 0.39	<0.001
Expecting positive result				
No or did not know	47.5 (105/221)	1	-	
Yes	62.2 (23/37)	1.81	0.89, 3.71	0.099
Perceived reason for HIV infection				0.037
Became unwell	66.7 (28/42)	1	-	
High –risk sexual contact [2]	42.7 (38/89)	0.37	0.17, 0.80	
Other (e.g. blood transfusion)	46.3 (25/54)	0.43	0.19, 0.99	
Factors stopping earlier HIV testing				
Had never considered may be HIV +				
No	52.0 (40/77)	1	-	-
Yes	49.7 (89/179)	0.91	0.54, 1.56	0.744
Well so no need				
No	47.2 (59/125)	1	-	-
Yes	53.4 (70/131)	1.28	0.79, 2.10	0.319
Afraid of the result				
No	48.9 (90/184)	1	-	-
Yes	54.2 (39/72)	1.23	0.71, 2.13	0.450
Afraid of the stigma				
No	48.9 (89/182)	1	-	-
Yes	54.1 (40/74)	1.23	0.72, 2.11	0.455
Fear of losing a relationship				
No	49.8 (11/237)	1	-	-
Yes	57.9 (11/19)	1.39	0.54, 3.57	0.498
Factors that would have made respondent test for HIV earlier				
If had been told were at risk				
No	43.6 (44/101)	1	-	-
Yes	54.8 (80/146)	1.57	0.94, 2.62	0.083
If felt would be supported if tested HIV positive				
No	52.4 (89/170)	1	-	-
Yes	45.5 (35/77)	0.76	0.44, 1.30	0.316
If no stigma attached to HIV				
No	50.6 (79/156)	1	-	-
Yes	49.5 (45/91)	0.95	0.57, 1.60	0.857
If HIV not so linked to sex				
No	49.7 (96/193)	1	-	-
Yes	51.9 (28/54)	1.09	0.59, 1.99	0.784
If knew could treat HIV				
No	51.7 (105/203)	1	-	-
Yes	43.2 (19/44)	0.71	0.37, 1.37	0.306
If knew could reduce MTCT				
No	50.0 (109/218)	1	-	-
Yes	51.7 (15/29)	1.07	0.49, 2.33	0.862
User of traditional medicines ever				
No	48.7 (114/234)	1	-	-
Yes	52.0 (13/25)	1.14	0.50, 2.60	0.755

[1] Base varies due to item non-response [2] Including sexual assault/rape MTCT= mother to child transmission

Table 7.6 Univariate analysis of reactions and attitudes to HIV associated with late presentation (CD4 <200 cells/µL at diagnosis)

	% (r/n)[1]	Crude OR	95% CI	p-value
Most partners of people who are HIV+ would leave if they knew about the HIV				
Agree or strongly agree	45.7 (74/162)	1	-	-
Disagree or strongly disagree[2]	56.6 (47/83)	1.55	0.91, 2.65	0.105
My family would stand by and support me if they knew about my HIV				
Agree or strongly agree	52.9 (91/172)	1	-	-
Disagree or strongly disagree[2]	42.5 (34/80)	0.66	0.39, 1.12	0.124
My friends would stand by and support me if they knew about my HIV				
Agree or strongly agree	55.4 (36/65)	1	-	-
Disagree or strongly disagree[2]	48.0 (86/179)	0.74	0.42, 1.32	0.311
HIV + people are at risk of isolation if their church/mosque finds out about their diagnosis				
Agree or strongly agree	45.9 (45/98)	1	-	-
Disagree or strongly disagree[2]	51.0 (76/149)	1.23	0.74, 2.04	0.434
There is a sense of personal failure associated with being diagnosed HIV+				
Agree or strongly agree	51.0 (79/155)	1	-	-
Disagree or strongly disagree[2]	46.7 (42/90)	0.84	0.50, 1.42	0.516
Being diagnosed HIV+ is a source of shame for family in Africa				
Agree or strongly agree	50.6 (84/166)	1	-	-
Disagree or strongly disagree[2]	48.1 (38/79)	0.91	0.53, 1.55	0.714

[1] Base varies due to item non-response

[2] Includes those neither agreeing or disagreeing

Table 7.7 Univariate analysis of beliefs around HIV and HIV services to late presentation (CD4 <200 cells/µL at diagnosis)

	% (r/n)[1]	Crude OR	95% CI	p-value
HIV causes AIDS				
Agree or strongly agree	53.3 (121/227)	1	-	-
Disagree or strongly disagree[2]	17.4 (4/23)	0.18	0.06, 0.56	0.001
HIV is a disease created by white people				
Agree or strongly agree	47.6 (10/21)	1	-	-
Disagree or strongly disagree[2]	49.3 (110/223)	1.07	0.44, 2.62	0.881
The medicines available work just as well on black people as white people				
Agree or strongly agree	49.5 (107/216)	1	-	-
Disagree or strongly disagree[2]	44.1 (15/34)	0.80	0.39, 1.66	0.557
The NHS meets the needs of African patients				
Agree or strongly agree	51.2 (103/201	1	-	-
Disagree or strongly disagree[2]	43.5 (20/46)	0.73	0.38, 1.40	0.343
The NHS treats African patients as fairly as other patients				
Agree or strongly agree	49.5 (102/206)	1	-	-
Disagree or strongly disagree[2]	50.0 (22/44)	1.02	0.53, 1.96	0.953

[1] Base varies due to item non-response

[2] Includes those neither agreeing or disagreeing

7.2.2.2 Multivariate analysis

Hierarchal model (table 7.8)

When incorporated into a hierarchal multivariate model four factors remained independently associated with late presentation. The adjusted odds of presenting late were lower for participants identifying as bi- or homosexual (AOR 0.16, 95%CI 0.04-0.62) compared to those identifying as heterosexual. Participants who had one sexual partner in the past year had lower adjusted odds of presenting late (AOR 0.27, 95%CI 0.12-0.62) than those who had no sexual partners. Being a French speaker was associated with reduced odds of late presentation (AOR 0.11, 95%CI 0.02-0.58). Participants expressing a belief that HIV does not cause AIDS had lower adjusted odds of late presentation (AOR 0.25, 95%CI 0.08-0.83) than those who believe it does.

Table 7.8 Multivariate analysis of factors associated with late presentation(CD4 <200 cells/μL at diagnosis) using hierarchal selection (n=229)[1]

Factor	Crude OR	Adjusted OR[2]	95% CI	P value
Gender[3]				
Male	1	1	-	-
Female	0.82	0.80	0.43, 1.52	0.503
Age (years)[3]				
<35	1	1	-	-
35+	1.15	1.00	0.55, 1.82	0.995
Sexuality[3]				
Heterosexual	1	1	-	-
Bi or homosexual	0.25	0.16	0.04, 0.62	0.009
French speaker				
No	1	1	-	-
Yes	0.11	0.11	0.02, 0.58	0.009
Number of sexual partners in past year				
0	1	1	-	-
1	0.45	0.27	0.12, 0.62	0.002
2 or more	0.56	0.45	0.18, 1.16	0.100
Belief that HIV causes AIDS				
Agree or strongly agree	1	1	-	-
Disagree or strongly disagree[4]	0.18	0.25	0.08, 0.83	0.023

[1] Some subjects had missing values on one or more of the independent variables

[2] Adjusted for all other variables in the model

[3] Retained in model on *a priori* basis

[4] Includes those neither agreeing or disagreeing

Non-hierarchal model (table 7.9)

When the same variables were incorporated into a non-hierarchal selection model four factors still remained significantly associated with the outcome however number of sexual partners was replaced by knowledge of medical confidentiality. The adjusted odds of presenting late remained lower for participants identifying as bi- or homosexual (AOR 0.20, 95%CI 0.06-0.74) compared to those identifying as heterosexual. Being a French speaker also remained associated with reduced odds of late presentation (AOR 0.15, 95%CI 0.03-0.70), as did expressing a belief that HIV does not cause AIDS (AOR

0.23, 05%CI 0.07-0.73). Finally those participants who had knew that Doctors were legally obliged to respect their confidentiality and not inform others about their HIV infection prior to their HIV diagnosis were also less likely to present late to HIV services (AOR 0.54, 95%CI 0.30-0.97) than those who did not.

Table 7.9 Multivariate analysis of factors associated with late presentation - non hierarchal selection (n=239)[1]

Factor	Crude OR	Adjusted OR[2]	95% CI	P value
Sexuality				
Heterosexual	1	1	-	-
Bi or homosexual	0.25	0.20	0.06, 0.74	0.016
Belief that HIV causes AIDS				
Agree or strongly agree	1	1	-	-
Disagree or strongly disagree[3]	0.18	0.23	0.07, 0.73	0.012
French speaker				
No	1	1	-	-
Yes	0.11	0.15	0.03, 0.70	0.016
Knowledge of medical confidentiality prior to HIV diagnosis				
No	1	1	-	-
Yes	0.54	0.54	0.30, 0.97	0.04

[1] Some subjects had missing values on one or more of the independent variables

[2] Adjusted for all other variables in the model [3] Includes those neither agreeing or disagreeing

7.3 Discussion

Half of all respondents had advanced HIV disease at the time of their HIV diagnosis. Risk behaviours and risk perception were generally not found to be associated with HIV presentation patterns in the univariate analysis. There were two exceptions: reduced odds of late presentation was associated with the number of sexual partners in the past year (those having one compared to none, but not those having two or more (although there was a non-significant reduced odds in this group)); reduced odds of late presentation was also found in respondents who associated their HIV acquisition with a risk exposure, compared to respondents associating their HIV acquisition with the onset of ill health. Factors reflecting poor health of respondents were, unsurprisingly, found to be associated with increased odds of late presentation, these included number of GP visits, ill health in the past 5 years, and site and reason for last HIV test.

The ability to access health information did not appear associated with late presentation, for example being GP registered showed no association with HIV presentation. Contrary to expectations respondents who's preferred language to read in was not English (including those who were illiterate), and who spoke French, were less likely to present late. Whilst people testing HIV positive after a previous negative test reflects failure in prevention messages, people who had previously tested for HIV (37.1%) were less likely to present to HIV services late. Knowledge of medical confidentiality prior to HIV diagnosis also was associated with reduced odds of late presentation.

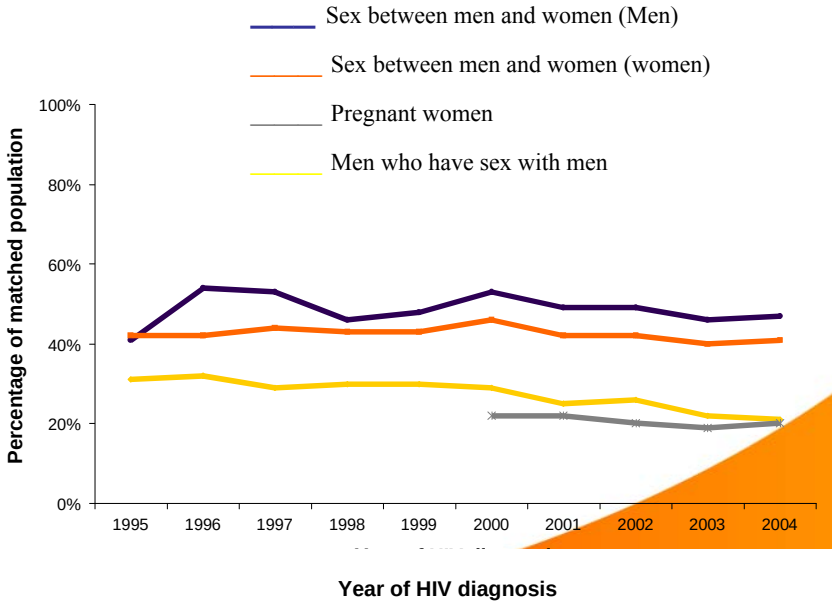
Multivariate analysis of factors associated with late presentation to HIV services

Unlike national data where late presentation is higher in older and male populations, no association between age or gender and late presentation was found in this study. This

may reflect sampling bias; clinicians were reluctant to deem the ante and post natal periods as an 'appropriate time' for study recruitment. The relative paucity of women diagnosed antenatally in the sample (9.4% of women) could influence both gender and age, as pregnant women tend to be younger and to present earlier (The UK Collaborative Group for HIV and STI Surveillance, 2006; Chadborn, 2005).

Routine antenatal testing accounted for 15.6% (274/1761) of new HIV diagnoses in black African women in the UK in 2006 (The UK Collaborative Group for HIV and STI Surveillance, 2007). In 2004 the median CD4 count at diagnosis of women diagnosed in pregnancy was 340 cells/µL, compared to 259 cells/µL in non-pregnant women, and 227 cells/µL in heterosexual men (Chadborn, 2005). Published data on late presentation by risk group typically merges pregnant and non-pregnant women into a 'heterosexually acquired – women' group. If women diagnosed antenatally were separated out, differences in presentation patterns between men and women with heterosexually acquired HIV would be less marked (figure 7.2).

Figure 7.2 Percentage of HIV infected adults diagnosed late (CD4 <200 cells/µL), England and Wales 2004



Source: CD4 surveillance, Health Protection Agency 2005

Participants identifying as bi or homosexual were less likely to de diagnosed with advanced HIV than heterosexuals. Whilst the differences in presentation and in reasons for HIV testing between the heterosexual and the gay community within the UK have been well documented (Burns et al., 2001; Boyd et al., 2005; Chadborn et al., 2006; Delpierre et al., 2007), little research to date has focused on explaining these differences (Erwin et al., 2002; Dodds, 2006), although it is assumed to relate to increased awareness of the benefits of testing and the increased accessing of sexual health services by the gay community.

Why participants who spoke French fluently should be less likely to present late is unknown. The Demographic Republic of Congo, Cote d'Ivoire, and Cameroon accounted for 72.2% (13/18) of all French speakers in the study. French speakers did not differ socio demographically from non-French speakers (data not shown). French language ability is presumably a proxy measure for cultural difference that influences HIV presentation patterns. Unfortunately the in-depth interviews (chapter 9) were limited to English speakers, thus cultural differences between former English and French colonies in knowledge, attitudes and behaviours were unable to be explored in this study.

Persons reporting one sexual partner in the last 12 months were less likely to present late than people with no sexual partners. Respondents reporting 2 or more partners also had lower odds of late presentation than respondents reporting no partners however the difference was not significant. This association may reflect perception of risk, state of health, or even exposure to health services. People with advanced HIV disease are often assumed to be less sexually active (as a direct consequence of ill health). However no association between number of sexual partners in the past year and perception of health (ever suffered from poor health, yes, no), or consideration of the possibility of HIV was

found (data not shown). Participants who had 2 or more sexual partners in the past year were less likely to be registered with a GP but no other association with health service use was found. Participants reporting no, or two or more, sexual partners in the past 12 months were also less likely to be married or cohabiting, possibly suggesting some association between HIV testing patterns and social support.

The belief that HIV does not cause AIDS was associated with reduced odds of late presentation in both models. How this belief influences HIV testing behaviour in this way is difficult to explain. It may reflect knowledge of medication, that is, HIV no longer has to lead to AIDS (as suggested by a handwritten comment within the questionnaire 'HIV causes AIDS if not treated'); participants not believing HIV causes AIDS may be less concerned about the diagnosis and thus more willing to test if the test was offered; or alternatively this belief may have remained in the model by chance.

In the non-hierarchical model HIV knowledge of medical confidentiality was significantly associated with late presentation, whilst number of sexual partners in the past year was no longer associated with the outcome. It makes sense that knowledge that confidentiality is respected in healthcare settings would facilitate HIV testing.

While all these variables were significantly independently associated with late presentation, the size of the confidence intervals reflects considerable uncertainty in the true magnitude of their effect.

7.3.1 Limitations

Several limitations of the survey have been previously discussed in chapter 6. As data on outcome and associated factors were collected simultaneously it is possible that the factors may not be relevant due to temporality, that is, the outcome (late presentation) may have occurred prior to the determinant, e.g. employment status, perception of

health. However this is unlikely to apply to any of the factors remaining in the multivariate model. Retrospective data also introduces the possibility of recall bias. Recall is unlikely to have been different for most explanatory variables in those who had or had presented late. Although detailed information on many potential confounders was collected residual confounding both from known and unknown factors is still possible.

Finally the term 'African' comprises an aggregation of heterogeneous population subgroups. Although data were collected to explore ethnic, cultural and temporal diversities of this population the study may have lacked power to fully explore their influences on late presentation.

The conceptual framework

Two approaches to multivariate analysis were used deliberately to test the influence of the conceptual framework based on a proximate-determinant model. The factors associated with late presentation varied according to the model selection criteria. Whilst this would be expected it is difficult to explain the differences. The hierarchal model is designed specifically to favour the distal factors. The hierarchical framework was to ensure that associations of more proximate factors with the outcome could not be explained by the more distal factors. The finding of significant proximate factors in the final model suggests there remain distal factors, such as psychological or cultural factors, that have not yet been identified.

The discrepancy between the models and failure of the hierarchal model to identify more socio-cultural and economic variables could be explained by several factors. Firstly it may be entirely due to chance. Some classification may have been insufficient to adequately measure important distinctions within and between parameters. The

conceptual framework may be at fault. Proximate determinant models have traditionally been used for biological outcomes and using one in the context of a behavioural outcome has yet to be formally tested. The framework, by necessity, is an over simplistic model of the determinants of behaviour and residual confounding is likely to exist. The framework, for example, has very limited ability to explore the influence of psychological and cultural factors. For example 'sense of security' may be an influential factor in HIV testing behaviour yet this would be very difficult to measure in a survey of this nature. A further difficulty in this model was in deciding whether the knowledge and attitudinal variables represented underlying or proximate determinants. It may be that these have been incorrectly placed.

A difficulty in the conceptualisation of this model was that it meant to explore timing of HIV testing among an HIV positive population specifically, rather than factors associated with HIV testing per se. Factors potentially on the causal pathway were excluded from multivariate analysis yet it is possible that these factors may, at some level, be independently associated with the outcome.

7.3.2 Implications

HIV presentation patterns appear to be governed by factors linked to the characteristics of, and response to, the HIV epidemic operating within people's sociocultural networks. Sexuality and French language ability do not directly determine individual HIV testing behaviours rather they are proxy measures of the affected populations knowledge, attitudes, and culture, which in turn influence behaviour.

Further work is needed to extricate the critical factors that determine group behaviours. For example, in the UK, compared to African communities the gay community has had more community mobilisation around HIV, it is comparatively well informed, and has

invested a lot of resource into reducing stigma and normalising HIV testing; are HIV testing behaviours influenced by one or all of these factors? It is difficult to know the mechanisms through which French-speaking cultures differ to non-French speaking cultures. HIV prevalence and hence personal contact with HIV is similar between the populations, however governmental or community mobilisation may differ, as may attitudes to sex, or perceptions of illness.

The success of universal antenatal testing for HIV in both its uptake and its ability for diagnosing women with HIV earlier should be extrapolated to opportunistic testing of partners in the antenatal setting and to other health care settings.

Quantitative questionnaires of this nature provide crude measures that help focus direction, but they are unable to disentangle the complex components of a culture in enough depth, to guide HIV prevention interventions. Qualitative work is required to gain deeper understanding of these factors and the interplay between them. The findings of 26 in-depth interviews conducted to explore late presentation are presented in chapter 9.

Chapter 8: Acquisition of HIV infection in Africans resident in England

Abstract

Objective: To determine the extent to which United Kingdom-resident HIV positive Africans acquired their infection in the UK.

Methods: A cross-sectional survey of newly diagnosed HIV positive Africans attending 15 HIV treatment centres across London (April 2004 to February 2006). Three independent assessors used information from confidential self-completed questionnaires linked to clinical records, in conjunction with previously developed criteria to attribute country of HIV acquisition.

Results: 263 questionnaires were completed (79.5% of patients approached). At least one in four HIV infections appeared to be attributable to UK acquisition. All cases acquired abroad indicated Africa as the probable region of acquisition. No significant differences were found in the country of acquisition by gender or age. Persons defining themselves as homosexual or bisexual were more likely to have acquired HIV in the UK than persons defining themselves as heterosexuals (47.4%vs.24.4%, p=0.028). Of 263 respondents, 61 (23.2%) fulfilled criteria for 'definitely acquired HIV abroad', 44 (16.7%) 'probably abroad', and 27 (6.1%) 'definitely in the UK', leaving 142 (54%) requiring more detailed assessment. After independent detailed assessment UK acquisition ranged between 25.1% and 35.4%, whilst 60.8% to 67.3% were assessed as acquired abroad.

Conclusion: Between a quarter to a third of HIV positive Africans, and nearly half of HIV positive African MSM, may have acquired their HIV in the UK, substantially higher than previously estimated. These estimates may increase given the increasing HIV prevalence and assortative sexual mixing in this community. HIV prevention interventions for Africans must focus on reducing transmission within the UK as well as addressing infections acquired abroad.

The findings within this chapter are published in *AIDS* (2008) United Kingdom acquisition of HIV infection in African residents in London: more than previously thought. F Burns *et al*., v.23: pp 262-266.

8.0 Introduction

In the UK the majority of HIV infection acquired through heterosexual transmission is in persons born in sub-Saharan Africa. Whilst most of these infections are

diagnosed for the first time in the UK, acquisition is thought to have predominantly occurred in Africa (The UK Collaborative Group for HIV and STI Surveillance, 2006). Previous studies suggest that people are most likely to form sexual partnerships with those from their own cultural and ethnic group (Ford et al., 2002; Barlow et al., 1997), sometimes referred to as assortative sexual mixing. As HIV prevalence in heterosexuals in the UK is highest in African communities (Sadler et al., 2007) assortative sexual mixing may place people of African origin living in the UK at increased risk of acquisition of HIV compared with others.

Previous work has suggested national data may underestimate heterosexual transmission of HIV among African communities in the UK (Sinka et al., 2003; Arthur, 2006). Underestimating the degree of transmission will undermine our potential for averting HIV amongst this population. An accurate understanding of transmission is also important for prevention interventions. An aim of the SONHIA study was to determine the extent to which acquisition of HIV infection in a UK African population may have occurred within the UK. Description of the processes used and our findings are presented in this chapter.

8.1 Methods

8.1.1 Participants

The study of newly diagnosed HIV infection among Africans in London (SONHIA) is a survey of newly diagnosed HIV positive Africans attending 15 HIV treatment centres across London conducted between April 2004 and February 2006. For the purposes of this study Africans were defined as persons born or raised in Africa, and as such included persons of all racial and ethnic groups. Participants had to be within 12 months of initial HIV diagnosis and aged 18 years or older. Detailed

description of the design and recruitment process is provided in chapter 5. All participants of the SONHIA study were included in this analysis.

8.1.3 Study instruments

As described in chapter 5 the survey consisted of a self-completed pen and paper questionnaire, available in English or French, linked to clinician completed clinical records. The confidential questionnaire collected quantitative data on socio-demographic characteristics, behavioural and social factors, sexual health and behaviour, HIV testing history, and migration history, which were then matched with CD4 and clinical data. Established criteria[13] (Paine et al., 1997) to assess possible region of infection were modified to include criterion that utilised additional data collected in the SONHIA study (see box 8.1). These modified criteria were then used to determine likely region of acquisition. Region of acquisition refers to either the African continent or the UK as whole, rather than specific countries within these, entities.

8.1.4 Statistical analysis

The data for all respondents was assessed according to the criteria in box 8.1 to rank the likelihood of HIV acquisition in the UK or abroad. Every respondent who fulfilled criteria for 'definitely or probably acquired their HIV in Africa' (categories 1 and 2) or 'definitely acquired their HIV in the UK' (category 6) was classified as 'determinate'; all others were classified as 'indeterminate'. Two independent assessors (both HIV clinicians) then repeated the process of assessing country of HIV acquisition using the same criteria on all indeterminate cases. This produced a range of estimates for region of acquisition apportionment. When there was

[13] First used for assessing possible country of infection from clinic notes in Lambeth, Southwark and Lewisham (LSL), Paine 1997.

Box 8.1 Criteria for assessing possible country of infection

based on 'Criteria for assessing possible country of infection from clinic notes in Lambeth Southwark & Lewisham'(Paine et al., 1997)

1 Those definitely infected abroad

- those who have never had unprotected sexual intercourse in the UK before their test
- those who tested positive before arrival
- those in the UK for less than 6 months when diagnosed with AIDS
- those who arrived in the UK symptomatic
- those who had a child born before they came who tested positive
- those who came less than a month before testing positive, whose test shows no seroconversion features

2 Those probably infected abroad

- those who had a positive partner abroad and negative partner(s) here
- those in the UK for less than 2 years when developing AIDS
- those in the UK for less than 2 years with a CD4<200 at presentation
- those 'visiting' the UK *(if short term visit and no features of seroconversion)**
- those who have had sex with commercial sex workers in high prevalence areas, and no other suspected HIV positive partners

3 Those likely to have been infected abroad

- those in the UK for less than 5 years when developing AIDS
- those in the UK for less than 4 years and a CD4 count <200 at presentation
- those who have had unprotected sexual intercourse in high prevalence country in past 10 years and since then no partners in the UK from abroad
- those with a presumed positive partner abroad and no known positive partner in the UK
- those who received blood/blood products in high prevalence country in the past 10 years; no other documented high risk
- *those with a history of STI abroad and no STI diagnosed other than HIV in UK**

4 Those likely to have been infected in the UK

- those with a presumed positive partner in the UK and no known positive partner abroad
- known positive partner in the UK, CD4 count <500 at presentation; no evidence of positive partner abroad

5 Those probably infected in the UK

- known positive partner in the UK, CD4 count>500 at presentation
- those in the UK for at least 12 years when developing AIDS *(with no unprotected sexual intercourse in high prevalence country since arriving in the UK)**
- those with a negative test before coming to the UK *(if test in same year of arriving in UK)**
- those with documented negative partner(s) abroad

6 Those definitely infected in the UK

- no UPSI except in the UK
- documented seroconversion in UK with no travel abroad within 2 months of test
- *prior negative HIV test in the UK and since then no overseas travel**

7 Those with a positive partner with whom they have had sex in the UK as well as elsewhere

- this group cannot be placed

8 Inadequate information to assess

* Text in italics reflects modifications used in this study.

discordance between the assessors' responses the data were reviewed to identify the degree with which disagreement occurred. Apportionment of region of acquisition was also ascertained utilising a measure entirely based on CD4 band at the time of diagnosis (and hence estimated time from seroconversion (table 8.1)) and time in the UK (Satten et al., 1996). Additionally each assessor was asked to identify the principal criterion(s) that influenced each coding decision.

Table 8.1 Estimated time of seroconversion based on CD4*

CD4 band (x10^6/l)	Median time from seroconversion to diagnosis
>499	24 months
350-499	50.4 months
200-349	74.4 months
<200	8.5 years

These criteria are currently used by the HPA (Arthur, 2006).

To enable comparative analysis the outcome measure (likelihood of HIV acquisition in UK or abroad) was regrouped into a binary measure of 'acquisition of HIV in the UK or abroad'. When an assessor had categorised country of acquisition as 'inadequate information to assess' or 'unable to place as HIV positive partner potentially both in UK and elsewhere', the case was assigned to 'HIV acquisition abroad' as acquisition within Africa is statistically more probable, and this would represent the most conservative estimate of acquisition within the UK.

Data were entered onto a secure database and systematically checked for errors prior to statistical analysis. Summary statistics, agreement rates and kappa statistics to assess inter assessor reliability are presented. Analysis was performed using Intercooled STATA 8.0 (Stat Corp., College station, Texas, USA) and SPSS12.0 (SPSS Inc., Chicago, Illinois, USA).

8.2 Results

Detailed description of the response rate and differences between those approached and not approached are presented in chapter 6

As stated in chapter 6 the median age of respondents was 34 years, 60.5% were women, and approximately 50% presented with late stage disease (CD4 <200x10^6/l at diagnosis). The median time in the UK prior to HIV diagnosis was 3.9 years. The majority of respondents identified as heterosexual (92.5%) and 93.5% identified as black African. The socio-demographic, behavioural and clinical characteristics of the study population are described in chapter 6.

Of 263 respondents, 61 (23.2%) fulfilled criteria for 'definitely acquired HIV abroad', 43 (16.3%) 'probably abroad', and 27 (6.1%) 'definitely in the UK', leaving 143 (54.4%) 'indeterminate cases' for further analysis. The proportion of all[14] HIV infections assessed as acquired in the UK ranged between 25.1% and 35.4%, whilst 60.8% to 67.3% were assessed as acquired abroad. All cases acquired abroad indicated Africa as the region of acquisition. Utilising the CD4/time in the UK criteria 35.1% of HIV was acquired in the UK, and 64.9% in Africa, however it had only a moderate level of agreement with the more detailed assessment (kappa[15] =0.427, n=262, p<0.001 (table 8.3)).

No significant differences were found in the region of acquisition by gender or age. Age on arrival in the UK was associated with region of acquisition, persons aged 30 or older on arrival were less likely to have acquired HIV in the UK than those aged

[14] Derived by adding determinate cases to proportions derived by the 3 assessors for the indeterminate cases.

[15] Kappa determines inter assessor reliability after accounting for chance. Levels of agreement as determined by kappa can be grouped into <0.0 poor; 0.0-0.20 slight; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 substantial; 0.81-1.0 almost perfect (Landis and Koch 1977, Biometrics).

Table 8.2 Agreement of CD4/Time in UK with assessors rating

	Agreement	Kappa	N	p-value
Assessor 1				
- All cases	75.6%	0.427	262	<0.001
- Indeterminate cases only	64.8%	0.293	142	<0.001
Assessor 2	64.1%	0.283	142	0.001
Assessor 3	62.7%	0.252	142	0.002

Table 8.3 Classification of region of acquisition by Assessors and CD4/time in UK criteria

Place of acquisition	**According to criteria in box 8.1**			**Measure based on CD4 at diagnosis and time in UK**
	Assessor 1 % (n)	**Assessor 2[a] % (n)**	**Assessor 3[a] % (n)**	**% (n)**
Africa (total):	**62.7 (165)**	**60.8 (160)**	**67.3 (177)**	**64.9 (170)**
Definitely in Africa	23.2 (61)	23.2 (61)	23.2 (61)	
Probably in Africa	16.7 (44)	17.5 (2+44=46)	18.6 (5+44=49)	
Likely in Africa	22.8 (60)	20.2 (53)	25.5 (67)	
UK (total):	**25.1 (66)**	**35.4 (93)**	**28.5 (75)**	**35.1 (92)**
Likely in UK	6.8 (18)	20.5 (54)	13.7 (36)	
Probably in UK	12.2 (32)	5.3 (14)	7.2 (19)	
Definitely in UK	6.1 (16)	9.5 (9+16=25)	7.6 (4+16=20)	
Unable to place[b]	10.3 (27)	0.4 (1)	0.4 (1)	
Inadequate information to assess	1.9 (5)	3.4 (9)	3.8 (10)	
Total:	**100 (263)**	**100 (142+132=263)**	**100 (142+132=263)**	**100 (262)[c]**

Highlighted cells assumed to be correctly assigned given criteria requirements and thus not reassessed by assessors 2 & 3 however figures added to final tally for assessors 2 & 3 to enable comparison.

[a] Determinate cases added to assessors tally

[b] Those with an HIV positive partner but information on duration and/or location of partnership missing

[c] Base 262 due to missing data on time in UK

less than 30 years (13.0% vs. 36.8%, odds ratio OR 0.21, 95% CI 0.11-0.42, p<0.0001). Persons defining themselves as homosexual or bisexual were more likely to have UK acquired HIV than heterosexuals (47.4% vs. 24.4%, OR 2.86, 95% CI 1.11-7.39, p=0.028), as were early compared with late presenters (35.6% vs. 14.5%, OR 2.87, 95% CI 1.58-5.21, p=0.001). The association between acquisition in the UK and early presentation remained when adjusted for sexual orientation (Adjusted odds ratio (AOR) 2.66 (95%CI 1.45-4.88, p=0.002).

The allocation of country of acquisition according to the three assessors is presented in table 8.3. Between 7% and 22.5% of cases were unable to be assigned, either due to insufficient information available or because a known HIV positive partner may have been a partner in both the UK or in Africa. Assessor 1 (the author) felt that if duration of the partnership (and hence whether it preceded migration to the UK) was not known then an assumption of place of acquisition could not be made. The principal factors influencing allocation of region of acquisition for the determinate cases are presented in table 8.4.

Focusing on the case-by-case agreement of indeterminate cases: Complete agreement (when all assessors agreed on the exact classification) was 38.7% (95%CI: 30.7-47.3%) (Table 8.5); However when assessing region of acquisition, rather than the degree of probability within that region, agreement was 63.0% (95%CI: 54.2-70.6%); this rose to 79.0% (95%CI: 71.2-85.3%) when including those cases where two assessors had complete agreement but the third felt unable to assess. In 18.9% (95%CI: 12.9-26.4%) of cases the assessors differed on country of acquisition.

Table 8.4 Major influences of factors in assessing country of acquisition – determinate cases (n=120)

Influencing factors by classification	% (n)
Definitely acquired in the UK (n=16):	
Prior negative HIV test in UK and since then no overseas travel	75.0% (12/16)
No unprotected sexual intercourse except in the UK (and no exposure to blood products abroad)	12.5% (2/16)
Other	12.5% (2/16)
Definitely acquired in Africa (n=61):	
No sex in the UK	73.8% (45/61)
AIDS within 6 months of arrival in the UK	6.6% (4/61)
Symptomatic on arrival in UK	4.9% (3/61)
No unprotected sexual intercourse in the UK	4.9% (3/61)
Diagnosed prior to or within one month of arrival (no seroconversion)	4.9% (3/61)
Other	4.9% (3/61)
Probably acquired in Africa (n=43):	
In the UK <2 years with CD4 <200 at presentation	30.2% (13/43)
In the UK <2 Years with AIDS at presentation	14.0% (6/43)
Sex with or as commercial sex worker in Africa and no other known HIV positive partners	18.6% (8/43)
Those on short term visit to the UK and no features of seroconversion	11.6% (5/43)
Those with an HIV + partner in Africa and negative partner here	9.3% (4/43)
Other (e.g. rape in Africa, probable vertical transmission)	16.3% (3/43)

Table 8.5 Measure of agreement of indeterminate† cases (n=143)

	Complete agreement[1]	Near Agreement[2]	Within country agreement[3]	Two complete agreement + one unable to assess[4]	Two unable to assess + one placed[5]	Two complete agreement + one different country[6]	Complete disagreement[7]
Number	56	33	1	23	3	14	13
Proportion (95%CI)	39.2% (30.7-47.3)	23.1% (16.6-31.1)	0.7% (0.02-3.9)	16.1% 10.6-23.3)	2.1% (0.4-6.1)	9.8% (5.5-16.0)	9.1% (5.0-15.1)
Within continent agreement (95%CI)		63.0% (54.2-70.6)					
			79.0% (71.2-85.3)			21.0% (14.7-28.8)	
Assessors differed in specified ROA							18.9% (12.9-26.4)

† 'Indeterminate' refer only to those cases who had not definitely or probably acquired their HIV in Africa or definitely acquired their HIV in the UK.

1 All three assessors agreed on exact classification of region of acquisition (ROA)

2 Two assessors agreed on exact classification and third differed on degree of probability by one as long as that difference did not alter country of acquisition, e.g. two assessors rated country of acquisition as 4 (likely acquired in UK) and one as 5 (probably acquired within UK).

3 All three assessors agreed on country of acquisition but differed on degree of probability, e.g. one rated ROA as 4 (likely acquired in UK) and another rated ROA as 6 (definitely acquired in UK)

4 Two assessors had complete agreement (see footnote 1) but third assessor felt there was either insufficient information to assess or that as respondent potentially had a positive partner in both Africa and the UK region of acquisition could not be placed.

5 Two assessors felt there was either insufficient information to assess or that as respondent potentially had a positive partner in both Africa and the UK region of acquisition could not be placed but third assessor felt able to assign region of acquisition.

6 Two assessors agreed on exact classification but third assessor differed on region of acquisition

7 All three assessors differed in their opinion (one placed ROA in Africa; one in UK; and one as unable to assess).

Figure 8.1 (located at end of chapter) shows the level of agreement between the assessors according to assigned region of acquisition for the indeterminate cases. The degree of complete agreement was similar according to whether HIV was assessed as acquired in Africa (56.1%, 95%CI: 44.1-66.6%) or the UK (50.6%, 95% CI: 39.3-61.9%); however agreement was substantially lower in cases felt unable to be assigned (9.3%, 95%CI: 3-22%). The overall measure of agreement for the indeterminate cases (with all cases unable to be assigned reclassified as likely acquired in Africa) was Kappa = 0.6 (n=142, $p<0.001$).

The principal factors influencing allocation of region of acquisition for the determinate cases are presented in table 8.5. HIV testing history in combination with travel history was the most important factor in determining whether HIV had definitely UK acquired; 75% (12/16) of those assessed as definitely acquiring HIV in UK had a prior negative HIV test in the UK and no subsequent overseas travel, a further 12.5% reported only ever having unprotected sex in the UK and no exposure to blood products abroad. Definite acquisition of HIV in Africa was most associated with reported sexual behaviour (no sex in the UK (73.8%)) and clinical factors (an AIDS diagnosis within six months of arriving, or symptomatic on arrival in UK (11.5%)). Time in the UK (<2 years) in relation to CD4 and AIDS defining illnesses were most associated with probable acquisition in Africa (44.2% (19/43)), followed by sex with or as a commercial sex worker in Africa with no other known HIV positive partners (18.6%).

The key criteria that were informative in assigning region of acquisition for the 142 indeterminate cases included sexual behaviour (number of partners in the UK, past history of STIs), time in the UK in relation to CD4 count at diagnosis, and partner issues (whether known HIV positive partner or not, country of origin of partner and

duration of partnership) (table 8.6). The influence of these three factors was consistent between assessors (range 78.9 to 80.5%), and for cases where the assessors agreed and disagreed on country of acquisition (data not shown).

Table 8.6 Influencing factors in assessing region of acquisition[1] –indeterminate cases (n=142)

Factor	Principal factor	Second factor	Third factor	Overall
Sexual behaviour /STI history	39.1%	34.2%	20.0%	34.1%
Time in UK in relation to CD4	17.4%	22.9%	37.9%	22.9%
HIV status of partner(s)	23.3%	23.8%	17.9%	22.6%
HIV testing history	13.2%	6.1%	8.4%	9.6%
Clinical reason	1.9%	4.8%	7.4 %	3.9%
Travel history	1.6%	6.5%	4.2%	3.9%
Other/exceptional reason e.g. rape, blood transfusion	3.5%	1.7%	4.2%	2.9%
Total	100%	100%	100%	100%

[1] As identified by assessors.

[2] Allocation could be influenced by 1, 2 or 3 factors depending on the case.

8.3 Discussion

These findings suggest that the proportion of UK-resident Africans who may have acquired HIV in the UK is substantially higher than previously estimated. Between a quarter to a third of all HIV positive Africans currently resident in the UK, and nearly half of HIV positive African MSM, were likely to have become HIV-infected in the UK.

National surveillance data from the Health Protection Agency (HPA) reports that in individuals of black African ethnicity approximately 8% of newly diagnosed heterosexually acquired HIV infections in the UK were probably UK acquired (The UK Collaborative Group for HIV and STI Surveillance, 2007). No breakdown of probable region of acquisition is provided by country of birth. The HPA's region of HIV acquisition data are based primarily upon voluntary confidential reports by

clinicians, with review and follow-up of incomplete data by national surveillance coordinators (Dougan et al., 2005). By systematically incorporating more detailed demographic, behavioural and clinical information, this study is able to draw on a richer source of information in assessing country of acquisition, which may account for the differences between these findings and those of the HPA.

The high transmission of HIV within the UK is supported by current research. There is a high background prevalence of HIV within African communities in the UK; 14% of respondents tested HIV positive in Mayisha II, and 66% of these infections were undiagnosed (Sadler et al., 2007). HIV positive Africans in the UK are also more likely to present later and with advanced disease than non Africans (Burns et al., 2001; The UK Collaborative Group for HIV and STI Surveillance, 2006; Chadborn et al., 2006). Undiagnosed infection and advanced disease (via high viral loads) are important components in facilitating the onward transmission of the infection (Quinn et al., 2000; Marks et al., 2006). When considered in conjunction with the high HIV prevalence and known assortative mixing patterns it becomes evident that an African resident in the UK is at substantially higher risk of HIV exposure than a non-African resident. However until now, the impact of this risk in terms of incident cases in the UK has not been quantified.

8.3.1 Limitations

Limitations of the study design in terms of selection and recall bias have been described in chapter 5. Participants had more advanced disease, as defined by CD4 at diagnosis, than non-participants. Acquisition of HIV in the UK was negatively associated with late presentation; hence our findings potentially underestimate infection acquired in the UK. No evidence to support a shift in HIV testing patterns within African communities currently exists which could account for our findings.

The data were not complete in that certain responses were missing. There were incomplete data on a number of variables that would have facilitated country of acquisition allocation. For example whether partners were resident in the UK, and country of origin and timing of last two sexual partners, were questions added after recruitment had commenced so data are only available for a relatively small proportion of respondents.

As with other clinic based surveys, reporting bias in response to sensitive subject matter (migration, sexual behaviour, HIV) may have influenced the reliability and validity of the reported data. For example, socio-culturally prescribed behaviours (e.g. sexual orientation or numbers of partners) may be underreported. Recall bias may have influenced the degree to which risk behaviours or the locations where they had occurred were reported based upon individuals' beliefs about their risks, or seroconversion episode. Misclassification may have occurred in ascertaining the likely country/region of acquisition, especially if the country with the higher HIV prevalence was presumed to be the country of infection. We attempted to minimise this by having multiple reviewers of each participant's record and assessing for concordance between them.

Criterion related to CD4 and time in the UK is located within the modified criteria and was second only to sexual behaviour as the most influential factor in assigning country of acquisition. However this data suggests that it would be insufficient to use this criterion in isolation as it had only fair levels of agreement with the modified criteria as a whole.

The modified criteria were shown to be an acceptable though imperfect tool in determining likely region of acquisition; a kappa score of 0.6 reflecting moderate to substantial levels of agreement between the assessors. This score only relates to the

indeterminate cases where allocation of country of acquisition was uncertain, the kappa score would have been substantially higher if the determinate cases had been included. However the criteria is not suitable for routine clinical use.

According to HPA data 2311 Africans were newly diagnosed with HIV in London in 2004-2005 (Kuczawski, 2007). SONHIA participants represent approximately 11% of this population. Comparison between the two populations demonstrates that the SONHIA sample was largely representative of the London wide (and indeed the UK) in terms of gender, age, and ethnic group (table 8.7). The high proportion of African MSM who may have acquired HIV in the UK is in keeping with national surveillance data which reports that 72% of ethnic minority MSM were probably infected in the UK (The UK Collaborative Group for HIV and STI Surveillance, 2007). The higher proportion of African MSM in SONHIA (7.5% vs 0.9%) probably reflects this fact and that the HPA used country of infection as a proxy marker of country of origin in supplying the comparative data (Kuczawski, 2007).

Determining region of HIV acquisition proved to be difficult, individuals may have had multiple partners within and outside the UK, and explicit robust criteria do not currently exist. Even after informal discussion with the national surveillance coordinators it was not always evident what criterion should be given precedence, with respondents often having conflicting clinical, migratory and behavioural parameters. Whilst the three assessors used the same data and criteria, and the key factors in influencing their decisions were almost identical, variation still occurred in the output due to differing interpretations.

Table 8.7 Comparison between adults associated with Africa[a] newly diagnosed with HIV in London in 2004-2005 and SONHIA participants

Characteristic	HPA data	SONHIA	
Total	2311	263	
Gender			P=0.229
Men	827 (35.8%)	104 (39.5%)	
Women	1484 (64.2%)	159 (60.5%)	
Age (years)			P=0.849
18-24	201 (8.7%)	20 (7.6%)	
25-34	1023 (44.3%)	113 (43.0%)	
35-44	772 (33.4%)	94 (35.7%)	
45+	315 (13.6%)	36 (13.7%)	
Exposure category			p<0.001
Heterosexual	2271 (98%)	234 (92.5%)[a]	
Sex between men	20 (0.9%)	19 (7.5%)	
Ethnic group			P=0.188
Black African	2106 (91.1%)	246 (93.5%)	
Region of infection/origin[a]			p<0.001
Central & Western Africa	697 (30.2%)	62 (23.6%)	
East Africa	539 (23.3%)	67 (25.5%)	
Southern & South-eastern Africa	813 (35.2%)	127 (48.3)	
Other (including unknown)	262 (11.3%)	7 (2.7%)	

[a] Individuals associated with Africa are defined by probable country of infection. The HPA use country of infection as a proxy marker for country of birth

[b] Missing data for 10 (n=253)

8.3.2 Implications

Our findings have implications for HIV prevention policy and practice within the UK. More work is now needed to develop user-friendly assessment tools to assist clinicians in their determination of country of acquisition for newly diagnosed HIV positive persons. Combining expanded clinical, demographic and behavioural markers can substantially improve the accuracy, reliability and validity of country of HIV acquisition determinations. However, there are trade-offs between the comprehensiveness and utility for such assessment tools, since busy clinicians are unlikely to use a complex questionnaire on a routine basis. Also, even in research settings, more comprehensive assessment tools are susceptible to residual interpretive error. Consequently, these approaches should be supported by new technologies such as HIV-incidence testing and phylogenetic mapping, technologies that are not yet routinely applied to newly diagnosed HIV-infected individuals in the UK. Without these developments clinicians and our national HIV surveillance data are likely to continue overestimating the burden of imported infections.

The dangers of continually underestimating the incidence of in-country HIV transmission and acquisition are multifaceted. It provides a false sense of security that HIV among Britain's migrant populations solely reflects global trends and not ongoing endemic transmission of HIV within the UK. It falsely assumes that the UK is homogeneously 'low prevalence' despite robust evidence to suggest that the HIV prevalence in particular sexual networks (e.g. MSM) or geographic settings (e.g. central London) exceed those of many parts of the world. It also systematically disenfranchises HIV prevention efforts for ethnic minority communities by failing to

comprehensively address the syndemics[16] of HIV and sexually transmitted infections, assortative sexual mixing patterns, and poor access to culturally-specific prevention programs.

Finally, failure to more systematically measure, track and respond to the endemic HIV transmission delays the urgency to develop and implement effective interventions earlier in the endemic phase. There are still no culturally specific effective behavioural interventions for migrant Africans in the UK (Prost, 2005), reflecting in part this broadly held assumption that acquisition has occurred abroad. These findings challenge this assumption and hopefully will encourage efforts to develop intervention programmes that support African communities to raise HIV awareness and reduce HIV transmission.

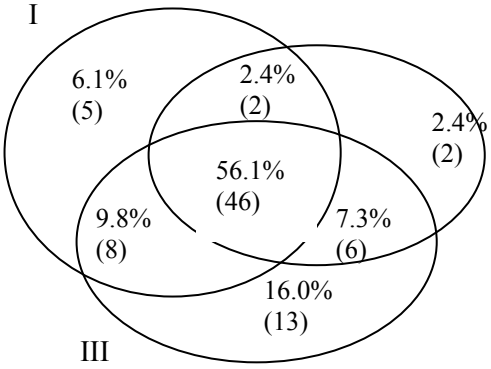
Delayed diagnosis of HIV facilitates the onward transmission of the infection as well as leading to poorer clinical outcomes. If the estimates of HIV acquisition within the UK in this study are correct it is likely that late presentation is a critical component. The following chapter uses qualitative methods to explore the context within which African migrants face HIV to help understand why late presentation continues to be a defining feature of HIV in this population.

[16] The synergistic interaction of co-existent diseases and social conditions at the biological and population level (Singer et al., 2006).

Figure 8.1 Agreement between three assessors

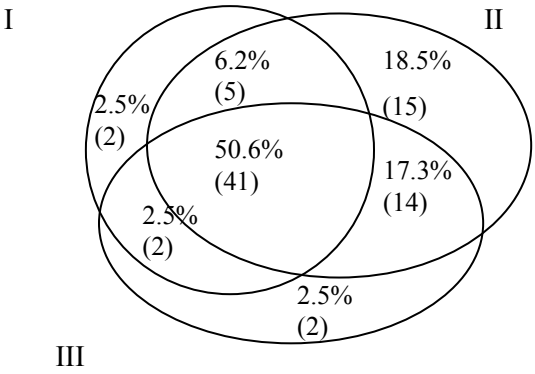
Region of acquisition = Africa* (n=82)

*Excludes all those assessors found unable to assess



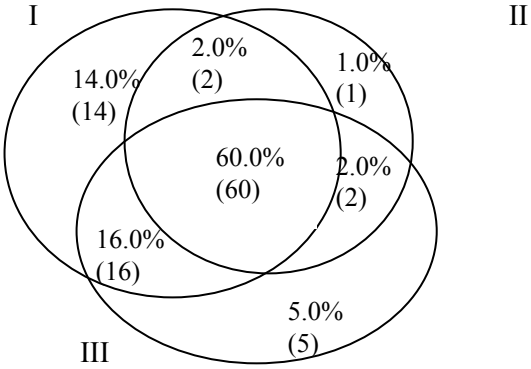
Region of acquisition = UK* (n=81)

*Excludes all those assessors found unable to assess



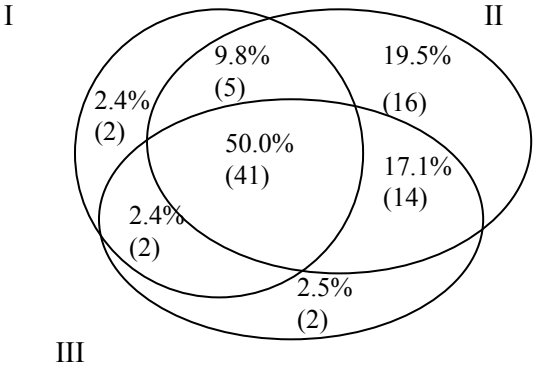
Region of acquisition = Africa* (n=100)

*All those assigned as unable to assess included in Africa



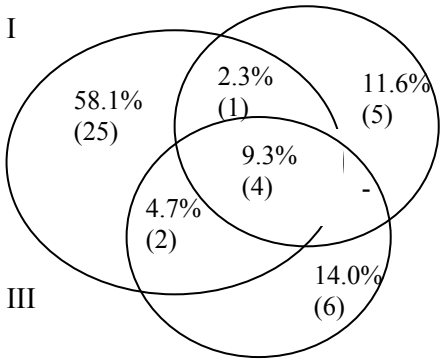
Region of acquisition = UK* (n=82)

* All those assigned as unable to assess included in Africa



Unable to assign region of acquisition* (n=43)

*Includes both those with inadequate information and those with a partner known to be HIV positive who potentially has been a sexual partner in both Africa and the UK.



Chapter 9: Qualitative study with purposively selected respondents

Abstract

Objective: To develop a contextual understanding of the factors contributing to late presentation to HIV services by Africans resident in the UK.

Methods: 26 in-depth interviews with a purposively selected sample of newly diagnosed HIV positive Africans were conducted between February and December 2005. Analysis was undertaken using Framework.

Results: The delay in HIV diagnosis appeared to be the consequence of interplay between stigma, perception of personal risk, lack of perceived benefit, and migratory and institutional factors. Stigma contributed to low risk perception by perpetuating the concept of 'otherness'; HIV was still seen as a disease that only certain types of people were at risk of acquiring. HIV was typically not considered until the onset of ill health. The lack of benefit in knowing ones serostatus was in part related to lack of knowledge about effective medications and in part because of the continuing negative repercussions in terms of stigma and discrimination, and disclosure to immigration services. The focus of people's lives was on financial or immigration issues, not on health. The narratives also recounted numerous missed opportunities for earlier HIV diagnosis within the health system itself. Improving the uptake of HIV testing was believed to be possible by the provision of more information utilising positive non-targeted images, and creating more testing opportunities.

Conclusion: These findings highlight the central role of HIV-related stigma and discrimination in influencing HIV testing behaviours among migrant Africans in Britain. Significant cultural work is needed to break down the associations that accompany HIV. Similarly the medical profession is complicit in perpetuating the cycle of late diagnosis and onward disease transmission by continuing to treat HIV differently to other chronic health conditions.

9.0 Introduction

In the preceding chapters factors associated with late presentation have been identified, missed opportunities for earlier diagnosis highlighted, and the consequent impact on HIV transmission and acquisition within the UK presented. The aim of this chapter is to

develop a contextual understanding of the factors contributing to late presentation to HIV services. It also aims to identify future means of improving access to HIV services for Africans in Britain.

The chapter begins with a detailed description of the methodology, followed by an overview of the sample interviewed. The findings relating to late presentation and how to improve access of services are then presented thematically, followed by my reflections on the interviews. The chapter concludes with a discussion of these findings.

9.1 Methods

A detailed description of the sample design and development of the topic guide is presented in chapter 5 (section 5.1.3). In-depth, semi-structured interviews were conducted with a purposively selected sub-sample of the 263 participants of the SONHIA study. A quota-based sample was used to ensure diversity of gender, age, length of time in the UK, partnership status, region of origin, and site of care.

Whilst originally 40 interviews were planned only 26 were conducted (table 9.1). The reduced sample was primarily due to time and resource limitations.

9.1.2 Patient identification and recruitment

As stated in chapter 5, the key worker at each study site facilitated recruitment to the qualitative sub-study. The key workers ensured respondents understood the aim of the interview, addressed concerns regarding the subject matter and provided reassurance of confidentiality. Having read the patient information sheet (appendix 5), and if the patient consented, their name and contact number was supplied to me. All participants were contacted by phone to assess eligibility to the interviews. A screening questionnaire established if the patient fulfilled required criteria according to the quota matrix (appendix 7). If eligible arrangements for the in-depth interview were made at a

mutually convenient and appropriate time and location. Written informed consent was obtained prior to commencing any interview. Patients receiving clinical care from myself, the sole interviewer, were excluded from participation in the interviews.

9.1.3 The interviews

Exploratory, semi-structured, in-depth interviews were used to develop a contextual understanding of the factors that inhibit African people seeking HIV care. All interviews were based on a topic guide (see box 9.1 and appendix 8) that covered key areas for investigation. The interviews were conducted either in the patients' own homes, or a private room on hospital premises depending on the wishes of the participant.

Box 9.1 Key areas of exploration within interview topic guide:

Areas to explore:

1. Personal circumstances: socio-demographic background and migration history
2. Personal & community attitudes: important influences, stigma, role of religion, and the role of the African community
3. Learning about and awareness of HIV: experiences, perceptions of risk, and knowledge of treatment options
4. Health & service history: perceptions and experiences both within the UK and Africa, including detailed sexual health history
5. Improvements to services and information: what would be effective and who should be targeted?

9.1.4 Quality control measures

A variety of quality control measures were employed throughout the study:

1. Prior to commencement of the study a five-day in-depth interviewing course run by the National Centre for Social Research was attended. This included training and practical sessions in the design, conduct and analysis of in-depth interviews.

2. Records were kept of the interviews and observations about the interview.

3. An experienced qualitative researcher listened to some of the recorded interviews and provided feedback throughout the study. He was involved in development of the thematic framework, checked the coding procedures, and reviewed data classification.

4. Finally, triangulation of the research findings with other studies and with the quantitative component of this study, was undertaken where possible.

9.1.5 Data collection and analysis

Data collection was carried out between February and December 2005. The majority (n=19/26) of interviews were conducted in a private room located within the participants HIV treatment centre, four were conducted in the participant's home and the remainder occurred within my office. Interviews lasted from one to three hours (average 80 minutes).

All in-depth interviews were electronically recorded where possible. On the two occasions where recording failed due to technical reasons extensive notes were taken during the interview and subsequently written up. The recorded interviews were independently transcribed verbatim. The tapes and transcripts are stored in a locked cupboard with access limited to the research team. No identifying data, such as name or hospital number are kept with the transcripts. No information about the respondents has or will be disclosed to other institutions or authorities.

The analysis was undertaken using 'Framework' (Ritchie et al., 1994). Framework (Box 9.2), a method of qualitative data analysis, involves ordering and synthesising verbatim data within a thematic matrix. The themes are developed from the research question and from the accounts of the research participants. This method is based on grounded theory

(i.e. based in and driven by the accounts and observations of the people it is about)(Strauss & Corbin, 1990). It allows full review of collected material, and detailed between and within case analysis. Data management and analysis of the transcribed interviews were facilitated by the use of the qualitative software MAXqda2 (VERBI software, Berlin, Germany).

Box 9.2 Stages of analysis using 'Framework'(Ritchie et al., 1994)

1. Familiarisation (reading transcripts/listening to tapes)
2. Identifying a thematic framework (and developing a coding scheme)
3. Indexing (codes systematically applied to the data)
4. Charting (rearranging data according to the thematic content to allow within and between case analysis)
5. Mapping and interpretation (defining concepts, mapping range and nature of phenomena, creating typologies, finding associations, providing explanations, developing strategies)

9.1.6 Critical examination of researcher's own role

As a white, middleclass New Zealander extra care had to be taken in the establishment of trust and rapport; key factors if open and frank discussion were to occur. It was also vital that as I was someone who worked 'for the establishment' that every effort was made to reassure about confidentiality and to empower participants to feel able to answer, or not, as they felt comfortable.

The establishment of rapport is crucial in conducting qualitative interviews, and there is on going debate about the importance of language and ethnic matching in establishing this rapport. Evidence suggests that a shared language is crucial in conducting interviews, with language matching influencing data collection and the nature of the data collected (Grewal & Ritchie, 2006). As solely an English speaker and the sole

interviewer, only people fluent in English were eligible for inclusion in this component of the study.

It was obviously not possible for me to be ethnically matched to the Africans interviewed. It makes intuitive sense that ethnic matching may facilitate rapport through fostering a sense of mutual experience, however strong evidence to support this assumption is lacking. Being an 'outsider' can be a benefit when disclosure to own communities is a prime concern (Grewal et al., 2006), indeed this was mentioned during piloting. Being an outsider can also help with objectivity as it distances the interviewer from some of the biases that might come from over familiarity. For example if colloquial language is used it has to be un-packed as it is not a familiar concept to the outsider; 'insider' researchers may assume to know the intended meaning and yet the nuances of local meaning and local dialect may make this assumption incorrect.

As with all researchers involved in any research, and qualitative research in particular, it is important to be aware how social and cultural characteristics of the interviewer (myself) and context of the interviews may impact on the data. I have not attempted to remove these 'interviewer effects' but have attempted to account for them and explain them within my findings, a process referred to as 'reflexivity' (Nazroo, 2006). In order to increase reliability and validity I have paid close attention to unusual cases ('the norm is often explained or illuminated by the exceptional'(Kellehear, 1998)); used my supervisors to help code and develop themes; provided simple counts of frequency; deliberately tested emerging themes; and triangulated findings with other studies and the quantitative component of this study whenever possible and appropriate.

9.2 Results

9.2.1 Overview of sample

Of the 26 participants all were Black African and 15 were women. Of the men, 10 were heterosexual and one bisexual. Ages ranged from 21 to 62 years with the majority in their thirties (see table 9.1). Seven were university educated, 8 had completed secondary education and 10 had been educated to a GCSE equivalent. The interviewees came from 10 countries. Zimbabwe was the most represented (n=6), followed by Uganda (n=4), and seven interviewees came from West Africa. Time in the UK ranged between 4 months and 35 years (mean 5.2 years).

Table 9.1 Characteristics of interviewees (n=26)

	Male	Female
Age		
18-24	1	1
25-34	4	8
35+	6	6
Partnership status		
Single	3	5
Partner – not co habiting	3	5
Partner - co habiting	6	4
Region of origin[a]		
Lower HIV prevalence (<5%)	1	2
Medium prevalence	2	3
High prevalence (>15%)	8	10
CD4 at diagnosis		
<50		7
50-199		9
200-350		6
>350		4
Residence in UK		
<5 years		15
5+ years		11
Recruitment site		
Central London teaching		7
District General		19

[a] According to UNAIDS data 2003

When asked why they had migrated to the UK seven participants mentioned political reasons, seven to seek a 'better life'/for economic reasons, four to study, five to join family or loved ones (chain migration), two 'to start afresh' after failed relationships, and one specifically to have an HIV test (although not to access care as she was unaware of ART). All seven who migrated for political asylum spoke with real fear for personal safety at the prospect of returning home. One woman provided a horrifying account of torture, murder and multiple rape at the hands of guerrilla and national armies.

Twelve of the participants were employed fulltime, three were fulltime students, and 10 were unemployed, 5 being unable to register for benefits. One woman worked as a sex worker in the UK and another had been employed in the sex industry in Africa. One man had also sold sex within the UK. The majority (n=11) were renting their accommodation, three owned their own homes, three were homeless, living in hostels or Bed and Breakfasts, and nine were living with friends or family.

Nine of the 26 interviewees had secured indefinite residential rights to remain in the UK, although one person's documents were 'unofficial'. Of the remaining 17 all bar two now wanted to remain in the UK. Whilst access to health services and ART in particular had not influenced decisions to migrate to the UK, residency in Britain was now felt imperative in order to guarantee access to ART; the two exceptions to this were in wealthy women who knew they would be able to afford medications in their home countries. Seven people were currently applying for leave to remain in the UK and six were seeking asylum (4 of which were within the appeal process).

Only two of the 26 were not registered with a GP, both these women entering the country 'underground'. They also both happened to be, or had been, sex workers.

Disrupted relationships, known to be a consequence of migration, were evident in the stories of the interviewees. Whilst the majority of interviewees (n=16/26) were within a relationship at the time of the interviews, in five instances this involved a spouse who was still living abroad. Two men with spouses abroad also had long-term partners in the UK. Four women were aware of their partners having other long-term relationships whilst married to them. Two respondents were widowed, one to probable HIV and another to political violence. Half of the interviewees had disclosed their HIV status to their current or ex partners; seven knew their partners to be HIV positive and three had HIV negative partners.

Most (n=19) of the respondents had children, although only 5 had their children living with them in the UK. Extended family in Africa provided most of the ongoing care for children, some as young as 3 months when left behind. Three respondents had experienced the death of a child, two known to be HIV related (both occurring in the UK), and one presumed (in Africa). Another two respondents had sick children, one known to be HIV related and another assumed by the mother to be HIV related. The HIV status was unknown for many of the children still in Africa. The three respondents (two women and one man) who had known HIV infected children (alive or dead) had all declined antenatal testing. One woman was pregnant at the time of interview, and the birth of his first child was imminently awaited for one man. Three of the women and one of the men interviewed had been diagnosed HIV positive as a consequence of antenatal screening.

This study draws upon the experiences of these recently diagnosed HIV positive men and women to contextualise the reality of HIV testing for migrant Africans in Britain.

9.2.2 Late presentation

The delay in HIV diagnosis appeared to be the consequence of interplay between stigma, perception of personal risk, lack of perceived benefit, and migratory and institutional factors. Each of these factors are discussed:

9.2.2.1 HIV/AIDS related stigma and discrimination

All of the respondents who came from countries with a high HIV prevalence had witnessed the consequences of HIV first hand. Many (n=17) had lost friends or family, yet despite this the association of HIV as an 'inferior' or 'dirty' disease remained.

> 'Well, it's a disease which people look upon you as somebody - it's an inferiority disease, do you know what I mean, it's a disease which community does not accept.'
>
> 37 year-old Zambian woman.

> 'And people, they find like it's a laughing thing if you've got HIV, they feel like maybe you're the most dirtiest person, you know. It's not like it's just proper sex, they think maybe you've been sleeping with so many man, that's the way they put it.'
>
> 34 year-old Malawian woman.

People with HIV continue to be socially excluded, predominantly in Africa but people were fearful of that within the UK as well.

The discrimination is grounded in a culture of blame (where the HIV infected person is perceived to have brought this upon themselves by their promiscuity) and also of fear. Being HIV positive was likened to a criminal offence:

> ‘The way they're saying it, it feels like it's your fault [that you are HIV positive], it feels like it's a crime that you committed, it feels like it's something that you did, you feel like a thief, you feel like you've committed a crime, you don't feel like a victim which is what you are really. I hate to be looked upon as a victim but - I'm not a victim, that's why I said I'm not a victim but you're treated as if you've done something wrong, as if you've stolen, as if you're a burglar, as if you're a killer, you're just basically whispered about.’
>
> 34 year-old Cameroonian woman.

The ‘crime’ being the importation of HIV into the community and subsequent risk for others. Whilst people knew rationally that HIV is spread sexually irrational fear about non-sexual (aerosol or fomite) transmission remained prevalent, often justified by the association of HIV with TB.

> ‘They'll say, oh my God, she's HIV, now she's coming to my house, she's using my bed sheets, she's using the same things we are using, she's sitting on my sofa, she's just using my bed. You know.’
>
> 31year-old Zimbabwean woman.

> ‘He had TB, most people with TB have HIV.
>
> **How do others react to them?**
>
> People become isolated. People are scared of TB patients, scared that they may contract it. And in those days people did not know how HIV contracted.’
>
> 37 year-old Zambian man.

Several respondents referred to the importance of community and communal responsibility evident in African communities. This was reflected in the narratives by the near universal practice of sending money home to extended family, descriptions of childcare and family responsibilities, the influence of social networks, and the

importance of keeping up appearances. As a consequence several respondents felt Africans, more than Europeans, experienced a lot of pressure to conform socially.

> '… the Europeans of course are much more relaxed, they don't care much, we [Africans] sometimes seem to care about things that are almost, er, useless to us… I have to look good, I have to have this, I have to have these clothes and everything, blah-blah-blah, whatever. You don't live well, you don't have any source of good income and you still have to, have to squeeze everything that you look better whatever. … you know, things like that, you know, so the mentality is completely different.
>
> **There's greater pressure for you to conform to an image back home?**
>
> Oh yes. Oh yes, of course, yeah, yeah…'
>
> 40year-old South African man.

The association with sexual acquisition was the rationale given by many for stigma that accompanied an HIV diagnosis, although other STIs were not stigmatising in the same way, presumably because they are not associated with death and suffering.

> **'What about other infections from sex like gonorrhoea or syphilis? Do people have the same attitude?**
>
> No, that one's completely different. That one, they wouldn't look at that way but HIV is just something different. I don't know why. People, I think we don't, people, they still don't understand how HIV, how you get HIV.
>
> **So they're frightened?**
>
> Yes'
>
> 34 year-old Malawian woman.

Only two men, both university educated professionals from high prevalence countries, felt that people with HIV were no longer socially isolated and that there was now a general acceptance that anyone could get it.

> ‘A lot of people now see it as it's only a matter of time before you fall sick as well so people really don't, you know there is no -
>
> **People aren't isolated any more?**
>
> No, they aren't isolated, … - I mean it is, it's like probably a country at war where somebody dying does not make news any more and people just get on with it and you don't know when the next bullet is going to hit you. So yes people have kind of accepted the fact that it could be anyone.’
>
> 30 year-old Zimbabwean man.

Neither man, despite purporting an acceptance of HIV, had disclosed his HIV status to anyone other than his spouse.

Those not from high prevalence countries were less likely to have experienced HIV directly but had still witnessed the consequent social isolation and suffering experienced by people with HIV in their home countries.

> ‘But I had seen people with AIDS at the hospitals. They are isolated, no one talks to them, and they go home and within a few weeks they die.’
>
> 19 year-old Cameroonian woman.

Despite many respondents recounting examples of how they had reacted supportively to friends and family with HIV, few interviewed trusted that they would receive similar support should they disclose their HIV status. However, almost all of the respondents who had disclosed to friends and family (n=10) had positive experiences of both the

process and its consequences. The exception to this was a woman disclosing to her sexual partner; he left her as a consequence.

Stigma is sometimes divided into 'felt' and 'enacted': the former referring to people's feelings and expectations of others reactions in relation to the condition, whilst the latter refers to peoples actual experience of stigma and discrimination (Jacoby, 1994). The HIV-related stigma, both felt and enacted, discussed in the narratives was predominantly set in the African context but it was with these eyes that the respondents continued to look at HIV. There was almost no imagery (good, bad or indifferent) of HIV within the UK to replace the African experience.

> 'I wouldn't think that there is HIV in this country. It's totally different. You wouldn't think, and I've never came across a person who I'd say I suspect, no. I don't want to lie, I don't think. Maybe because people have the thing because of the medication, the food, everything, their lives, whatever, you won't think.'
>
> 38 year-old Malawian woman.

Even for those respondents who thought they would test negative, or who had not considered themselves to be at risk of HIV, the very process of presenting for an HIV test was a frightening proposition. People expressed fear that to test for HIV exposed oneself to the same promiscuous label as for those testing HIV positive. This was because the perception was that only people at risk of HIV would or need to consider testing.

There was also the fear that if people saw you attend HIV testing services they would assume you were HIV positive, and hence you become the subject of stigma and discrimination, regardless of the outcome or of what you said was the outcome.

> ‘Even if you go [for a test] and you're negative they can't believe it. They say, ah, she’s been there, she’s happy, that means that she's lying. As long as you come here they want to know.’
>
> 33 year-old Zimbabwean woman.

Stigma and discrimination made people extremely fearful of the consequences of HIV testing, both in accessing the service itself and in the possibility of a positive diagnosis; it also fundamentally altered people’s self-perceived risk of HIV.

9.2.2.2 Perception of risk

Despite the proximity of HIV in many of the respondents’ lives relatively few (n=6) perceived themselves to be at risk of the infection prior to diagnosis. This appeared to be related in part to the invincibility of youth and in part to the concept of ‘otherness’ – HIV is something that only happens to other people, not you and not your associates.

> ‘Because HIV from - it's like it's the kind of thing you think happens to everybody and not to you, it's like death, you think everyone else dies, not you, so it's like something you think happens to everyone else but you and people around you.’
>
> 34 year-old Cameroonian woman.

People trusted their perception of their partners past and present as it reflected their own judgement, thus it was as difficult to perceive sexual partners as at risk of HIV as it was of them self.

The association of HIV with Africa, and with certain risk groups also influenced risk perception:

> ‘Well, it [HIV testing] was just something I looked like at - [pause] - just a waste of time, do you know what I mean? Something I shouldn't just bother to go through. I didn't know the importance of it. To me the disease was not - it was for homosexuals, sorry about that, that's what I thought, drug users and all that. Somebody with a straight life how they get it?’ 37 year-old Zambian woman.

> ‘It's more something here because back home we never discuss about until I went to South Africa, but South Africa it's not gay people that get it, it's heterosexual people. But when I got here I realised it's a gay thing.
>
> **So did you - you didn't know that before that?**
>
> Not until here, because the information is right here.’
>
> 39 year-old Ghanaian. man (MSM).

> ‘I thought I was too young to have HIV’
>
> 19 year-old Cameroonian woman.

The West Africans interviewed all associated HIV as a regional rather than pan sub Saharan African issue, with Southern and Eastern Africa as the regions affected. Their awareness of HIV generally and self perceived risk of HIV infection tended to be lower then the other interviewees. The following quote demonstrates how stigma and risk perception are interconnected.

> ‘In Ghana we are not very promiscuous. South Africa, Botswana, they are promiscuous because I have been there, I know how the places, how they are.’
>
> 39 year-old Ghanaian man

Sex, and sex education, were not considered suitable topics for conversation at home or by peers; knowledge about sex and HIV often coming from direct experience or from outside agencies such as schools or the church. The silence around discussing sex generally probably contributes to the notion that sexual practices outside the norm are required to put oneself at risk of HIV.

Since being diagnosed HIV positive the disease has become all-consuming for most of the respondents yet prior to diagnosis it had simply not entered their consciousness.

That is, it was not only about absence of perception of risk but absence of any thought to the matter of HIV testing at all, and if HIV testing did cross their minds, it would often do so fleetingly.

> ‘I know it is existing and it is a very nasty disease but I never take it to be so serious for sure.
> **You never felt at risk?**
> Never. Never thought about it.’
>
> 31 year-old Ugandan man.

> ‘**And after the heat of the moment?**
>
> Then you realise you did a mistake, a big mistake, then you start worrying for a couple of days. Then something has come to your mind then that it's gone.’
>
> 39 year-old Ghanaian man.

Whilst all respondents rationally knew people could appear physically well and have HIV, the physical health of themselves and their partners was often used as a means to account for the lack of perceived exposure to HIV. The use of visual clues in ascribing HIV status to an individual was repeatedly mentioned.

> ‘When people fall, fell sick for a long time, they may begin saying he was bewitching, this and this and this. They come to realise like, like when, sometimes they happen to realise it's AIDS depending on which symptoms someone gets. One may say, no, that's not AIDS because the patient has no rashes. You get what I mean?’
>
> 35 year-old Ugandan woman.

> ‘But now when I'm looking at myself I can see some changes on my body, that's when I can say this person has got like - my hair, I can look at someone and say she's got hair like mine, red lips, you know, that's when I'll say she might be.’
>
> 31 year-old Zimbabwean woman

‘**And in 1999 did they offer you HIV testing in pregnancy?**

At that time they did offer me but I was very healthy. And that was the last thing on my mind. You know, sometimes you think you hear of something and you always think, oh, it cannot happen to me, not knowing it's on your back yet. It was something which was not even close to my mind because I was healthy, I was carrying out my normal duties, everything was normal.’

37 year-old Zambian woman.

Indeed HIV infection was typically not considered until the onset of ill health; this appeared especially true of men. None of the 11 men interviewed had actively sought HIV testing, although three had previously tested. Eight of the men tested on the advice of a clinician after becoming unwell. Only one of these men was expecting a positive HIV result despite all of them having advanced HIV disease (CD4<200) at the time of diagnosis, half were symptomatic with HIV related conditions and half had an AIDS defining illness. The man expecting the result had been advised by his GP four months prior to diagnosis he may have HIV, whilst not believing himself to be at risk he had tested at this time but had failed to collect his result; Only when he collapsed on the street did he accept he probably had HIV.

The other three men tested because their partner or child had been diagnosed HIV positive. As a consequence all were expecting a positive result at the time of testing All 3 men were asymptomatic and had a good CD4 count at the time of diagnosis.

In comparison, six of the women had recognised that they may be at risk of HIV and had either suggested to the GP that they should be tested or presented to sexual health services for the test. This recognition was precipitated by physical stigmata of HIV in self, or illness/death of a child or a concurrent or previous sexual partner of their spouse.

> ‘Now I realised my health was not going on very well, I visited my GP several times. She was doing all her best but I was getting - I wasn't getting any better and I was paying for my prescriptions. … I suggested to my GP that I think I should have thorough check-up so that she gets to treat what she understands better and she said to me like what do you want me to examine you exactly? I said, I said, I said to her that I may be HIV positive and she wanted to know why I suspected myself to be in that kind of situation. And I told her my background while back home which was my husband while with me got another woman and had 3 children with the woman and now the woman's dead and one of the children is dead.’
>
> 35 year-old Ugandan woman.

One woman had experienced acute STIs within her marriage and consequently anticipated a positive HIV result. Another woman sought an HIV test because of multiple rape experiences in Uganda.

> ‘I was worried about HIV as you can’t have sex with more than 100 men and not think about HIV.’
>
> 31 year-old Ugandan woman.

However the one interviewee who had engaged in sex work in Africa, often without a condom, had not perceived herself to be at risk of HIV. This was probably due to her youth and lack of awareness/knowledge about HIV generally.

Married women often did not perceive themselves to be at risk of HIV:

> ‘I was just like, oh no, I can't test that thing, it's not for me. I'm OK with what I am, I'm OK with me, I'm OK just because I'm married.’
>
> 38 year-old Malawian woman.

Five women had previously had an HIV test, two antenatally, one on request because of her husband’s infidelities, and two as part of routine check-ups. Prior testing was

associated with lack of perceived risk at the time of HIV diagnosis. Twelve of the 15 women interviewed were asymptomatic when diagnosed with HIV.

Men like women associated HIV risk with sexual behaviour. No men or women felt their behaviour put them at risk yet women often felt at risk by recognising risk in the sexual behaviour of their partners. Denial of HIV risk was evident in accounts from both men and women, but particularly the men. For example one man's wife had tested HIV positive six months earlier however he could not accept he may be positive and waited until he developed TB before presenting to services. Another of the men had witnessed his 18 months old child die three years earlier, despite coming from a high HIV prevalence community he attributed this to 'bewitching'.

> 'Even though you know you might be you live your life as if you're not '
>
> 30 year-old Zimbabwean man.

> 'Occasionally you'd think about it but then you want to be, you want to brush it off your mind and you say, oh no, not me, it's someone else have it, not you. No, you are careful but you are not because sometimes you have unprotected sex as well.'
>
> 39 year-old Ghanaian man.

> 'the first time I looked at the mirror before I even came to hospital I'd lost weight and I looked, because all those cheeks had gone, I had a flashback of someone who was dying of AIDS who I'd seen a long time ago at home and that's why, that's why I decided to come to hospital as well.
>
> **So did you think about getting an HIV test when you had that thought?**
>
> No, I didn't think as, I said to myself if I go to hospital and then we have to talk to my GP, … I mean because I'm just concentrating on the weakness of my - of my leg, I didn't - I looked at that side. The other thing was like I wasn't eating properly and the stresses hit me so that's why I'm like this.
>
> **You're finding other reasons?**
>
> Yeah, yeah, I'm trying to run away.'
>
> 32 year-old Zimbabwean man.

The only interviewee who routinely tested for HIV and other STIs never actually perceived herself at risk of HIV. She did feel at risk of other STIs such as Chlamydia (hence the accessing of sexual health services) and tested for HIV solely as it was offered as part of the screening package.

HIV testing was in itself perceived by some to be a risky practice due to fears around inadequate sterilisation of needles.

Several respondents mentioned witchcraft during the course of the interviews. A strong belief in the power of witchcraft remains among many African communities (Middleton & Winter, 2004). It was used to account for ill health but was no longer used or believed in as a means of treating HIV. The impact of witchcraft on HIV testing was in reducing perceived risk by offering an alternative explanation for ill health.

> 'I wasn't feeling very well, and my menses still hadn't come, I had fevers and my skin was no good. I was worried that maybe it was witchcraft from Africa that was causing me no menses. The King is a powerful man and could get someone to do that.'
>
> 19 year-old Cameroonian woman.

All respondents denied that traditional therapies would be accessed in lieu of conventional medicine, primarily because it was evident from the number of deaths that traditional therapies did not work for HIV. Conspiracy theories as to the origin of HIV, whilst not common were evident in the accounts of some respondents. Unlike the belief in witchcraft, beliefs as to the origin of HIV did not appear to impact on health seeking behaviour.

Death was not feared as much as ill health. The narratives suggested that whilst undiagnosed HIV may kill you, ill health was associated with diagnosed HIV.

9.2.2.3 Perceived benefit of HIV testing

HAART has been freely available in the UK since 1996 yet respondents' knowledge as to its availability and/or effectiveness was either lacking or incomplete. In Africa the focus is on condoms and avoidance of HIV, it is not on HIV testing to access medications. Consequently there was little to counteract the negative associations of HIV testing, or tilt the balance in favour of knowing ones HIV status regardless of perceived personal risk.

> 'Maybe here but back home I don't think most people know about the treatments because once you're diagnosed and the next is you wait for death to come. And the talk and the humiliation, the stigma and everything else.'
>
> 31 year-old Nigerian woman.

> 'I knew of course about the disease and I - sometimes I used to think maybe, maybe it's necessary to test because it's positive, I mean it's possible I could be positive, maybe I need to test but then I didn't have enough motivation to - [laughs] - and courage.'
>
> 38 year-old Zambian man.

> **'What do you know about HIV?**
> That it is incurable. All I know is that I will die.'
>
> 19 year-old Cameroonian woman.

The lack of perceived benefit in HIV testing was compounded by the perceived risks of testing.

> 'I feel, people feel to have a test to find out the results costs you more stress, damage and things. … you don't check because people say when they check it puts up their stress and makes them get worried and fall sick, you know.'
>
> 39 year-old Ghanaian man.

> ‘People will always hold back for their own self-esteem, you know what I mean, they always, they're always going to be - because you know that, OK, right now I'm enjoying life, I don't have to worry about anything except maybe normal things like credits or whatever, things that can be rectified in months and then be better so. But once you come into knowledge that you are like this, it's for a long time this thing so it's going to hurt you almost for the rest of your - no-one want to really, you know…’
>
> 40 year-old South African man.

The association most respondents had was of HIV testing followed by rapid decline and death. This was often seen as a direct consequence of knowing your status definitively (‘it is the thinking about it that kills you’) and the subsequent social exclusion.

> ‘What destroys people at home, they feel shunned, abandoned, you know, no-one comes near anymore. What's the point of living? I think this is the main thing that really kills people.’
>
> 40 year-old South African man.

> ‘He say, ah no, me, I'm dying [because he had been diagnosed with HIV], I have to just say bye-bye to everyone. So he just woke up dead because of the brain, he wasn't sick.’
>
> 33 year-old Zimbabwean woman.

An asylum seeker expressed concern that testing HIV positive may lead him to be incarcerated with other HIV positive asylum seekers and that all his future health complaints would be taken in this context denying him proper care. So whilst he did not consider himself likely to be HIV positive he was not prepared to take this risk when offered HIV testing by his GP.

The impact of HIV testing extended beyond the individual. The desire to protect parents in particular from the expectation of death that accompanies an HIV diagnosis was widely recounted.

The lack of accessible effective medication within the African home countries meant the alternative reality of a newly diagnosed HIV positive person moving from unwell to healthy was not often experienced. In the UK there are thousands of HIV positive Africans accessing care (The UK Collaborative Group for HIV and STI Surveillance, 2007) and living 'almost normal lives', but because of the fear of discrimination there remains relative silence and a lack of role models.

Two women considered themselves to be HIV positive but deliberately avoided HIV testing. This related to fear of stigma and discrimination and the lack of perceived benefit in having their HIV status confirmed.

A couple of respondents did have knowledge as to the effectiveness of medications. Ironically in this instance they were too optimistic, suggesting that it was safe to delay diagnosis as long as possible as medication would make everything all right. There was not much awareness that delayed diagnosis, even with access to HIV medications, is still associated with high morbidity and mortality. Knowledge of medication was not in itself enough of a precipitant to test, an additional factor such as ill health of self or an associate appeared to be required - A dammed if they do and dammed if they don't scenario.

> 'Even if they think about it, if you are well you are well, you can't have this. You look at people and it's so funny because you get people talking about somebody, or somebody has died of AIDS, say, well, they shouldn't have, they shouldn't have, you know, blah-blah-blah, to say a lot of things that they shouldn't, how can you be here and still die of this illness when you could have got tested. Then you think to yourself, well, have you been tested - [laughs]'
>
> 30 year-old Zimbabwean man.

> ‘Every Black African knows [about HIV testing] but they will never come. They'll come when they're sick and when they are really sick, that's when they'll come.’
>
> 33 year-old Zimbabwean woman.

Three respondents had declined antenatal testing, all subsequently testing because their children had been diagnosed with or died due to HIV. One woman declined because she had previously tested and could not see the point, the other two because they did not perceive themselves at risk. The narratives would suggest that when antenatal testing was declined no attempt was made to make the parents aware of the benefits of testing in this scenario or the lack of harm in taking the test.

> ‘It's nobody to blame in that sense. You know, in other ways we should have done it, in other ways she [the midwife] should have explained, she should have found out why are you not taking that test, you know, and because it's really when to find out in later stages that pregnant mothers nowadays you don't ever go without that test. If you say no, they say yes, do it. You know.’
>
> 26 year-old Zimbabwean man.

> ‘Well, when they offered, the thing is when they offered me the test, partly I blame it on my GP because she didn't really emphasise, you know what I mean, like as I said, explaining, you know, sometimes things need to be explained to people to understand them properly.’
>
> 37 year-old Zambian woman.

9.2.2.4 Structural factors

Structural factors refer to institutional or societal factors that influence individual agency and hence impact on health and health seeking behaviours (Farmer, Nizeye, Stulac, & Keshavjee, 2006); immigration policies, gender inequalities, and quality of health services are examples.

Most respondents were well educated and from the African middle class, yet most were experiencing economic hardship within the UK. Less then a quarter of respondents were working in the UK at an equivalent level to their African experience within their chosen profession. Prior to diagnosis half were either not working or employed in jobs that fell far short of their experience and qualifications, for example a businessman working as a street cleaner, or teachers employed in domestic work. All bar one of the interviewees who did not have official rights to remain were employed on a cash-in-hand basis. Asylum seekers were not allowed to work despite their qualifications and desperate desire to be employed.

How this change in socioeconomic position impacted on health seeking behaviour was difficult to disentangle. Respondents spoke of the pressure to work, not only to support families in the UK but also many had families back in Africa still dependent on them financially. The focus of people's lives was on financial or immigration issues, not on health.

> 'They're not thinking about this disease because they know it's there but they still have, it's my family back home, have they eaten today?
>
> **Other issues more high up?**
>
> Yes, they're thinking of have they eaten today and to have enough money to send them back home. What's going to happen to me here? If the Government says to me go back to Zimbabwe today what's going to happen if I go to Zimbabwe right now…'
>
> 32 year-old Zimbabwean man.

Several respondents spoke of the time it took to get a check up, time that could have been spent earning, and how this dissuaded others from attending health services.

> ‘you want an HIV test, you are not sure whether you are HIV or not but you have got to go there, queue for, I don't know, 4 hours sometimes and wait. A lot of people are just going to say, well - and most people are being paid per hour in this country and they aren't going to, you know, wait for 4 hours because that's about half-a-day's wage they're going to lose in there.’
>
> 30 year-old Zimbabwean man.

Respondents typically had friends from a range of cultural groups although the majority had close relationships only with other African nationals. Social networks were generally small. A lack of trust of other Africans was evident in many narratives, this revolved around gossip and fear of deportation, even in those with secure residency rights.

> ‘There's a lot of suspicion about each other. Mainly stemming from the immigration issue. A lot of people are very sceptical about, wary about who is looking into their affairs and people will only interact socially in a social gathering and it probably ends there. Because, yes, it's - no, there's no trust, no. I think it's even worse here than back in Zimbabwe.’
>
> 30 year-old Zimbabwean man.

Consequently disclosure of HIV in order to help redress HIV-related stigma and discrimination was not seen as a viable option for most.

Racism was not reported as widely encountered although here I wondered if this was partly out of respect to me. The socio economic position of the respondents could suggest that it was operating at some level.

> ‘And then being a Black person when you go for interviews, not that I have specifics but I just feel that sometimes because you talk different, because probably you approach things differently it's harder for you to get a job because it took me quite a while after I graduated, you know, and even though it was all over the place that they needed youth workers, well, I was out for about more than a year without a youth - you know, without a job in youth so I just think being a Black woman didn't help.’
>
> 34 year-old Cameroonian woman.

None of the interviewees were aware of media reports linking African migrants with loss of job opportunities for British nationals and the 'HIV plague'.

Gender inequalities influenced women's ability to control the risk of HIV exposure; it also impacted some women's ability to access HIV services.

> '…because [when I] explained to her what it was, we have been never at any point ill, never been admitted, because that's what they ask you, have you been admitted within the last 3 month or 4 months, say, oh, we've never been to the hospital. And with this she says she has never taken any medication.
>
> **So she thought there's no point?**
>
> It was not up to her, there was no point.'
>
> 26year old Zimbabwean man on wife being offered antenatal testing and why it was declined.

> '**And could a woman ask a man to have an HIV test?**
>
> It's difficult to in our culture, for really approaching, say, your husband and telling him that we should go for an HIV test is really difficult. I don't lie to you, it's difficult. Because most of the time we see men as the head of the house and then the women are still like subordinates, yes. You can be educated, you have a nice house, have money but still the men will always be on top, that's how it is in our culture.'
>
> 29 year-old South African woman.

Many narratives unwittingly highlighted the subjugated position of women. Examples included lack of autonomy, the accepted practice of polygamy for men, that transactional sex was a necessary commodity for many women, domestic violence, and the frequency and value ascribed to rape. A couple of the men held women responsible for the spread of HIV; perceiving them as deliberately deceitful and promiscuous vectors of the disease.

Most (n=20) of the respondents had visited a GP in the 2 years prior to HIV diagnosis. Knowledge of how to register with a GP tended to come via friends and family with

little official information on the NHS readily available (unless already within services). For a significant minority access was delayed due to fears around disclosure of self to immigration services. The perception was that health services and the home office were linked, principally because of the need to provide your address when registering with a GP.

> ‘There are people who are living here illegally … that person can never get tested. They would even fall sick and still not get tested until they are actually helpless themselves and they have got to be taken to hospital because they are so much afraid of the law. Of the consequences of being sent back …’
>
> 30 year-old Zimbabwean man.

> ‘So to get the medicine I tried the pharmacy, they say we can't, they can't give me tablets, I have to go for the GP and I tried and the GPs, the GPs I went, oh, we check documents and because of that I just say, ah, let me go to the walk-in, that's when I came here.’
>
> 33 year-old Zimbabwean woman.

Attitudes and experiences of primary and secondary care were mixed. Within primary care the appointment system, short consultations, and reception staff were criticised; whilst hospitals were perceived as unclean and the nurses too open with patient details during handover. The tendency for reception staff to discuss and disclose patient information was a particular concern for many.

> ‘I trust my GP but I don't trust those, the ladies, those young girls who work at the reception. Yes. You can see that they are young, they talk all the time. You can hear, they talk, they check somebody's file and then they start talking about the patients which is not good.’
>
> 33 year-old Zimbabwean woman.

All respondents were extremely satisfied with the HIV care they had received, and no concerns regarding confidentiality were expressed.

Unfortunately the narratives recounted numerous missed opportunities for earlier HIV diagnosis within the health system itself, predominantly within primary care. As one could argue that health professionals should have identified HIV as a potential risk for this population, the widespread failure to discuss HIV or HIV testing represents a systematic or structural failing.

> ‘**Did your GP know you had been raped in Africa?**
> Yes, I told him everything.
> **Did he ever mention HIV testing or a sexual health screen?**
> No never.’
>
> 31 year-old Ugandan woman.

Particularly concerning were the occasions when the respondent had identified HIV as part of the differential diagnosis but the GP had dismissed their fears without testing.

> ‘Like the very first day when I went to see [the GP], I told her I've got some rashes that I don't know where they're coming from and I heard some people with HIV they do develop some symptoms, then she goes, ah, I don't think it's that. So that's what made me think I was ok … that.’
>
> 27 year-old Zimbabwean woman.

Two men recounted how they had considered HIV when they had acquired shingles but again been reassured by the GP failing to raise the issue. In one instance the GP appears to have considered HIV too but rather than suggest testing he tells the man to collect some condoms on the way out:

‘People do know because I think shingles develops as a sign of your immune system weakening which could be a result of stress, which could be a result of your HIV status and, yes, people do know.

Did it make you think about HIV?

Well, I did but then I sort of got the comfort from the fact that the doctor that I was seeing was of the strong opinion that Chickenpox was responsible.’

30 year-old Zimbabwean man.

‘The only thing what happened was - it's quite funny really, I got shingles.…. And I went to see my GP and he looked at me and says, don't worry, it's just shingles, and he said to me are you living by yourself? I said, at the moment yes. He says to me, when you go out ask the nurse for some condoms… He didn't mention getting tested or anything. I still remember that day because we joked when I was on the door, he says ask the nurse if she can give you some condoms. …It was like does he know I've got AIDS or - you know - when somebody says something to you they might not really like tell you what's going on but I said to myself probably when, because he didn't explain everything or something, the GP, so I thought does he mean that I have to protect for HIV or something, does he know that probably I've got HIV, maybe I don't have HIV, so it was a problem. It was in a joking way that I have to be careful of this so he told to me that condoms obvious protection from sexual diseases and I just walked out and I saw the nurse and asked the nurse and she gave me condoms.’

32 year-old Zimbabwean man.

Although there were examples of people declining HIV tests, most felt they would have accepted a test earlier if offered. Declining a test predominantly related to the combination of lack of perceived risk of HIV and lack of perceived benefit in having the test.

‘Would there have been anything 3 years ago that someone might have said to you that would have made you have an HIV test?

Well, of course I wouldn't listen to that person at that time. I wouldn't, I wouldn't listen to him then because that I would have thought HIV, it's beyond me.’

40 year-old Nigerian man.

Testing for HIV predominantly occurred in GUM clinics, the exception to this being antenatal testing. Whilst GUM clinics had been the initial point of access for a few respondents in most cases they were accessed only after referral from other services. This complicated pathway to access HIV testing is another example of a structural barrier.

Several respondents had been referred to sexual health services (for management of syphilis and infertility) by their GP without mention of HIV. Whether the GP had considered HIV when referring is unknown. The process of onward referral to sexual health services was a barrier due to the stigma attached to accessing these services, and the logistics of having to attend another service. In all instances it delayed diagnosis.

> 'I think people here, right, are not, they don't mind going to the GU centres, you know, but for people from Africa or from Zimbabwe, from my own point of view, it's a big thing to walk in there, someone would feel everybody's staring at me. I've seen people like back home, people would rather have a friend who is a nurse, a pharmacist or a doctor to come privately, look at them and then go and bring some tablets for them because people don't want to go through this whole process of, you know, getting to the, you know, GU centre, you know, which still for HIV even makes it worse because this person is not even, feels they are not part of that kind of community.'
>
> 30 year-old Zimbabwean man.

> 'It takes a lot of courage to walk-in and a have a test. It took me, it took me, umm, four months from when the GP mentioned it before I went to [the GUM clinic]'
>
> 37 year-old Zambian man.

The circumstances behind previous negative HIV tests offer some insight into how to get people to test before they become unwell. Six of the seven prior negative tests occurred opportunistically; two antenatally, three as part of a sexual health screen, and one as a visa requirement. In all of these instances the respondent had not considered or

been seeking an HIV test, however one was offered (or required) routinely and the offer was accepted.

> 'So when I came here I talked to the doctor, then he told me do you feel if at all you have HIV testing as well. Well, it wasn't in my mind to have that test but after I said OK, it's better if I get it and to know my status, how am I standing. But I never expected it.'
>
> 39 year-old Ugandan man.

The remaining test occurred due to fear of HIV as a consequence of ill health in a concurrent partner of their spouse.

Over half of respondents had solicitors, usually involved in processing visa or asylum applications. Despite solicitors being privy to personal information such as rape and torture in no instances did a solicitor suggest accessing health services, or provide information to assist in this endeavour. Criminalisation of HIV was not a factor influencing HIV testing patterns for any of the respondents; several believed it had the potential to further dissuade people from testing, whilst others felt it would help control the spread of infection.

9.2.3 Improving the system

Improving the uptake of HIV testing was believed to be important and possible. The provision of more information was the most fundamental element identified. The information needed to highlight the positive benefits of accessing therapy so as to live a healthy life with HIV. The negative imagery of people dying due to HIV was recognised as fuelling stigma, and needed to be replaced with a 'before and after' image demonstrating that testing made a positive difference. The importance of timely access to medication needs to be made clear and the images used need to be of people that others want to identify with.

Clear unambiguous statements on HIV in the era of effective ART were needed. The mixed messages inherent in HIV literature – for example that clinicians say that the medications are effective yet mortgage and insurance companies continue not to cover HIV positive people; or that adverts say 'you don't need to die of HIV – use a condom' not mentioning that you don't need to die of HIV even if you are already infected - made people mistrust the information that was provided.

Most felt that more positive role models of people successfully living with HIV would help break down stigma. The disclosure by Chris Smith, cabinet minister, of his long-standing HIV status was repeatedly identified as a good example. The disclosure by Nelson Mandela that his son had died of HIV/AIDS was seen as positive but not as influential as Chris Smith's disclosure because he was not successfully living with HIV.

The need for more information on entitlement and access to health services, confidentiality, and that health care is free was frequently mentioned.

> 'I did see some leaflets in his surgery, which told me about HIV testing and the fact treatments were available and that they were free. That was what made me ask him for the test. I didn't know there were treatments or that it was free until then.'
>
> 31 year-old Ugandan woman.

Information on HIV and health services was available once people were accessing services. Other than television news items no reference to HIV information could be identified by any of the respondents. All felt that more information and prevention messages, such as occurs within Africa, was needed.

Respondents felt strongly that HIV prevention and testing messages should be universal and not targeted at African communities. Targeting would simply fuel stigma and discrimination towards Africans generally, and be 'insulting'.

‘HIV is HIV. Don’t look at it as ‘African’ or ‘European’. HIV is just there. HIV has no age, colour…so I think the message has to be general.’

37 year-old Zambian man.

‘**If your GP says to you, you know, you're from Malawi or Zimbabwe, there's a lot more HIV, I'd recommend you have an HIV test?**

Ah, but then that would be an insult to me.

That would be an insult?

Yeah, it would be an insult really, that's because I expect that disease to be everywhere. … I would just want someone simply saying would you mind to go for it without mentioning that, oh, Africa has got that. Yeah, I wouldn't mind.’

38 year-old Malawian woman.

‘I don’t know how they would need to package it to target it at a certain group of people because some people would feel offended, to say, look, why do you think, why are you targeting this information at us and not everybody else? So it’s a little bit of mystery ... to see how, how to package it really. If there is, for instance, a grouping of maybe African people, I don’t know, they meet somewhere and that kind of thing, maybe such groups need to be targeted to take it on board. The groups can take it on board but if it is seen to be, to be specifically targeted from a very high level like government level, it would seen to be even racial or all kinds of things. And in that case I think you may not achieve the right - the right result.’

38 year-old Zambian man.

However community mobilisation and support would be beneficial. Youths were identified as being particularly at risk with calls for more information in schools, youth groups, and health services.

Access to medication was not necessarily enough of a carrot and further incentives to test would be beneficial. The right to remain in the UK was identified, though half-heartedly, as possibly being that incentive. Whilst not likely to impact on HIV testing

directly the ability to work was identified as the single thing that would most improve the lives of asylum seekers living with diagnosed HIV.

Health services need to expand HIV testing opportunities; in particular GPs were identified as the preferred venue for HIV testing.

> ‘**How do you think we could improve health services?**
>
> I think GPs are the key. Everyone goes to the GP. You only go the hospital if you are really sick. People are scared to come to this place [Sexual Health Clinic].’
>
> 31 year-old Ugandan woman.

> ‘Probably through the GPs, yes, that is one way because they need to be made more aware and much more active in this work. I think they need to talk about it more, more openly with their patients.’
>
> 38 year-old Zambian man.

It was acknowledged that GPs might not be comfortable with this recommendation and that further training may be required:

> ‘But I think also it's not just for the people but it's also for the GP, GPs to be comfortable. I don't think it's something that they're comfortable offering to patients, they might say, well, if I offer it she might think what I'm making of her, you see. But it's just something that they have to train to tell people in a way that doesn't seem like they're judging you but it's just like something they're offering to anybody because who knows, if they offered it more…’
>
> 34 year-old Cameroonian woman.

Similarly addressing concerns regarding confidentiality and reception staff would be beneficial.

Walk-in centres, where official documentation to register is not required, were identified as suitable venues for HIV testing. The concept of ‘high street clinics’

specifically for HIV VCT were not widely popular, principally because they, like GUM clinics, would be too associated with HIV and hence disclosing to the wider community. Whilst information on HIV/STIs and condoms should be widely available, religious institutions and social venues were not thought appropriate for VCT.

Provision of services and information are only effective if people choose to make use of these resources and opportunities. However most migrants do access health services and most of the interviewees reported that had an HIV test been offered in an appropriate manner earlier they would have accepted.

Opportunistic HIV testing was widely supported. Those who had been diagnosed in this way were thankful to know their status and all acknowledged they would not have requested testing if it had not been offered. The two respondents who had HIV testing discussed in their partners presence felt this had significantly eased the disclosure process, and facilitated testing of both parties. Both felt couple counselling and testing, especially in the antenatal setting, should be encouraged. A man with an HIV positive child felt antenatal testing should be made compulsory.

9.2.4 Personal reflections on interviews

Conducting these interviews was a rewarding and humbling experience. Interviewees expressed a sense of release in the opportunity to tell their story. They all hoped, and some believed, it would help make a difference.

> 'No it was good to talk. It's not often one gets to talk and it's like, it's like …a release. ….. To know people care. People, like yourself, are interested and taking time to find out how to fix things. It makes me feel more positive towards the future….'
>
> 38 year-old Zambian woman.

Although the respondents appreciated the opportunity to talk for many the interviews were a painful experience reliving distressing life events. At times I felt inhibited in

delving deeper due to the obvious emotional pain the subject matter was evoking, for example discussing declining antenatal testing in someone who has subsequently lost their child to HIV. Occasionally feelings were too raw or respondents too depressed/ shocked at their HIV diagnosis to enable full exploration of factors. At these times the interviews felt more like therapy sessions in which a person 'unloads' than an interview. During these occasions I was aware that my different hats, clinician, researcher, mother, and 'friend', could all influence the direction the interview might take.

I became very aware of how important social realities were in influencing perception of HIV and what it means, mine as a physician practising HIV medicine in the UK with no personal experience of HIV within my home (New Zealand) country could not have been more at odds with theirs.

As a relatively new mother expecting my second child I found it difficult to understand the apparently very common practice of leaving one's children with relatives to raise; especially as this did not always seem to be driven by extreme hardship. For me it reflected a fundamental cultural difference - the individualistic British versus the communal African societies.

Unfortunately the interviews also made me very sad. Whilst having immense respect for the individuals I spoke to, I was repeatedly disappointed in how people interact and behave with each other, men in particular. The medical incompetence reported, usually within the UK, was equally shocking and disappointing. Fortunately the personal strength, dignity and gratitude with which the respondents went about their often very hard lives compensated for the reported behaviour of others.

> 'I thank God that I am alive in 2005, I am blessed.'
>
> 31 year-old Ugandan woman who had experienced multiple rape and torture.

9.3 Discussion

These findings highlight the central role of HIV-related stigma and discrimination in influencing HIV testing behaviours among migrant Africans in Britain. By creating a culture of 'otherness' people do not identify themselves at risk. The secrecy and silence with which HIV positive individuals live their lives further perpetuates the myth that it is an illness of others. People do not realise that HIV is all around them, in people much like themselves, in people who appear well.

For those aware of the possibility of HIV infection the negative repercussions of knowing their serostatus are often perceived to outweigh any potential benefits. This is exacerbated by the context with which migrant Africans experience and view HIV. Migrant Africans approach HIV testing with substantially more experience of HIV and preconceptions of the consequences of both testing and diagnosis than the majority of the British population. Few have witnessed the benefits of ART directly yet all have seen the suffering and dying of people infected with HIV. For those with insecure residency rights there is no guarantee that diagnosis will result in access to medications; either because of entitlement regulations or via deportation.

Fear of non-sexual HIV acquisition was often the rationale for HIV-related stigma and discrimination. If people truly believed in incidental transmission then one would expect a higher perception of HIV risk, and similarly there to be less stigma. Given neither of these occur the fear of transmission may be a means of rationalising the social isolation of HIV positive people. The inconsistencies in the basis for HIV-related stigma and discrimination reinforced my interpretation that stigma and consequent discrimination provides a coping mechanism for many African communities. It

physically and emotionally distances people from those affected/infected, making it (theoretically) easier to cope when they die, something seen as inevitable.

Stigma, in African communities, may be a more powerful influence on testing behaviours than it would be within a more individualistic society. The communal culture of African communities may make operating outside common practice, for example being socially inclusive of people with HIV, more difficult. HIV/AIDS related stigma and discrimination in this context could be seen as a form of self-protection – it helps define group identity and offers a mechanism of addressing irrational fears.

The stigma accompanying an HIV diagnosis within African communities in the UK has been widely reported (Doyal et al., 2005; Flowers et al., 2006; Dodds et al., 2004; Anderson et al., 2004) however there is a paucity of literature exploring how stigma directly impacts on service utilisation in this population (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007). Aggleton (2005) and Busza (1999) have modelled the impact of HIV-related stigma and discrimination on accessing HIV services, uptake of care, and prevention in resource limited settings (Aggleton, Wood, Malcolm, & Parker, 2005; Busza, 1999), these findings suggest that stigma and discrimination plays a pivotal role in vulnerable populations wherever the setting.

The themes arising from this work show considerable consistency to those identified in the key informant interviews (chapter 4, (Burns et al., 2007)). Both studies identified the high awareness but low perception of personal risk of HIV, the central role of stigma, and the structural barriers to HIV testing. The failure of primary care clinicians to address HIV effectively is also supported by both the key informant interviews and the SONHIA survey data (Burns et al., 2008). Similarly the fear of disclosure to immigration services has been previously identified as a barrier to accessing health services (Erwin et al., 1999).

9.3.1 Limitations

A limitation of this study is that only involves Africans newly diagnosed with HIV, and as such is a retrospective study of the factors influencing access to care. As with all studies of this nature it may be subject to recall bias. For example, the circumstances around testing HIV positive may influence people's recall of events leading up to the diagnosis. Similarly, knowing you are HIV positive may influence how feelings and attitudes towards HIV are reported or discussed.

Migrant Africans comprise a heterogeneous aggregation of population sub-groups. Group analyses may falsely construct homogeneity and the reduction of complexity. By employing purposive sampling techniques this study deliberately ensured relative diversity in the sample. By using Framework, which allows for within and between case analyses, the analysis should be sensitive to important distinctions between sub-populations. The study also focuses on individual experience, providing a voice for the participants.

9.3.2 Implications

The narratives of newly diagnosed HIV positive Africans in the UK have not been heard before. By understanding the contextual issues related to delayed presentation within this population more culturally appropriate interventions may now be developed. It is unrealistic to believe that simply providing information on HIV testing and medication will be sufficient to change behaviours in this context. Significant cultural work is needed to break down the stereotypes and associations that accompany HIV before a change in the attitudes of migrant Africans towards accessing HIV services can be expected.

Similarly the medical profession continues to treat HIV differently to other chronic health conditions and is complicit in perpetuating the cycle of late diagnosis and onward disease transmission within the UK. If a test is not offered it is unlikely to be sought when perceived risk is low, especially when the testing process itself is seen to have negative consequences. Services could and should be adapted to reduce the potential for stigmatisation. The release of national guidelines on HIV testing (British HIV Association, British Association of Sexual Health and HIV, & British Infection Society, 2008) will hopefully stimulate initiatives to address this issue. All medical practitioners should consider HIV testing routinely on a regular basis among higher-risk populations.

In November 2008 the Department of Health issued a call for proposals to reduce the proportion of undiagnosed HIV, African communities being specifically identified as a group at need of targeting (Orton, 2008). As highlighted in this study encouraging Africans to access HIV services does raise important ethical considerations about entitlement to care and residency rights. To be diagnosed HIV positive in the UK but not have entitlement to antiretroviral therapy could be considered inhumane, as could the deportation of HIV infected persons back to countries where access to therapy is unlikely.

By placing these findings within the wider body of work undertaken within SONHIA and the literature generally a more holistic understanding of HIV service utilisation by African migrants resident in London should emerge; This will be the focus of the concluding chapter.

Chapter 10: Discussion of findings and future work

10.0 Introduction

This final chapter summarizes and contextualises the key findings with work done by other investigators and the current socio-political climate. It further explores limitations of the research, outlines work in progress arising from this thesis, and discusses the public health and policy implications of this research.

10.1 Key findings

In this thesis I set out to explore the factors contributing to the continuing late diagnosis of HIV among Africans living in London, and UK acquisition of HIV in this population. Three pieces of preparatory work (a literature review (chapter 2), an analysis of a national probability sample of black Africans on the factors associated with HIV testing (chapter 3), and a qualitative study of specialists working in the field of HIV and African communities (chapter 4)) helped frame the research objectives and formulate the design of the main focus of the thesis, the 'study of newly diagnosed HIV among Africans in London' (the SONHIA study) (chapters 5-9).

The key findings are summarised in the following text and in box 10.1.

10.1.1 The importance of context

The literature review (chapter 2) provided context in which to set the research questions. It highlighted how historical links and past experience shape attitudes and the HIV epidemic within the UK. Internal and external factors influence health care access, be they social, political or cultural. HIV exceptionalism has unwittingly become a barrier

to care for many people affected by HIV and work to normalise HIV within the medical establishment as well as the wider community is required.

10.1.2 HIV testing

An analysis of a national probability sample of black Africans on the factors associated with HIV testing (chapter 3) found that approximately 40% of Black Africans have ever tested for HIV, compared to the 12-13% tested in the general UK population (McGarrigle et al., 2005). No association between testing and risk perception was found and almost half (48.9%) of the men and 71% of the women perceived themselves 'not at all at risk of HIV'.

10.1.3 Expert opinion

Considerable agreement about the major issues influencing uptake of HIV services by African communities in the UK existed amongst the key informants (chapter 4). Informants believed there was high HIV awareness within African communities in Britain but this did not translate into perception of individual risk. Home country experience and community mobilisation was highly influential on HIV awareness, appreciation of risk, and attitudes to health services. All informants identified confidentiality, stigma and migration issues as major influences on uptake of HIV services. The interviewees highlighted the role of NHS service structures in perpetuating poor access for migrant Africans, in particular the failure of primary care to address HIV effectively.

10.1.4 Missed opportunities for earlier HIV diagnosis

In chapter 6 I identify missed opportunities for earlier HIV diagnosis in Africans in the UK. Africans were accessing health services yet these opportunities for earlier diagnosis of HIV were not being utilised. Primary care services in particular were identified as

failing to meet the needs of these communities regarding HIV prevention and care. Opportunities for HIV testing remain restricted to certain settings, creating barriers for clinicians and patients alike. A need to normalise HIV, including the testing process, was frequently cited. Routine opportunistic testing, when offered, had been well received.

Entitlement to care concerns and fear of disclosure to immigration services was reported as influencing care-seeking behaviours for many Africans, regardless of residency status.

10.1.5 Late presentation to HIV services

In London many Africans with HIV infection continue to present late to HIV services. Half of people participating in SONHIA had a CD4 count below 200 cells/μL at the time of diagnosis representing advanced disease, and three quarters (74.1%) had a count below 350 cells/μL – the level at which initiation of HAART is now recommended in the UK (Gazzard, 2008). Despite high awareness and knowledge of HIV, personal perception of risk was often low. Late presentation was not found to be associated with access to services, risk behaviours, or most socio-demographic variables (chapter 7). Gay men, French speakers, and persons not believing HIV causes AIDS (perhaps representing knowledge about the benefit of medication) were the only groups found to be consistently associated with reduced odds of late presentation.

10.1.6 UK acquisition of HIV

As discussed in chapter 8 the proportion of HIV acquired in the UK among Africans was higher than currently reflected in national surveillance statistics. A quarter to a third of SONHIA participants may have acquired their HIV in the UK. The proportion acquiring HIV whilst resident in the UK would be even higher; 6.5% (17/263) of all

participants had unprotected sex with a new partner on their last visit to Africa and hence acquisition is placed within Africa, although residence at the time of acquisition was the UK.

UK acquisition was supported by findings of high-risk sexual behaviours in African men, assortative and concurrent sexual mixing patterns, and high rates of previous sexually transmitted infections.

10.1.7 HIV-related stigma and discrimination

The central role of stigma in influencing HIV testing behaviours, and attitudes to HIV, was highlighted in the literature review, the key informant interviews, and in both the quantitative and qualitative components of SONHIA. Stigma and discrimination are discussed in detail in chapter 9.

The culturally embedded associations of HIV with sexual promiscuity, sin, and death mean Africans either often do not identify themselves at risk, or for those aware of the possibility of HIV infection the negative repercussions may be perceived to outweigh any potential benefits of knowing their serostatus. The association of AIDS with the 'heterosexually promiscuous population'(Serwadda et al., 1985) and commercial sex workers was identified, and reported on from the very beginning of the HIV/AIDS epidemic in Africa (Piot et al., 1984; Piot et al., 1984; Kreiss et al., 1986; Serwadda et al., 1985; Quinn et al., 1986). And commercial sex workers continue to be the focus of much HIV research and intervention work in Africa (Cowan et al., 2005; Morris & Ferguson, 2006; Kaul et al., 2004; Schwandt, Morris, Ferguson, Ngugi, & Moses, 2006). It may well be that this focus has unwittingly helped create the stereotype which the HIV community is now trying to dispel.

Significant work is needed to break down the stereotypes and associations that accompany HIV before a change in the attitudes of migrant Africans towards accessing HIV services can be expected.

Box 10.1 Key messages arising from this thesis

Key messages:

1. Low appreciation of personal risk and lack of perceived ill health within the African communities means clinicians need to be more proactive in addressing HIV for this population.
2. Africans are accessing health services but clinicians are failing to use these opportunities effectively for preventive and diagnostic purposes with regards to HIV infection.
3. Africans continue to present with advanced HIV disease with consequent high morbidity, mortality and probable onward transmission of infection.
4. A quarter to a third of HIV in Africans resident in the UK may have been acquired in the UK.
5. Stigma and discrimination continue to hinder HIV prevention efforts.
6. Taking a more holistic approach and addressing immigration issues, entitlement to health services, gender inequalities, and lack of access to antiretroviral medication in Africa may be required to effectively tackle HIV in African communities within the UK.

10.2 Limitations

Most of the studies' limitations have been discussed in the preceding chapters 3-9. Ideally the thesis would have included detailed investigation of African people who had tested HIV negative and people who had never HIV tested. However, I was able to explore demographic, behavioural and attitudinal associations in those who presented late compared to early. The median time between HIV diagnosis and questionnaire completion was 3.5 months. The short time period hopefully minimised recall bias as to the factors influencing decisions to test.

The potential downside of a short interval between testing and questionnaire completion may lie in the psychological consequences of receiving an HIV diagnosis. Most people go through an adjustment reaction of some kind on receiving an HIV diagnosis, for many this involves free floating anxiety or reactive depression (Miller & Riccio, 1990). Whilst it is probable that responses will be influenced by the affective state of the respondent, the barriers and fears identified in this thesis, in particular the stigma and discrimination, are in keeping with findings from other UK studies involving HIV positive Africans (Anderson et al., 2004; Doyal et al., 2005; Dodds, 2006; Erwin et al., 1999; Flowers et al., 2006).

Throughout the thesis it has been acknowledged that reducing all migrant African subpopulations into the composite variable 'African' may falsely construct homogeneity and the reduction of complexity. The concept of ethnicity is also controversial as an epidemiological variable. Research focusing on ethnicity can be perceived as 'racist' (Bhopal, 1997), however the exclusion of such information in research and surveillance data can effectively hide health inequalities between ethnic groups (De Cock & Low, 1997). Ethnicity remains one of the most effective concepts in demonstrating population

variations in disease (Bhopal, 2001). This work was conducted in order to reduce health inequalities; it is in no way intended to serve as a vehicle to further alienate migrant African populations. The African community reference group was involved in design, implementation and interpretation of findings within this work specifically to minimise this potential and ensure cultural acceptability.

Despite these limitations this thesis is able to compare and contrast the findings of a national probability survey, key informant interviews, and quantitative and qualitative investigation of Africans with newly diagnosed HIV infection. This ability to triangulate findings from a variety of data sources and research methodologies provides a means of validating the work and enables a comprehensive overview of the factors associated with HIV presentation in Africans resident in the UK.

10.3 Policy, practice and research implications

The findings within this programme of work highlight the need for further investment in research and intervention development with African communities. Areas for future research and practice, some of which are already works in progress, are discussed below.

10.3.1 HIV testing and missed opportunities

Compared to the general UK population black Africans living in the UK are more likely to test for HIV (40% vs. 13%) (McGarrigle et al., 2005). However the figure of 40% ever tested is low compared to the 50 to 75% of MSM in the UK who have ever tested (Williamson, Dodds, Mercey, Johnson, & Hart, 2006). Even the highest UK testing figures for MSM, the group most at risk of HIV exposure in the UK, are low compared to those found in Australia and the USA where over 90% of MSM have ever tested for HIV (Prestage et al., 2008; Branson et al., 2006). There also appears to be less of a

culture of regular screening in the UK. Of those MSM ever tested for HIV 35% had tested in the last year in the UK compared to over 60% of MSM in Australia (Dodds, Mercer, Mercey, Copas, & Johnson, 2006; Prestage et al., 2008). Frequency of HIV testing has not been investigated among the UK migrant African population. In this work we found that 37.1% of newly diagnosed HIV positive Africans had previously tested negative for HIV, the median time between last negative HIV test and testing HIV positive was 2.8 years. Africans may not frequently access services where HIV testing is routinely offered. However, if they do uptake of HIV testing appears higher than for UK-born individuals (The UK Collaborative Group for HIV and STI Surveillance, 2007), a finding supported by the narratives in chapter 9 in which most people reported that they would have tested earlier if offered the opportunity.

Targeted or risk-based testing policies are affected by access to care issues as well as the potential for individuals to be unaware of their risk, or unwilling to admit to potentially stigmatising risk behaviours – factors all identified within the findings of this work.

The cost-effectiveness of routine HIV screening in the USA, even in populations with relatively low prevalence, is comparable to other commonly accepted interventions (Sanders et al., 2005). Routine HIV testing in a range of health care settings has been recommended in the USA for several years (Branson et al., 2006). In September 2008 UK national guidelines for HIV testing were published. Universal HIV testing is recommended at GUM, antenatal, pregnancy termination, drug dependency, and TB, lymphoma, and hepatitis clinics. In addition the guidelines state that consideration should be given to offering HIV testing to all general medical admissions and to all men and women registering in general practice in areas where the prevalence of diagnosed HIV infections is greater than two per 1,000 (British HIV Association et al., 2008). The

guidelines also favour a more targeted approach in some settings such as patients presenting for healthcare where HIV enters the differential diagnosis.

These developments are welcome but do not fully address the issue. The UK guidelines may increase one off opportunities to be offered an HIV test but they do not promote a culture of regular screening. Also a testing programme based around medical admissions, i.e. once an individual is already unwell, fails to address the importance of earlier diagnosis.

Transmission during primary HIV infection may account for up to 25-49% of incident infections (Pao et al., 2005; Brenner et al., 2007; Lewis, Hughes, Rambaut, Pozniak, & Leigh Brown, 2008; Wawer et al., 2005). Whilst the guidelines may decrease the period of undiagnosed infection they are unlikely to help detect incident infections, for this promotion of highly sensitive tests such as pooled nucleic acid amplification is required (Pilcher et al., 2005). Research and funding are also required to guide service development as to the most effective, acceptable or efficient model to improve HIV testing within general medical settings, especially given the trust and confidentiality concerns expressed in SONHIA regarding primary care services, and the anxiety expressed by GPs in offering HIV tests (Kellock et al., 1998).

For African communities expanding HIV testing into non-sexual health settings should improve access to services, however this will only occur if these opportunities are delivered in a non-stigmatising way. Normalisation of testing can occur through 'opt-out' strategies where an HIV test is seen as routine care. Such strategies have increased testing in sexual health and antenatal health care settings (Simpson et al., 1998; The UK Collaborative Group for HIV and STI Surveillance, 2007) and successful roll out of such a strategy into primary care could have a major impact on reducing late

presentation and the proportion of undiagnosed HIV infection in the African communities within the UK.

The continuing care relationship inherent in general practice provides an ideal context for ongoing HIV prevention messages. Primary care is also well placed to address issues pertaining to risk perception as it provides a setting for personalised and targeted health information. Advice from doctors, be they primary or secondary care based, is influential with 40.2% of SONHIA respondents testing for HIV specifically because of clinician recommendation. Section 10.3.5.2 below provides some recommendations to improve service provision of HIV testing outside of GUM settings.

The higher level of sexual risk among African men in particular suggests that reducing levels of undiagnosed HIV may not in itself be enough to stop new infections. Prevention strategies should include risk reduction behavioural interventions - in those diagnosed, undiagnosed and at risk of acquiring HIV, as well as frequent HIV testing.

10.3.2 Modelling the impact of earlier diagnosis

Data from SONHIA are now being used in collaboration with Imperial College to develop a mathematical model to explore the impact earlier diagnosis would have on HIV transmission and clinical progression. The stochastic individual based mathematical model will estimate the impact late diagnosis in heterosexual Africans in the UK has on the potential for onward transmission of HIV within the UK. This model will enable calculation of the potentially preventable transmission events should HIV diagnosis have been made earlier. The model will also be able to contribute to calculations of the cost effectiveness of different HIV testing models by providing data on transmission and clinical events averted with earlier diagnosis.

A recent paper using a similar model has controversially suggested that regular universal HIV testing and initiation of antiretroviral therapy regardless of CD4 count could eliminate HIV in high prevalence settings (Granich, Gilks, Dye, De Cock, & Williams, 2009; Garnett & Baggaley, 2009). This model will inform current debate on the utility of earlier diagnosis and treatment as a prevention tool.

10.3.3 Disease progression and viral subtypes

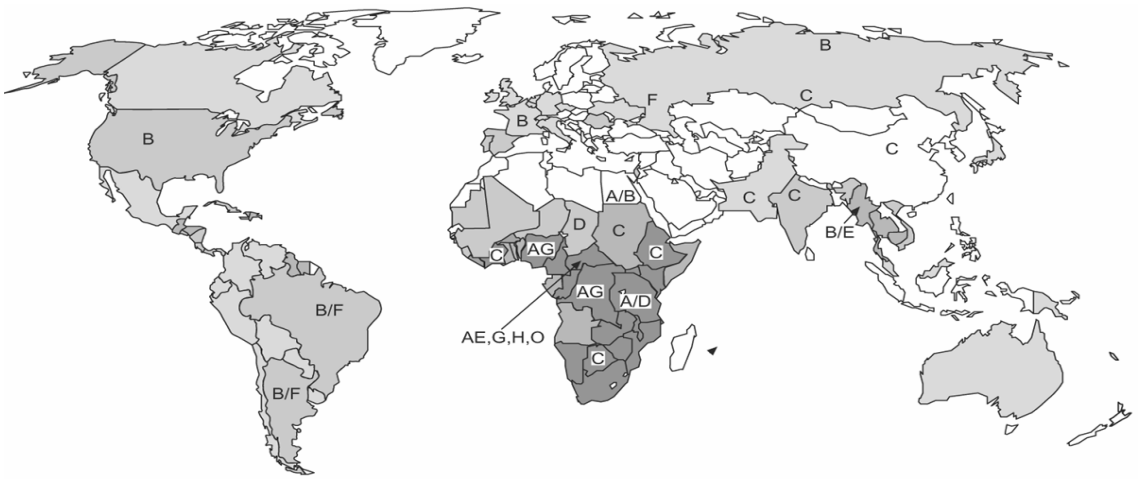
Chapter 8 assessed the proportion of newly diagnosed HIV positive Africans who may have acquired HIV within the UK using predefined criteria. It was not always evident what criterion should be given precedence, with respondents often having conflicting clinical, migratory and behavioural parameters. It was apparent that on several occasions when HIV was classified as 'definitely acquired within the UK' based on HIV testing history and risk exposure, the CD4 count was lower than would be expected given the time in the UK data.

Previous work reports that once accessing care HIV positive Africans in the UK have the same progression to AIDS and survival once adjusted for gender, age, and clinical stage and CD4 count at diagnosis (Del Amo et al., 1998). This work also looked at the rate of CD4 decline between Africans and non-Africans and found no difference. However this later conclusion was based on a comparatively small proportion of the cohort (34%, n=697) and no data is presented as to what viral subtypes or clades the cohort contained, although at the time clades A and C were the most prevalent clades in black Africans and clade B in UK-born individuals (Clewley, Arnold, Barlow, Grant, & Parry, 1996; Arnold, Barlow, Parry, & Clewley, 1995). As study participants were enrolled at the time of diagnosis, not at seroconversion, and required five or more CD4 counts to be included in this component of the analysis, the data will be subject to survival bias.

There is accumulating evidence that viral subtype may influence the rate of CD4 decline and disease progression. Three seroconverter studies from across Africa have now demonstrated faster CD4 decline, progression to AIDS and higher mortality in non A HIV-1 subtypes compared to subtype A (Kanki et al., 1999; Kiwanuka et al., 2008; Baeten et al., 2007). In particular individuals with recombinant types, multiple subtypes and subtype D appear to have more rapid progression (Baeten et al., 2007; Kiwanuka et al., 2008). Data from Cascade, a European seroconverter cohort, also appears to support more rapid CD4 decline in individuals with non-B compared to B clade infections (Porter, 2009). Figure 10.1 shows the diverse geographical distribution of HIV-1 clades.

Viral subtype data was only available for 26% (69/263) of all SONHIA respondents: 4% (3/69) had subtype A; 4% subtype D; 23% had recombinant subtypes; and 52% subtype C (table 6.12). Viral subtype data was available for 7 men who defined themselves as MSM, 57% (4/7) were subtype B in keeping with the dominant subtype among UK MSM and supporting the high proportion of HIV acquired in the UK in this population as described in chapter 8.

Figure 10.1 Geographical distribution of HIV-1 clades



Letters indicate the predominant HIV-1 clade circulating in selected countries. A/B, B/E and B/F indicate co-circulation of two dominant clades; AE and AG indicate circulating recombinant forms. Reprinted with permission (Wainberg, 2004)

The diversity of viral subtypes found in SONHIA and the mounting evidence of differing disease progression and CD4 decline according to viral subtype suggests that further work is required to investigate the relationship between viral clade and clinical progression in the UK. Differences in rate of CD4 decline may in part explain the high proportion of Africans with advanced HIV disease at diagnosis and further emphasises the need for increasing opportunities for earlier diagnosis and care. A clear understanding of the relationship between clade and CD4 decline is important in guiding individual clinical decisions on when to initiate HAART, and in surveillance of acquisition in the UK; especially as the HPA is considering moving to an estimate primarily based on CD4 count at diagnosis in relation to time in the UK and country of origin for black Africans (Rice, 2009).

10.3.4 Surveillance

The SONHIA data suggests that the proportion of HIV acquired in the UK by African migrants is substantially higher than currently acknowledged in national statistics. These findings have been presented to the HPA Centre for Infections. The HPA is currently refining its systems for recording probable country of infection, and preliminary analyses suggest that in London at least the proportion of HIV acquired in the UK is indeed higher than previously reported (Pebody, 2009).

Currently if a heterosexual resident in the UK travelled to Africa and had sex in both the UK and Africa, and was subsequently found to be HIV positive, this would be classified by the HPA as HIV acquired in Africa. However country of residence, and not travel history, takes precedence in surveillance of HIV acquisition in MSM, and if the same scenario occurred for a gay man this would be categorised as HIV acquired in the UK (Rice, 2009). This could be interpreted as inconsistent classification; Despite the background HIV prevalence being similar in UK MSM and black African populations

(Health Protection Agency, 2008c; Health Protection Agency, 2008b) the implications and responsibility of the infection are located within the UK for MSM but not for heterosexuals.

Surveillance of HIV incidence, sexual behaviour, and prevalence of HIV, in migrant African communities would enhance the ability to systematically measure, track and respond to endemic HIV transmission.

10.3.4.1 Incidence testing

When the original proposal for SONHIA was written it included serological testing algorithm for recent HIV seroconversion (STARHS) (Janssen et al., 1998; McFarland et al., 1999). STARHS works by testing a single anti-HIV positive specimen in two enzyme immunoassays: a sensitive screening assay and a modified or 'detuned' assay to make it relatively less sensitive. The sensitive assay will be positive for any HIV positive individual but the modified assay will only be positive in those with a fully developed antibody response. If the sensitive assay is positive but the detuned assay is not the specimen is considered to have come from an individual recently infected (within 129 days). At the time STARHS was not validated for non-B clade HIV-1 and there was concern that a proportion of non-B infections may give rise to greatly extended window periods. Reviewers also felt that as the vast majority of HIV in the UK African population had acquired their HIV abroad the cost of this component could not be justified. In view of the uncertainty concerning interpretation of incidence when applied to the African population, and the reticence to fund this component, STARHS was dropped from the proposal.

More recently the HPA has been evaluating an avidity test to measure incident HIV infections (Chawla et al., 2007). Avidity tests measure the strength of binding between

IgG antibodies and the corresponding antigen, a process that increases over a period of months in newly acquired infections (Thomas et al., 1996). Whilst false positive results do occur with advanced disease (hence need to interpret results in context with clinical presentation), they do not appear to be influenced by viral clade (Chawla et al., 2007). Currently the HPA conducts incidence testing on all tests found to be HIV positive through unlinked anonymous testing when the sample is identified as from a man who has sex with men; it is not routine practice to conduct incidence testing on samples from other populations (Parry, 2007).

My work found that between a quarter to a third of HIV-positive Africans, and nearly half of HIV-positive African MSM, may have acquired their HIV in the UK (chapter 8), substantially higher than the national estimate of 8% for heterosexually acquired HIV among black Africans (The UK Collaborative Group for HIV and STI Surveillance, 2007). HIV acquisition in the UK was also associated with earlier presentation to HIV services. Identification of newly acquired HIV infection can provide information on transmission networks, epidemic dynamics, patterns of drug resistance, and guide public health intervention programmes (Brown et al., 2009; Fisher et al., 2007; Pao et al., 2005). The large amount of HIV acquired in the UK among Africans in this work, coupled with the availability of a validated measure, supports the introduction of incidence testing on all HIV positive samples, regardless of risk group.

Whilst incidence testing in conjunction with travel history would help monitor HIV transmission within Africans in the UK, given that many Africans have advanced disease at the time of diagnosis, it would only be able to detect a small fraction of new HIV infections and hence be unable to provide an accurate measure of incidence in this population. The exception to this is HIV diagnosis among women as a consequence of antenatal screening. Incidence testing in this latter population, in conjunction with the

unlinked anonymous HIV testing of pregnant women (Health Protection Agency, 2009), may provide a suitably large unbiased sample to determine HIV incidence rates for heterosexual communities.

10.3.4.2 Sexual behaviour

Sexual behaviour is a major determinant of sexual health, and population patterns of sexual behaviour are major determinants of STI and HIV transmission (Johnson et al., 2001). High-risk behaviours were frequently reported by African men in both the Natsal sample (chapter 3) and the SONHIA sample (chapter 6); these included: high rates of new partner acquisition, concurrency, paying for sex, and sexual partners from outside the UK. Almost half the men in SONHIA, and 17% of black African men in Natsal reported a previously diagnosed STI.

The SONHIA findings are in keeping with those from Natsal and Mayisha II (Fenton et al., 2005; MAYISHA II Collaborative Group, 2005). Compared to the white British population black African men have been found to have higher numbers of lifetime sexual partnerships, higher rates of concurrency, and are more likely to have had a previously diagnosed STI (Fenton et al., 2005). As may be expected in an HIV positive sample SONHIA found higher concurrency (58.8% vs. 34.5%), more exposure to commercial sex work (23.3% vs. 14.9%), and higher reporting of a previous STI (47.7%[17] vs. 16.2%) than in the general black African population sample (Fenton et al., 2005; Burns et al., 2005). These differences relate to male respondents, there was little difference in previous STI diagnosis between black African women in the SONHIA or Natsal sample; concurrency was more frequently reported by women in the SONHIA sample (24.4% vs. 7%).

[17] Data relates only to STIs diagnosed prior to UK due to routing error in questionnaire and lack of clarity as to whether STI diagnosis in UK preceded or accompanied HIV diagnosis.

These findings highlight the importance of understanding sexual behaviour patterns. The identification of high-risk behaviours within populations enables appropriate targeting of behavioural interventions and health promotion messages. Although Africans are the second largest group affected by HIV in the UK, compared to the gay community there is relatively little data on the sexual attitudes and lifestyles within UK African communities. There is currently no regular survey of black Africans knowledge, attitudes or behaviours associated with diagnosed or undiagnosed HIV infection.

10.3.4.3 HIV prevalence

In 2007 black Africans accounted for 40% of all new HIV diagnoses in the UK, the majority being acquired heterosexually. An estimated 3.7% of black Africans aged 15-59 living in England are living with diagnosed HIV compared to just 0.09% of white people the same age (Health Protection Agency, 2008c). The HPA also estimates that 32% (6300/19550) of HIV positive Africans are living with undiagnosed HIV (Health Protection Agency, 2008a). These estimates of the diagnosed and undiagnosed fraction are derived by the HPA through a range of methods including unlinked anonymous surveillance and the annual survey of HIV-infected persons accessing care (The UK Collaborative Group for HIV and STI Surveillance, 2007).

Unlinked anonymous HIV antibody surveys are carried out in a variety of settings: GUM clinics, neonatal dried blood spots, pregnancy termination services, antenatal clinics, and specialist services for injecting drug users (The UK Collaborative Group for HIV and STI Surveillance, 2007; Nicoll et al., 2000). By incorporating a variety of services the aim is to capture those individuals at higher behavioural risk (GUM clinic attendees and injecting drug users) and those at lower or general risk (antenatal, termination and neonatal sampling). Thus the derived estimates of the prevalence of

undiagnosed HIV rely to a degree on how representative the users of these services are to the populations they represent.

Whilst between 18 to 40% of MSM have attended a GUM clinic in the past year (Dodds et al., 2006), only ~20% of black Africans have attended a GUM clinic ever (Burns et al., 2005). In the general population the proportion of black African women utilising antenatal services in the past five years was 57.5% (chapter 3) however this data does not capture whether these services were abroad or in the UK; amongst newly diagnosed HIV positive African women only 15.9% had accessed antenatal services in the UK in the past five years, yet 69% had children (chapter 6). It is therefore possible that current unlinked anonymous screening may not adequately capture a representative sample of the migrant black African population.

Mayisha II, the largest community-based survey of sexual attitudes and lifestyles of African communities in England, found an HIV prevalence of 14% using unlinked anonymous testing of oral fluid, with 66% of infections undiagnosed (Sadler et al., 2007); both substantially higher than current HPA estimates. The differences may arise from possible over-sampling of Africans from high prevalence communities (47.0% of participants were from South Eastern or Eastern Africa compared to 12.8% from West Africa), and from over sampling of HIV positive black Africans, suggested by the high proportion who had ever attended a GUM clinic (42.4%) (MAYISHA II Collaborative Group, 2005). However, the markedly higher undiagnosed fraction suggests that there needs to be further research to establish with certainty the true HIV prevalence and undiagnosed fraction in this population.

Providing a summary composite measure for ‘black Africans’ will mask the diversity of behaviours and HIV prevalences within the African communities in the UK. This is probably essential to minimise further stigmatisation and discrimination of those

communities most at risk, and to prevent a false sense of security in African communities at lower risk by generating a sense of 'otherness' (HIV is something that affects 'other people' not me or those around me).

10.3.4.4 New migrant communities

Despite awareness of the high prevalence of HIV in sub-Saharan Africa and increasing immigration from this region, UK health services were relatively unprepared for the impact of this population on the epidemiology of HIV within the UK. Even now research and effective interventions for these communities are sparse (Prost, Elford, Imrie, Petticrew, & Hart, 2008). Health care providers and policy makers need to be attuned to the prevailing international disease epidemiology, and migrant communities are increasingly a feature of HIV cohorts throughout Europe (Hamers et al., 2004).

The importance of the health and welfare of migrant communities, and the impact these communities can have on HIV and STI epidemiology is now widely recognised. I have extended my work to focus on new migrant communities and the Medical Research Council has funded a study on the sexual attitudes and lifestyles of London's Eastern Europeans (the SALLEE project) in which I am the principal investigator (UCL News, 2007). This study will explore the sexual and reproductive attitudes, knowledge and behaviours of Central and Eastern European migrants to inform policy and service development.

10.3.5 Interventions

10.3.5.1 Community level interventions

The Department of Health has responded to the HIV epidemic among Africans in the UK by funding and sponsoring the National African HIV Prevention Programme (NAHIP) (Department of Health, 2005), and in 2008/9 the programme received

approximately £500,000. The African HIV Policy Network (AHPN), an alliance of African community-based organisations, manages NAHIP.

NAHIP has developed a multi-agency collaborative health promotion network to take charge of delivering a series of national (England-wide) HIV prevention education campaigns and interventions (Fakoya, Atim, & Imrie, 2007). Currently very little exists in the way of evaluation of these campaigns and interventions, and estimates of intervention efficacy, impact and cost-effectiveness are derived primarily from process evaluations. Evidence exists that behavioural interventions can significantly reduce risk behaviours in many populations.(Elwy, Hart, Hawkes, & Petticrew, 2002; Johnson et al., 2008; Sangani et al., 2004) To date there has not been a single rigorous evaluation of a HIV prevention intervention with Africans living in the UK (Ellis et al., 2003; Prost et al., 2008).

With the increasing number of infections among Africans that are occurring within the UK, there is an urgent need to develop or adapt suitable evidence-based group and community level behavioural prevention interventions for effectiveness trials in the UK. The majority of HIV prevention interventions for African communities have focused on secondary prevention, with detection and intervention to control disease being the principal objective (NAHIP, 2009). Both primary (the protection of health) and tertiary (reducing the impact of chronic disease) prevention interventions are also required.

Care must be taken in the delivery of these programmes to ensure they are culturally acceptable. The narratives of those interviewed clearly stated that HIV prevention and testing messages should be universal and not targeted at African communities. This does not mean that interventions directed at African communities should be abolished, rather more sophisticated and innovative audience segmentation and targeting strategies need to be adopted to avoid and ameliorate feelings of discrimination.

10.3.5.2 Interventions at the service provider level

Since 2000 there has been a 179% increase in the number of heterosexual men and women seen for HIV care in the UK, the majority of whom are African (The UK Collaborative Group for HIV and STI Surveillance, 2005). High uptake of HIV testing (Fenton et al., 2002; Burns et al., 2005) and primary care services (McMunn et al., 1998) by African communities have been known for some time, and Sullivan et al. (Sullivan, Curtis, Sabin, & Johnson, 2005) reported that 17% of newly diagnosed HIV positive patients had sought medical care with symptoms suggestive of HIV in the 12 months preceding diagnosis.

Given that Africans may not perceive themselves at risk of HIV and are unlikely to actively seek HIV testing it is imperative that clinicians take a more proactive approach on HIV. Primary care, as discussed above, is ideally placed to more effectively screen for HIV, much as it does for other health conditions. Primary care clinicians can currently attend short training courses such as the Sexual Health in Practice (SHIP) (Matthews, Mullineux, Quinn, & Kelly, 2004) or the British Association of Sexual Health & HIV STI Foundation course. Whilst these have been shown to increase STI knowledge and screening for chlamydial infections no increase in HIV testing has yet been demonstrated; and as attendance is voluntary and costly only those with a special interest in this area are likely to attend (Bailey, Dean, Hankins, & Fisher, 2008).

Whilst improved health service research would assist in our understanding of how best to address clinician concerns and increase HIV testing in non specialist settings, financial incentives (or penalties) may also be required if the UK is to see a change in current practice. Recent work has demonstrated that point of care testing for HIV at GP surgeries is feasible and acceptable (Prost, Wright, Anderson, Griffiths, & Hart, 2008).

It remains to be seen if the recent call from the Department of HIV for proposals to reduce undiagnosed HIV will deliver successful pilots from which to build on.

The education and training of medical undergraduates provides an ideal forum to normalise HIV diagnosis and care for future clinicians of all specialities. Ideally medical undergraduates should observe, and potentially offer, HIV testing in a variety of medical settings, not just within GUM clinics. Demystifying HIV testing for medical undergraduates could rapidly impact on HIV testing practices given that junior medical staff initiate the majority of baseline investigations in hospital settings.

Diagnosis of HIV is a critical step in secondary and tertiary HIV prevention. However keeping HIV positive people engaged with services is also imperative. The SONHIA study found 17% (120/711) of all eligible patients were lost to follow up 12 months after initial diagnosis. As discussed in chapter 6 people are lost to clinic follow up for multiple reasons including transferring care to other centres, dispersal/emigration, those unable to come to terms with their HIV diagnosis, and those who found HIV services unacceptable. HIV services need to develop systems to monitor and address this phenomenon. The NHS electronic patient record system (House of Commons Health Committee, 2007) currently in development may assist in delineating those retesting at another site (as a means of personal confirmation or disclosure), and those people transferring care to other centres. Other more innovative interventions will be required to tackle lost to follow up for other reasons.

10.3.6 Immigration law

Migrants with HIV generally do not seek health care for several years after arrival and often have advanced disease at the time of HIV diagnosis (House of Commons Health Committee, 2005; The UK Collaborative Group for HIV and STI Surveillance, 2007).

Findings supported by the SONHIA data where the average time respondents had lived in the UK prior to HIV diagnosis was 3.9 years, and 50% had advanced disease at diagnosis. This is not consistent with 'health tourism' (migration specifically to access health services). In December 2003 the government announced plans for overseas visitors and failed asylum seekers to have to pay in advance for NHS services, specifically to discourage health tourism (BBC News, 2003). This serves as an additional barrier to accessing HIV services and fuels stigma and discrimination in already vulnerable populations.

The Health Select Committee in 2004 found no evidence of health tourism occurring with regard to HIV treatment and care, and acknowledged the clear threat of untreated and undiagnosed HIV infection to public health (House of Commons Health Committee, 2005). Hence they argued that all people, irrespective of immigration status, should be entitled to free NHS treatment for HIV. The findings within this thesis strongly support this recommendation, and it could be argued that there is a moral and ethical duty to provide HIV treatment to all members of our population.

Allowing asylum seekers to work whilst awaiting immigration decisions could significantly improve the lives of many people. Asylum seekers constitute some of the UK most vulnerable and disadvantaged groups and health inequalities, especially in mental health, are widely acknowledged (British Medical Association Board of Science and Education, 2002). Work within this thesis demonstrates the importance of placing health in the broader context of people's lives. The ability to work could help foster self-esteem, reduce stigma and discrimination, and may save public finance expenses on benefits.

10.4 Conclusions

There are now almost 25,000 black Africans estimated to be living with HIV in the UK, significant proportions remain unaware of their HIV infection, and no reduction in late presentation has yet been seen (Health Protection Agency, 2008a; Health Protection Agency, 2008c). However, the incentive to diagnose and treat people with HIV earlier has never been greater: Cohort studies are consistently reporting improved life expectancy in HIV positive individuals accessing treatment and care (Fang et al., 2007; Lohse et al., 2007; Lewden et al., 2007), and for those with a CD4 count greater than 500 cells/μl it is approaching that of the general population (Bhaskaran et al., 2008). Also individuals with undiagnosed infection are now believed to have a disproportionately large impact on onward disease transmission (Marks et al., 2006).

This thesis presents a programme of work designed to explore newly diagnosed HIV infection in Africans living in London. The results of the studies presented in this thesis can be applied to clinical practice, surveillance methods and health promotion strategies. They have been referenced in calls to reduce late presentation and the roll out of HIV testing to non-specialist settings; they feed into the current review of country of acquisition surveillance at the HPA; and have been used by NAHIP in designing prevention interventions.

The key recommendations arising from this work are presented in box 10.2

When conducting such a broad piece of work it is easy to concentrate on specific biomedical aspects such as HIV testing. This reductionism enables focus on components amenable to intervention by clinicians and policy makers alike. However, it would be naïve to forget that without also making social, economic, and structural

changes both in the UK and abroad we are unlikely to greatly improve the lives of many Africans affected by HIV.

The recently proposed Equality Bill for the first time gives public bodies, including health and education authorities in England and Wales, a "social economic duty" to consider inequalities in their service provision (Government Equalities Office, 2009; BBC News, 2009). Whilst not specifically designed to meet the needs of migrant communities this Bill has the potential to impact on structural elements in society that contribute to health inequalities and help perpetuate stigma and discrimination. Other measures should include full entitlement to HIV treatment and care in the UK irrespective of residency status in keeping with other infectious diseases of public health importance, allowing migrants to work whilst awaiting immigration decisions, and continuing financial and technical support in the roll out of antiretroviral programmes throughout Africa.

Box 10.2 Key recommendation arising from this thesis

Key recommendations:

1. Routine HIV screening in primary and secondary care setting where HIV prevalence exceeds 0.05 per cent.
2. Funding to enable full evaluation of HIV testing pilots to guide service development.
3. Normalising HIV testing through training of medical undergraduates, junior doctors and general practitioners.
4. Financial incentives to increase HIV testing.
5. Develop or adapt evidence based risk reduction interventions for effectiveness trials in African communities in the UK.
6. Develop systems to monitor and address loss to follow up of HIV infected individuals.
7. Fund research into impact of viral clades on drug resistance and disease progression.
8. Develop clear guidelines on determining country of acquisition of HIV.
9. Enhance current surveillance with incidence testing.
10. Regular surveys of the sexual attitudes and lifestyles of high-risk communities, and further research into how to establish the true prevalence of HIV and the undiagnosed fraction in hidden populations.
11. Full entitlement to HIV treatment and care in the UK irrespective of residency status.
12. Allowing migrants to work whilst awaiting immigration decisions.

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Appendix 1: Dissemination of findings to date

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- UK acquisition of HIV infection in Africans resident in London. Health Protection Agency Centre for Infections. 17 September 2008.
- Acquisition of HIV infection by Africans resident in London: how much and how to assess. ASDTA-BASHH. Oral 012. New York, USA May 2008.
- Could primary care be doing more? Improving access to HIV services for Africans in the UK. 12th Annual conference of the British HIV Association, Brighton 31/3/06
- SONHIA: Study Of Newly diagnosed HIV Infection amongst Africans in London. Wellcome Research Training Day. 17/5/2005

Appendix 2: Topic Guide for Key Informant Interviews

1. Introduction.

- 'SONHIA' is about how African people living in London view HIV, their experiences with health services and how this influences when people test for HIV.
- This study will help determine the factors associated with late presentation of HIV disease so that in the future we can target resources to better meet the African communities health needs.
- Brief outline of purpose of interview –i.e. identify the key issues facing health service access for African communities affected by HIV so as to be able to generate topic guide and questionnaire for future study.

Explain: *Timing*
Confidentiality

2. Key informant particulars.

- Occupation
- How long working in this field?
- How much contact with African communities in London?

3. Community Attitudes.

I would like to start by asking you about what you believe are the important factors operating at a community level.

- What do you believe are the important influences on learning and attitudes about HIV amongst African communities in London?
- Perception of risk amongst the African communities in London?
- How aware of symptoms and signs of HIV prior to diagnosis do you believe the African communities to be?
- Influences on learning and attitudes health care access

4. **Health Services & Service History**

Now I would like to focus on how the health care system itself impacts on HIV testing.

- What do you believe to be the barriers to health care access
- What are the success stories in terms of improving health care access for these communities
- Utilisation of Services within the UK
  - Prior hospitalisation
  - Primary Health Care
  - HIV testing: barriers to uptake

5. HIV Treatment options

- Extent to which treatment options have influenced HIV presentation
  - decision making – factor in testing decision
  - perception in the community
  - antenatal
- Belief in and utilisation of other forms of therapies/healing: traditional; herbal; faith

6. Improvements to Services and Information

Finally I would like to get your opinion on how we can improve the services and information available on HIV and HIV testing

- Effective forms of encouragement – to test.
- Improvement to information available on HIV – form and content
- Improvement to Services available – type, location, availability.
- Who should be targeted – age, type required.

Thank interviewee
Provide contact details
Obtain address so as to be able to send future findings etc.

Appendix 3: SONHIA questionnaire

CONFIDENTIAL

STUDY OF NEWLY DIAGNOSED HIV INFECTION AMONGST AFRICANS IN LONDON

What is this study about?

This is a study about what African people living with HIV infection think about health services in the UK, what they think about HIV, and how we could improve services in the future.

Confidentiality

The questions in this booklet are mostly personal. Your answers will be treated in strict confidence; the person who gave you this questionnaire does not need to see them.

When you have finished, put the booklet in the envelope provided and seal it. Your name will not be on the booklet or envelope.

How to answer

Just put a tick in the box opposite the appropriate answer like this ☑, OR write in the box provided like this 1987

Not all the questions will apply to you; follow arrows and instructions. Please ask for help or explanations if you are not sure.

Importance

It is very important to the whole study that you answer these questions completely honestly and as accurately as you can.

Some things may be hard to remember, so please take your time

Unique Serial Number:

Date:

Please read these notes before answering the questions.

They are just to make sure everyone applies the same meaning to certain terms we use.

Partners (sexual partners)
People who have had sex together – whether just once, or a few times, or a regular partner, or as married partners.

Sexual intercourse, or 'having sex'.
This includes vaginal, oral and anal sexual intercourse[1].

GP (General practitioner)
These are family or student health doctors in the UK. They are not the doctors who you see when you attend Accident and Emergency, or hospital.

[1] Vaginal sexual intercourse: A man's penis in a women's vagina. (This is what people most usually think of as 'having sex' or 'sexual intercourse')

Oral sex (oral sexual intercourse): A man's or a women's mouth on a partner's genital area.

Anal sex: A man's penis in a partner's anus (rectum or back passage)

Section A:This first section includes general questions about you, your health, and your family

1. Are you male or female? Male ☐1 Female ☐2

2. How old are you? PLEASE WRITE IN NUMBER ☐ YEARS OLD

3. What is your nationality?
PLEASE WRITE YOUR ANSWER IN THE BOX ☐

4. Which languages do you feel comfortable talking in? *Tick all that apply*

An African Language (e.g. Shona, Swahili, Yoruba) ☐1
English ☐2
French ☐3
Arabic ☐4
Other ☐555

5. What is your preferred language to read in?
PLEASE WRITE IN BOX ☐

6. What is your country of birth?
PLEASE WRITE IN BOX ☐

7. What country(s) were you living in when you were between 10-16 years of age?
PLEASE WRITE IN BOX ☐

8. What term best describes your racial/ethnic background?

Black African ☐1
Black Caribbean ☐2
Black British ☐3
Black Other ☐4
Mixed ☐5
White ☐6
Arab ☐7
Asian ☐8
Other (PLEASE WRITE IN BOX) ☐555

☐

9. Currently are you: *Tick one only*

Living in the UK ☐1
Visiting the UK ☐2
Studying in the UK ☐3

In the UK on short term work contract ☐ 4

Other (PLEASE WRITE IN BOX) ☐ 555

10. What best describes you?

(Remember all the information you provide is confidential and will NOT be passed on to others)

Tick one only

UK Citizen ☐ 1
EEC Member ☐ 2
Permanent resident ☐ 3
Visa entry to UK ☐ 4
Currently applying for a visa ☐ 5
Asylum seeker ☐ 6
Refugee ☐ 7
Other ☐ 555

PLEASE WRITE IN THE BOX

11. Who do/did you rely on most for **immigration advice**?

Tick one only

Solicitor ☐ 1
Refugee Council ☐ 2
Friends/family ☐ 3
Citizens Advice Bureau ☐ 4
Terrence Higgins Trust ☐ 5
Other ☐ 555

PLEASE WRITE IN THE BOX

Not relevant ☐ 888
No one ☐ 0

12. When did you first begin living in the UK? *(month and year)*

Don't know/can't remember ☐ 999
Not applicable ☐ 888

13. Which of these descriptions applies to you?

Full time college/school/training ☐ 1
Employed full time ☐ 2
Employed part time ☐ 3
Unemployed/registered for benefits ☐ 4

Unemployed/not registered for benefits ☐ 5
Unable to work (long-term sickness or disability) ☐ 6
Voluntary work ☐ 7
Home/family caring ☐ 8

14. If you are employed, please write your job title in the box below.

15. What is your **highest educational qualification**? *Tick one only*

I have no formal educational qualifications ☐ 1
O-levels/GCSEs/CSEs or equivalent (left school at age 15/16) ☐ 2
A-levels or equivalent (left school at age 17/18) ☐ 3
University Degree or higher ☐ 4
Other, such as vocational or professional qualifications ☐ 555

PLEASE SAY WHAT IN BOX

16. Do you **own or rent** the place where you currently live? *Tick one only*

Own – outright or with a mortgage / loan ☐ 1
Rent – housing association/council ☐ 2
Rent – private landlord ☐ 3
Tied to your job ☐ 4
Live with friends and/or relatives ☐ 5
Bed and breakfast /hostels/homeless ☐ 6
Not applicable ☐ 888
Other (PLEASE WRITE IN BOX BELOW) ☐ 555

17. What is **first part of** your **postcode?**
(Example: for SW3 5BP write SW3)

Don't know ☐ 999
Not applicable ☐ 888

18a. Do you have a **solicitor**? Yes ☐ 1 No ☐ 0 → GO TO Q19

b. If yes, for how long have you had a solicitor? ☐ MONTHS OR ☐ YEARS

19a. Do you have a **GP** (family doctor) in the UK?

Yes ☐ 1 No ☐ 0 → GO TO Q20

b. If yes, for how long have you had a GP? ☐ MONTHS OR ☐ YEARS

20a. Do you attend any **community or sports groups?**

Yes ☐ 1 No ☐ 0 → GO TO Q21

b. If yes, which one(s)?
PLEASE WRITE IN BOX ☐

21a. What is your religion? *Tick one only*

None	☐ 1
Christian – Roman Catholic	☐ 2
Church of England/Anglican	☐ 3
Baptist	☐ 4
Protestant	☐ 5
Other Christian	☐ 6
Islam/Muslim	☐ 7
Other (PLEASE WRITE IN BOX BELOW)	☐ 555

☐

b. How important is your **faith/religion** to you**?** *Tick one only*

Very important	☐ 1
Important	☐ 2
Neither important nor unimportant	☐ 3
Not at all important	☐ 4

c. Apart from special occasions (eg. weddings, funerals) how often do you attend services? *Tick one only*

Once a week or more	☐ 1
Once a month or more	☐ 2
Twice a year	☐ 3
Once a year	☐ 4
Never/practically never	☐ 0

GO TO Q23

22a. Do you use the **Internet**? Yes ☐ 1 No ☐ 0 →

b. If yes, how often do you use the internet? *Tick one only*

Most days	☐ 1
At least once a week	☐ 2
Several times a month	☐ 3
Monthly or less often	☐ 4

23. At present are you… *Tick one only*

Married (and living with your (wife/husband))	☐ 1
Living with your partner as a couple	☐ 2
In a relationship, but living apart	☐ 3
Widowed	☐ 4
Divorced	☐ 5
Separated	☐ 6
Single and never been married	☐ 7

Remember all the information you provide is confidential and will NOT be passed on to other people.

24. Is your **partner** (boyfriend/girlfriend/wife/husband) **HIV….**? *Tick one only*

Positive	☐ 1
Negative	☐ 2
Untested	☐ 3
Don't know	☐ 999
I do not have a partner at present	☐ 0

25a. Do you have, or have you had, any children of your own that you are the natural parent of? Please include any who don't now, or never did, live with you as part of your household.

Yes ☐ 1 No ☐ 0 → GO TO Q26

b. If yes, how many children have you had? ☐ Please include any stillbirths or children who may have died

c. In what year and country were your children born?

Child	Year of birth	Please tick if born in UK	Child	Year of birth	Please tick if born in UK
1			4		
2			5		
3			6		

26. In general would you say that your **health 12 months ago** was? *Tick one only*

- Excellent ☐ 1
- Very good ☐ 2
- Fair ☐ 3
- Poor ☐ 4
- Terrible ☐ 5

27. In general would you say your **health now** is? *Tick one only*

- Excellent ☐ 1
- Very good ☐ 2
- Fair ☐ 3
- Poor ☐ 4
- Terrible ☐ 5

28. If you suffer from poor health now, how long have you suffered poor health (if at all)? *Tick one only*

- More than 5 years ☐ 1
- 1- 5 years ☐ 2
- 6 - 12 months ☐ 3
- Less than 6 months ☐ 4
- Not at all ☐ 0

29a. In the **two years before** you were **diagnosed with HIV** did you visit a **GP** (family doctor)?

Yes ☐ 1 No ☐ 0 → GO TO Q30

b. If yes, why did you visit a GP? *Tick ALL that apply*

- For contraception or pregnancy ☐ 1
- The flu or chest infection ☐ 2
- Skin condition ☐ 3
- Minor Injury ☐ 4
- Child vaccination or child unwell ☐ 5
- Other (PLEASE WRITE IN BOX BELOW) ☐ 555

30a. In the **last five years** or so, have you had any **illness or accident** (apart from HIV) that has affected your health for at least 3 months?

Yes ☐ 1 No ☐ 0 → GO TO Q31

b. If yes, what illnesses or accidents have you had? PLEASE WRITE IN BOX BELOW

31a. In the **year before** you were diagnosed with HIV did you visit a hospital **outpatient department/centre**? (APART FROM STRAIGHTFORWARD ANTE- OR POSTNATAL VISITS)

Yes ☐ 1 No ☐ 0 → GO TO Q32

b. If yes, **why** did you visit the hospital outpatient department/centre?
PLEASE WRITE IN BOX

c. **Where** did you visit hospital outpatient centres in the past year? *Tick all that apply*

UK ☐ 1
Africa ☐ 2
Elsewhere ☐ 3

32a. In the **year before** you were diagnosed with HIV were you ever **admitted** (overnight or longer) to a hospital? EXCLUDE VISITS FOR PREGNANCY

Yes ☐ 1 No ☐ 0 → GO TO Q33

b. If yes, **why** were you admitted to hospital? (PLEASE WRITE ANSWER IN BOX BELOW)

c. **Where** were you admitted to hospital? *Tick all that apply*

UK ☐ 1
Africa ☐ 2
Elsewhere ☐ 3

33a. In the **last five years** have you attended an **ante-natal clinic** or **ante-natal service** at a hospital or at your GP's (family doctor) in the UK because you were pregnant?

Yes ☐ 1 No ☐ 0 → GO TO Q34

b. If yes, for how many pregnancies? ☐

34. In the last 2 years who have you had sex with?

Tick one only

Men	☐ 1
Women	☐ 2
Both men and women	☐ 3
Not had sex in last 2 years	☐ 0

35. How do you describe your sexuality?

Tick one only

Heterosexual (person who prefers sex with someone of the opposite sex)	☐ 1
Homosexual (person who prefers sex with someone of the same sex)	☐ 2
Bisexual (person who likes sex with people of either sex)	☐ 3
Other	☐ 555

Section B: These questions are about you BEFORE you were diagnosed HIV positive.

1a. Have you ever had a **negative** HIV test?

Yes ☐ 1 — No ☐ 0 — Don't know ☐ 999 — GO TO Q2

b. If yes, how many negative tests have you had? ☐ TIMES

c. **When** was your last negative HIV test? *(month and year)* ☐

d. **Where** was your last negative HIV test?

- In Africa ☐ 1
- In a UK sexual health (GUM or STD) clinic ☐ 2
- In a UK antenatal clinic ☐ 3
- Elsewhere in the UK ☐ 4
- Elsewhere ☐ 5

2a. How often did you see a GP (family doctor) in the 12 months before your HIV diagnosis?

☐ TIMES OR NONE ☐ 0 → GO TO Q3

b. Did the GP (family doctor) ever mention HIV testing?

- Yes ☐ 1
- No ☐ 0
- Don't know ☐ 999

3. How long had you been in the UK before you knew where to go to have an HIV test?

Tick one only

- Less than 6 months ☐ 1
- 6 to 12 months ☐ 2
- Between 1 and 2 years ☐ 3
- Between 2 and 5 years ☐ 4
- More than 5 years ☐ 5

4. In the UK how did you find out where to have an HIV test? *Tick one only*

- From a GP (family doctor) ☐ 1
- The Media (radio, magazines, newspapers) ☐ 2
- Internet ☐ 3

Partner(s) ☐ 4
Friends or family ☐ 5
HIV organisations (THT, IVO) ☐ 6
Pastor/Religious minister/Church ☐ 7
It was offered to me whilst in hospital ☐ 8
Other (PLEASE WRITE IN THE BOX BELOW) ☐ 555

5a. **Before** your HIV diagnosis did you **ever try but were unable** to have an HIV test?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999 GO TO Q6

b. If yes why were you not able to have an HIV test?

Tick ALL that apply

The doctor did not offer it ☐ 1
No appointments available ☐ 2
I did not know where to go ☐ 3
I was unable to get to the clinic ☐ 4
No one was able to look after my children ☐ 5
The clinic was not open when I could go ☐ 6
Other (PLEASE SPECIFY IN BOX) ☐ 555

6. **Before** you tested HIV positive what **type of person** did you think got HIV?

Tick ALL that apply

Anybody ☐ 1
People who do not believe in God ☐ 2
Only people who sleep with lots of people ☐ 3
Only people who have sex in Africa ☐ 4
Drug addicts ☐ 5
Gay men ☐ 6
Other (PLEASE WRITE IN THE BOX BELOW) ☐ 555

7a. **Before** being HIV positive can you remember **discussing** HIV with anyone?

Yes ☐ 1 No ☐ 0 → GO TO 8

b. If yes, who? *Tick ALL that apply*

My partner/husband/wife	☐ 1
HIV positive people/friends	☐ 2
Friends	☐ 3
Health care professional	☐ 4
Counsellor	☐ 5
I don't like to talk about HIV issues	☐ 6
Internet / Chatlines	☐ 7
Advice Helplines	☐ 8
Don't know	☐ 999
Other (PLEASE WRITE ANSWER IN BOX BELOW)	☐ 555

8. **Before** testing HIV positive how many people did you know that were HIV positive? *Tick **ONE** only*

0	☐ 1
1	☐ 2
2-4	☐ 3
5 or more	☐ 0
Don't know	☐ 999

9. In the UK what were your sources of information about HIV, before testing HIV positive? *Tick ALL that apply*

Health Care Workers (e.g. doctor/nurse)	☐ 1
HIV positive friends	☐ 2
Other friends	☐ 3
The Media	☐ 4
HIV positive press	☐ 5
Internet	☐ 6
Partner(s)	☐ 7
HIV organisations (THT, OPAM)	☐ 8
Pastor/Religious minister/Church/Mosque	☐ 9
Other (PLEASE WRITE IN BOX BELOW)	☐ 555
None	☐ 0

10. Before testing HIV positive, which ONE source listed above in question 9 was your MAIN source of information about HIV?

Tick ONE only

- Health Care Workers (e.g. doctor/nurse) ☐ 1
- HIV positive people/friends ☐ 2
- Other friends ☐ 3
- The Media ☐ 4
- HIV positive press ☐ 5
- Internet ☐ 6
- Partner(s) ☐ 7
- HIV organisations (THT, OPAM) ☐ 8
- Pastor/Religious minister/Church/Mosque ☐ 9
- Other (PLEASE WRITE IN BOX BELOW) ☐ 555

☐

- None ☐ 0

11. Did you know that HIV testing would be free in the UK when you first arrived in the UK? Yes ☐ 1 No ☐ 0

12. Did you know that Doctors are legally obliged to respect your confidentiality and not inform others of your HIV infection before your HIV test?

Yes ☐ **1** No ☐ **0**

13. **How important were each of the following reasons in preventing YOU from testing earlier.**

PLEASE ANSWER (a)-(g) BY TICKING **ONE BOX** ON **EACH LINE**	Very important	Important	Neither important or unimportant	Probably not important	Definitely not important
a. Distance to health services	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Personal financial resources	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. Level of knowledge about HIV/AIDS in the community	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. Stigma or shame within the African community in the UK	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e. Lack of employment opportunities for HIV positive people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f. Having to go to a sexual health clinic	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g. The assumption that all HIV is spread sexually.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The next few questions are about your sexual health. Some of the questions are quite personal but remember this questionnaire is completely confidential. Again these questions relate to the time BEFORE you tested HIV positive.

14a. Since moving to the UK and **before** being diagnosed HIV positive have you returned to Africa?

Yes ☐1 No ☐0 → GO TO Q15

b. If yes, in what year did you last visit? ☐☐☐☐ YEAR

c. Which country(s) did you visit? ☐

d. Thinking of this time when you visited Africa did you have sexual intercourse with any people for the **first** time whilst you were there?

Yes ☐1 No ☐0 → GO TO Q15

e. Did you use a condom with these new sexual partners?

Yes, used on every occasion ☐1
Yes, used on some occasions ☐2
No, not used ☐3
Not sure ☐4

15a. Now thinking of the time since you moved to the UK and **before** being diagnosed HIV positive how many people did you had sexual intercourse with in the UK? ☐☐☐

b. Was a condom used?

Yes, used on every occasion ☐1
Yes, used on some occasions ☐2
No, not used ☐3
Not sure ☐4
Not had sex since moving to UK ☐0

16. In the past year how many people have you had sexual intercourse with? ☐☐☐

b. Was a condom used?

Yes, used on every occasion ☐1
Yes, used on some occasions ☐2
No, not used ☐3
Not sure ☐4
Not had sex in past year ☐0

17a. Have you ever paid (or given gifts) for sex?

Yes ☐1 No ☐0 → GO TO Q18

b. Where was this? *Tick ALL that apply*

In the UK	☐1
In Africa	☐2
Elsewhere	☐3

18a. Have you ever been paid (or received gifts) for sex?

Yes ☐1 No ☐0 → GO TO Q19

b. Where was this? *Tick ALL that apply*

In the UK	☐1
In Africa	☐2
Elsewhere	☐3

19a. **Before moving to the UK**, had you ever been told by a doctor that you had any of the following? (Please tick **each** that applies, or tick **none** (the last box))

	a)Tick if 'YES '	**b) When was the last time? (year)**
Herpes (genital herpes)	☐1	
Trichomonas (Trich, TV)	☐2	
Gonorrhoea	☐3	
Syphilis	☐4	
Chlamydia	☐5	
NSU (non specific urethritis)	☐6	
Genital warts (veneral warts, HPV)	☐7	
Thrush (Candia, yeast infection)	☐8	
Women only:		
Pelvic inflammatory disease (PID)	☐9	
Bacterial vaginosis (BV)	☐10	
A sexually transmitted infection but cannot remember it's name	☐11	
None of these	☐0 → GO TO Q20	

b. Was HIV or HIV testing mentioned at the time you were told you had the above infection(s)? Yes ☐1 No ☐0 Don't know ☐999

20a. **Since moving to the UK**, had you ever been told by a doctor that you had any of the following? (Please tick **each** that applies, or tick **none** (the last box))

	a)Tick if 'YES '	b) When was the last time? (year)
Herpes (genital herpes)	☐ 1	
Trichomonas (Trich, TV)	☐ 2	
Gonorrhoea	☐ 3	
Syphilis	☐ 4	
Chlamydia	☐ 5	
NSU (non specific urethritis)	☐ 6	
Genital warts (veneral warts, HPV)	☐ 7	
Thrush (Candia, yeast infection)	☐ 8	
Women only:		
Pelvic inflammatory disease (PID)	☐ 9	
Bacterial vaginosis (BV)	☐ 10	
A sexually transmitted infection but cannot remember it's name	☐ 11	
None of these	☐ 0 → GO TO Q21	

b. **Where** were you treated for this condition(s)? *Tick ALL that apply*

At a GP surgery ☐ 1
At a Sexually Transmitted Disease clinic (STD or GUM clinic) ☐ 2
Somewhere else ☐ 3

c. Was **HIV** or **HIV testing** mentioned at the time you were told you had the above infection(s)? Yes ☐ 1 No ☐ 0 Don't know ☐ 999

21a. Did any advertising influence your decision to have a HIV test?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

b. If yes, in what form was this advertising?

Radio ☐ 1
Magazine ☐ 2
Health or HIV publication ☐ 3
Leaflet ☐ 4
Poster ☐ 5
TV ☐ 6
Other (PLEASE SPECIFY IN BOX BELOW) ☐ 555

Section C: This section is about your experiences of BEING diagnosed HIV positive.

1. **When**, if ever, were you first diagnosed HIV positive in **Africa**?

YEAR OR I was not diagnosed with HIV in Africa ☐ 0

2. **When** were you first diagnosed HIV positive in the **UK**?
(month and year)

Don't know ☐ 999

3. **Where** were you first diagnosed with HIV in the UK? *Tick ONE only*

In a Sexual Health Clinic (GUM/STD/HIV clinic) ☐ 1
At a GP (family doctor) ☐ 2
In hospital (on a ward or outpatient clinic) ☐ 3
In an ante-natal clinic ☐ 4
Other/None of the above (PLEASE SAY WHERE IN BOX BELOW) ☐ 555

4. What was the main reason **for you having your last HIV test?** ***Tick ONE only***

A hospital or clinic doctor advised me to test ☐ 1
I had health complaints that I thought may be related to HIV ☐ 2
I was advised to by my GP (family doctor) ☐ 3
I had sexual contact with someone known or thought to have HIV ☐ 4
My child tested HIV positive ☐ 5
It was related to pregnancy of my partner or myself ☐ 6
It was part of a routine check up ☐ 7
It was part of insurance, mortgage, or visa requirements ☐ 8
Other (PLEASE WRITE IN BOX BELOW) ☐ 555

5. Were you expecting the positive result?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

6a. When did you first think you became HIV positive? YEAR

b. Why do you think this is when you became HIV positive?

I had sex with someone now known to be HIV positive	☐ 1
I had sex with someone at high risk of HIV	☐ 2
I was raped/sexually assaulted	☐ 3
I started being unwell	☐ 4
I had a blood transfusion	☐ 5
I was given an injection or vaccination	☐ 6
Other (PLEASE WRITE IN BOX BELOW)	☐ 555

7. What stopped you testing for HIV earlier?

	Tick **ALL** that apply	**Single most important reason** Tick **ONE** only
I had not considered the possibility that I may be HIV positive	☐ 1	☐ 1
I was well so no need	☐ 1	☐ 2
I did not know where to go for a test	☐ 1	☐ 3
I was afraid of the result	☐ 1	☐ 4
I was afraid of the stigma associated with HIV	☐ 1	☐ 5
I was afraid it might influence my immigration application	☐ 1	☐ 6
Fear of losing a relationship	☐ 1	☐ 7
I did not want to ask my GP (family doctor)	☐ 1	☐ 8
I did not want to attend a sexual health centre	☐ 1	☐ 9
Other reason (PLEASE WRITE IN THE BOX BELOW)	☐ 1	☐ 555

8. What would have made you test for HIV earlier?

	Tick **ALL** that apply	**Single most important reason** Tick **ONE** only
If someone had told me that I was at risk	☐ 1	☐ 1
If I felt that I would be supported if I tested positive	☐ 1	☐ 2
If there was no stigma associated with HIV	☐ 1	☐ 3
If HIV was not so linked to sex	☐ 1	☐ 4
If I had known there were medicines available	☐ 1	☐ 5
If I had known you could make it less likely for babies to become infected	☐ 1	☐ 6
Other reason (PLEASE WRITE IN THE BOX)	☐ 1	☐ 555

Section D: This section is about your experiences SINCE being diagnosed HIV positive.

1. Who have you told that you are HIV positive? **(TICK ONCE ON EACH LINE)**

	YES	NO	NOT RELEVANT AS I DO NOT HAVE ONE
Your partner	☐ 1	☐ 0	☐ 888
Your GP (family doctor)	☐ 1	☐ 0	☐ 888
Your mother	☐ 1	☐ 0	☐ 888
Your father	☐ 1	☐ 0	☐ 888
My solicitor	☐ 1	☐ 0	☐ 888
Social services	☐ 1	☐ 0	☐ 888

	ALL	SOME	NONE	NOT RELEVANT
Your children	☐ 1	☐ 2	☐ 0	☐ 888
Your brothers/sisters	☐ 1	☐ 2	☐ 0	☐ 888
Your friends	☐ 1	☐ 2	☐ 0	☐ 888
Your work colleagues	☐ 1	☐ 2	☐ 0	☐ 888
Your ex partners	☐ 1	☐ 2	☐ 0	☐ 888

2. With whom are you most likely to **talk about HIV issues?** *Tick ALL that apply*

- My partner/husband/wife ☐ 1
- HIV positive friends ☐ 2
- Other friends ☐ 3
- Health care professional ☐ 4
- Counsellor ☐ 5
- I don't like to talk about HIV issues ☐ 6
- Anyone who cares to listen ☐ 7
- Internet / Chatlines ☐ 8
- Advice Helplines ☐ 9
- Don't know ☐ 999
- Other (PLEASE WRITE ANSWER IN BOX BELOW) ☐ 555

3. Do you think the internet would be a good place to obtain information about HIV services in the UK?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

4. If you knew HIV testing was free and confidential at sexual health clinics would you have tested earlier?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

5. If you knew HIV testing was free and confidential at sites other than sexual health clinics would you have tested earlier?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

6. If you had known that anti-HIV medicines may stop you getting sick or of dying from HIV/AIDS would you have tested earlier?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

7. If there was a cure for HIV would you have tested earlier?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

7. Would most people you know have an HIV test if they thought they were at risk of HIV?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

9. How many people that you know have had an HIV test?

	Tick ONE only
Most	☐ 1
A few	☐ 2
None	☐ 3
Don't know	☐ 999

10. What do you see as the benefits of knowing your HIV status?

	*Tick **ALL** that apply*	**Which of these is the single most important benefit** *Tick **ONE** only*
It's a weight off my shoulders	☐ 1	☐ 1
I can prevent spreading HIV to others	☐ 1	☐ 2
I could take medicines to reduce the chance of my baby becoming infected with HIV	☐ 1	☐ 3
I can take medicines to keep me healthy and alive longer	☐ 1	☐ 4
It has provided me social support	☐ 1	☐ 5
It helps with future planning for myself and family	☐ 1	☐ 6
It gives me control over my own health	☐ 1	☐ 7
None	☐ 1	☐ 8
Other	☐ 1	☐ 555

PLEASE WRITE IN THE BOX

11. What do you see as the main reasons not to have an HIV test?

	Tick ALL that apply	**Which of these is the single most important reason** *Tick ONE only*
Discrimination within my community	☐ 1	☐ 1
Discrimination in my job	☐ 1	☐ 2
Makes it difficult to plan a family	☐ 1	☐ 3

More likely to be deported	☐ 1	☐ 4
Insurance and mortgage difficulties	☐ 1	☐ 5
No point as nothing can be done about HIV	☐ 1	☐ 6
No point as God will protect me	☐ 1	☐ 7
Knowing makes you ill	☐ 1	☐ 8
Fear	☐ 1	☐ 9
Other	☐ 1	☐ 555

PLEASE WRITE IN THE BOX ☐

12. Do you access any HIV support groups (eg. Body & Soul, IVO)?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

13a. Do you use any **traditional or herbal medicines** to improve your health?

Yes ☐ 1 No ☐ 0 → GO TO Q14

b. If yes, what for? (PLEASE WRITE ANSWER IN BOX BELOW)

☐

c. When was the last time you used traditional or herbal medicines? *Tick one only*

In the last 7 days?	☐ 1
Between 7 days and 4 weeks ago	☐ 2
Between 4 weeks and 1 year ago	☐ 3
Longer than 1 year ago	☐ 4

d. For how long have you used traditional or herbal medicines?
(PLEASE WRITE ANSWER IN BOX) ☐

14a. Do you believe that **faith alone** can **cure HIV?**

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

b. Do you believe that taking anti-HIV medicines implies a lack of faith in God?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

Section E: These questions are about the future. This is the final section.

1a. Do you feel you can **trust** the staff at your **HIV clinic/hospital**?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

b. If not, what are your main concerns?

Links with other government departments (e.g. immigration)	☐ 1
Lack of confidentiality (e.g. in the clinic, misdirected mail)	☐ 2
Disclosure of HIV status to others	☐ 3
Discrimination	☐ 4
Lack of knowledge about HIV	☐ 5
Behaviour and attitudes of reception staff	☐ 6
Other (PLEASE WRITE IN THE BOX BELOW)	☐ 555

2a. Do you feel you can **trust** the staff at your **GP** (family doctor) surgery?

Yes ☐ 1 No ☐ 0 Don't know ☐ 999

b. If not, what are your main concerns?

Links with other government departments (e.g. immigration)	☐ 1
Lack of confidentiality (e.g. in the clinic, misdirected mail)	☐ 2
Disclosure of HIV status to others	☐ 3
Discrimination	☐ 4
Lack of knowledge about HIV	☐ 5
Behaviour and attitudes of reception staff	☐ 6
Other (PLEASE WRITE IN THE BOX BELOW)	☐ 555

3. Who else, if anyone, do you feel you can trust? (PLEASE WRITE ANSWER IN BOX BELOW)

4. These next few questions are about **people's reactions and attitudes to HIV**.

PLEASE ANSWER (a)-(f) BY TICKING **ONE BOX** ON **EACH LINE**	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a. Most partners of people who are HIV+ would leave if they knew about the HIV	☐1	☐2	☐3	☐4	☐5
b. If my family knew about my HIV they would stand by me and support me	☐1	☐2	☐3	☐4	☐5
c. If my friends knew about my HIV they would stand by me and support me	☐1	☐2	☐3	☐4	☐5
d. People who are HIV+ are at risk of isolation if their church/mosque finds out about their diagnosis	☐1	☐2	☐3	☐4	☐5
e. There is a sense of personal failure associated with being diagnosed HIV+	☐1	☐2	☐3	☐4	☐5
f. Being diagnosed HIV+ is a source of shame for family in Africa	☐1	☐2	☐3	☐4	☐5

5. Please assess how much you agree with the following statements.

PLEASE ANSWER (a)-(e) BY TICKING **ONE BOX** ON **EACH LINE**	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a. HIV causes AIDS	☐1	☐2	☐3	☐4	☐5
b. HIV is a disease created by white people	☐1	☐2	☐3	☐4	☐5
c. The medicines available work just as well on black people as on white people	☐1	☐2	☐3	☐4	☐5
d. The NHS meets the needs of African patients	☐1	☐2	☐3	☐4	☐5
e. The NHS system treats African patients as fairly as other patients	☐1	☐2	☐3	☐4	☐5

Other comments

Did you feel able to answer all the questions honestly?

Yes ☐ 1 No ☐ 0

If not which questions were difficult to answer honestly?

We are very interested in your thoughts about this questionnaire. If you have any comments on particular questions asked, the way the questionnaire was written, or anything else about the questionnaire, then please write them in the box below.

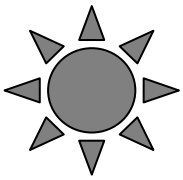
If there is anything else you would like to tell us about your experiences of HIV or health services in the UK please do so here.

THANK YOU VERY MUCH FOR YOUR HELP
Please check you have answered all the questions that apply to you and then put this questionnaire back in the envelope provided.

Results of this study will be published and made available at your clinic. As the study is recruiting new patients until June 2005 the results will not be available until after this date.

If you would like to know more about the study or to find out about the results please contact Dr Fiona Burns on 0207 387 9300 ext. 8970.

Appendix 4: Clinical data form



SONHIA

Study Of Newly diagnosed HIV Infection amongst Africans in London

CLINICAL DATA FORM

NOT TO BE GIVEN TO RESPONDENT

To be completed using patient database and case records.

Unique Serial Number: (Attach sticker)

Date:

Clinic Number (or attach clinic label)

a. DOB: ☐☐/☐☐/☐☐

b. Gender: Male ☐ Female ☐

c. Country of birth: _____

Information from time of first diagnosis:

d. Date HIV diagnosis: ☐☐/☐☐/☐☐

e. CDC Classification at time of HIV diagnosis: ☐☐ (see classification below)

f. CD4 at time of HIV diagnosis: ☐☐☐☐ x 10^6

g. Viral load at time of HIV diagnosis: _____ copies/ml

h. Was a primary resistance test taken around the time of first diagnosis?
Yes ☐ No ☐ Don't know ☐

i. If yes, was primary resistance detected? Yes ☐ No ☐ Don't know ☐

i. Was there evidence that this patient was seroconverting or had incident infection (a positive detuned assay) at the time of diagnosis?
Yes ☐ No ☐ Don't know ☐

Complete at six months post diagnosis*:

a. CDC Classification at 6 months: ☐☐ Not applicable ☐

b. CD4 count at 6 months*: ☐☐☐☐ x 10^6 Not applicable ☐

c. Viral load at 6 months*: _____ copies/ml Not applicable ☐

*Please provide results from bloods taken as close to 6 months post diagnosis as possible and give date bloods taken here ☐☐/☐☐/☐☐

d. Has viral typing been performed on this patient?

Yes ☐ No ☐ Don't know ☐

e. If yes, what was the result? _____

f. Date first AIDS diagnosis: ☐☐/☐☐/☐☐ Not applicable ☐

g. Please list all AIDS defining illnesses (ADI) within first 6 months:

ADI (see below for code)

Not applicable ☐

h. Has the patient taken any anti-retrovirals since diagnosis? Yes ☐ No ☐

i. Date of death: ☐☐/☐☐/☐☐ Not applicable ☐

Codes for AIDS Defining Illnesses

1=Recurrent Bacterial pneumonia	11=CMV retinitis	21=Other
2=Lymphoma	12=CMV other	
3=Oeso. Candida	13=Toxoplasmosis	
4=PCP	14=TB pulmonary	
5=PML	15=TB disseminated	
6=Cryptococcosis	16=HSV	
7=Crptosporidiosis/Isoporiasis	17=Wasting Disease	
8=Mycobacteriosis	18=KS mucocutaneous	
9=Cervical cancer	19=KS visceral	
10=Salmonella septicaemia	20=HIV encephalopathy/ADC	

CDC Classification List as A1, B2 etc.

Category A – documented HIV infection, asymptomatic – includes PGL and acute seroconversion.
Category B – symptomatic, conditions not in category C
Includes: recurrent thrush (oral and vulvovaginal), mod to severe cervical dysplasia, fever (38.5) or diarrhoea greater than 1 month, OHL, herpes zoster (shingles) greater then 1 episode or more than 1 dermatome, ITP (thrombocytopenia), PID and peripheral neuropathy.
Category C – AIDS defining conditions
Category 1 – CD4+ greater or equal to 500 or 29%
Category 2 – CD4+ equal to 200 – 499, or 14-28%
Category 3 – CD4+ less than 200, or 14%

Thank you

Please keep these forms on site and notify Dr Fiona Burns, ph. 02073879300, email: fburns@gum.ucl.ac.uk, to come and collect.

Appendix 5: Information sheets

Key informant interviews

University College London

13/06/03

SONHIA :
Study of Newly diagnosed HIV Infection amongst Africans in London.

Information Sheet

As an individual with extensive experience in the area of HIV and sexual health, working with African communities, or in health service access, we are asking you to help in the development of a research study's instruments. The study is to find out more about African people who are diagnosed with HIV. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. If there is anything that is not clear or if you would like more information on, please ask. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

HIV/AIDS among Britain's African communities is a major public health concern, yet to date relatively little research has focused on this group. Africans with HIV often have delayed presentation and poor uptake of health services compared to non-Africans. This can result in poorer health, both physical and psychological, as well as greater economic costs to the health service. Many opportunities for earlier diagnosis and treatment of HIV/AIDS among Africans are missed. The study aims to describe the health beliefs, heath care utilisation and clinical presentation patterns of newly diagnosed HIV positive Africans in London. We hope to use this information to identify ways to prevent progression to AIDS in the future, as well as in the development of culturally appropriate health promotion and disease prevention initiatives. Recruitment to the study will run for 18 months starting in October 2003.

The specific aims and objectives of the study are: To describe the health beliefs, heath care utilisation and presentation patterns of newly diagnosed HIV positive Africans in London in order to inform the development of culturally appropriate HIV prevention interventions.

Specific objectives:

To describe the demographic characteristics, migration history, HIV/sexual health history, patterns of service utilisation and levels of psycho-social support among this group.
To determine the extent to which acquisition of their infection may have occurred within the UK, and in so doing, determine opportunities for earlier diagnosis of their HIV disease.
To determine the factors associated with delayed presentation (CD4<200) to treatment services

To explore in a qualitative study, the contextual, social and economic factors, which influence timely access to and uptake of HIV prevention and treatment.

Why have I been chosen?

Because you are an individual with extensive experience in the area of HIV and sexual health, working with African communities, epidemiology, or in health service access.

Do I have to take part?

No. It is up to you to decide whether or not to take part.

What do I have to do?

An informal face to face interview will be requested and if granted conducted at the venue of your choice. The semi-structured interview will be used to identify the key issues facing health service access for African communities affected by HIV. Clinical practice, other than how policy and the structure of health services affect it, will not be discussed.

Will my taking part in this study be kept confidential?

Yes. All information which is collected during the course of the research will be kept strictly confidential. The information you provide will be used to help develop the topic guide and questionnaire.

What will happen to the results of the study?

You have the option of reviewing the instruments (topic guide and questionnaire) once they have been developed and will be fully informed of the studies findings. Results of the study will be published in leaflets that will be available in the clinics. They will also be written up for publication in journals, and relevant information fed back to the African communities and relevant organisations. Preliminary results should be available in June 2004, and final results by October 2005.

Who is organising and funding this research?

This research is funded by a Wellcome Training Fellowship grant. Dr Fiona Burns is the person organising the study and is responsible for all the data. Ethical approval for this study has been attained from both the Multi-centre and your local Research Ethics Committee.

Thank you very much for taking the time to help.

Contacts for further information:

Dr Fiona Burns	Ph. 0207 3879300 ext.8970
Research Team:	Dr Fiona Burns, Dept. of STDs, UCL Dr Kevin Fenton, Dept. of STDs, UCL Dr James Nazroo, Dept. of Epidemiology & Public Health, UCL Prof. Anne Johnson, Dept. of Primary Health Care & Population Sciences, RFUCMS, UCL

SONHIA

Study Of Newly diagnosed HIV Infection amongst Africans in London

Information Sheet for Questionnaire

We are asking you to be involved in a research study to find out more about African people who are diagnosed with HIV in the UK and how we can improve health services for them. Before you take part it is important to understand why this work is being done. Please take the time to read the following information and discuss it with others if you wish. Please ask us if anything is unclear or you have any concerns. Take time to decide if you want to take part or not.

What is the purpose of the study?

HIV/AIDS is an important health problem among Britain's African communities. Africans with HIV tend to wait a long time before they seek help from the NHS. This often means they are too unwell to benefit from all the new treatments and services available for people with HIV. We know that earlier diagnosis and treatment helps people with HIV live longer and healthier lives, as well as help stop the spread of HIV. The aim of this study is to understand how we can improve opportunities for earlier diagnosis and treatment of HIV among Africans. Using this information in collaboration with African organisations we hope to develop a more effective and acceptable HIV prevention strategy.

Why have I been chosen?

The study is being undertaken at HIV treatment centres throughout London. All people born or raised in Africa and diagnosed HIV positive during the study period will be asked to participate in the study. We are hoping to get at least 330 people involved in the study. Recruitment to the study will run for 18 months beginning in January 2004.

Do I have to take part?

It is up to you whether or not to take part. If you decide to take part you will be given this information sheet to keep and a consent form to sign. You will also be given a copy of the consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision not to take part, or to withdraw at any time, will not affect the care you receive in any way.

What would I have to do?

You would have to fill-in a questionnaire. The questionnaire should take approximately 45 minutes to complete, and would be at a time and place convenient for you. A small token of £10 will be provided to cover your expenses. The questionnaire is available in

both English and French, we can also usually provide access to translators for other languages if this is required.

If for any reason you do not want to complete the questionnaire, we would be grateful if you would give us permission to take some basic details from your patient records, that is your age, gender, country of birth, length of time in the UK, CD4 count and CDC stage. We would remove your name and any identification from this information before using it in our study. The reason we would like to collect this information is so that we can find out if the people who do not complete the questionnaire are similar to the people that do complete the questionnaire.

Will my taking part in this study be kept confidential?

Yes. All information will be kept strictly confidential. We will remove all identifying data, such as name, address or clinic number, so that you will not be recognised. We will keep all the information under lock and key at UCL. The completed questionnaires will be kept until all analyses are complete and then destroyed. We realise that some of the questions are very personal but your co-operation and help will be greatly appreciated. Any question that you really do not wish to answer, or feel unable to answer, can be missed out. All the information you provide will be extremely useful in developing better services.

If you have difficulty with any of the questions the clinic staff will be pleased to help you. If you would like to speak to someone about issues raised by this study please feel free to approach a health advisor, doctor, nurse or member of the research team.

What will happen to the results of the study?

The results will be shared with all the participating clinics, African communities and relevant organisations. Leaflets detailing the important findings and recommendations will be available in the clinic. They will also be written up for publication in journals. The first results should be available in January 2005, and final results by December 2005. If you are interested copies of the results will be available from the research team.

Who is organising and funding this research?

This research is funded by a Wellcome Training Fellowship grant. Dr Fiona Burns is the person responsible for the study and all the data. Ethical approval for this study has been attained from both the Multi-centre and your local Research Ethics Committee.

Thank you very much for taking the time to consider taking part in this study.

Contacts for further information:

Dr Fiona Burns Ph. 020 7387 9300 ext.8970

Version 3 11.11.03

SONHIA

Study Of Newly diagnosed HIV Infection amongst Africans in London

Information Sheet for In-depth Interviews

We are asking you to be involved in a research study to find out more about African people who are diagnosed with HIV in the UK and how we can improve health services for them. Before you take part it is important to understand why this work is being done. Please take the time to read the following information and discuss it with others if you wish. Please ask us if anything is unclear or you have any concerns. Take time to decide if you want to take part or not.

What is the purpose of the study?

HIV/AIDS is an important health problem among Britain's African communities. Africans with HIV tend to wait a long time before they seek help from the NHS. This often means they are too unwell to benefit from all the new treatments and services available for people with HIV. We know that earlier diagnosis and treatment helps people with HIV live longer and healthier lives, as well as help stop the spread of HIV. The aim of this study is to understand how we can improve opportunities for earlier diagnosis and treatment of HIV among Africans. Using this information in collaboration with African organisations we hope to develop a more effective and acceptable HIV prevention strategy.

Why have I been chosen?

The study is being undertaken at HIV treatment centres throughout London. All people born or raised in Africa and diagnosed HIV positive during the study period will be asked to participate in the study. We are hoping to get at least 40 people involved in this part of the study. Recruitment to this part of the study will run for 6 months beginning in February 2005.

Do I have to take part?

It is up to you whether or not to take part. If you decide to take part you will be given this information sheet to keep and a consent form to sign. You will also be given a copy of the consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision not to take part, or to withdraw at any time, will not affect the care you receive in any way.

What would I have to do?

It would involve an 'in-depth' interview with a qualified interviewer. The interview will be about you and your experiences and thoughts around HIV. The interviews

should normally take about 90 minutes. The interviews would be conducted at a time and place convenient to you. A token of £20 will be given to you to cover any expenses and in appreciation of the time the interviews take. All the interviews will be conducted in English. The interviews will also be tape-recorded and transcribed by qualified personnel. No identifying data, such as your name, will be kept with the transcripts and only people on the research team will have access to them. We record and transcribe the interviews to ensure we do not forget or miss important information that you tell us. The tapes will be destroyed as soon as all analyses are complete. If you really do not want to be tape-recorded you have the option to opt-out from this.

Will my taking part in this study be kept confidential?

Yes. All information will be kept strictly confidential. We will remove all identifying data, such as name, address or clinic number, so that you will not be recognised. We will keep all the information under lock and key at UCL. Data collected as part of this study will be kept for a maximum of 5 years or until all analyses are complete. We realise that some of the questions are very personal but your co-operation and help will be greatly appreciated. The information you provide will be extremely useful in developing better services.

If you have difficulty with any of the questions the clinic staff will be pleased to help you. If you would like to speak to someone about issues raised by this study please feel free to approach a health advisor, doctor, nurse or member of the research team.

What will happen to the results of the study?

The results will be shared with all the participating clinics, African communities and relevant organisations. Leaflets detailing the important findings and recommendations will be available in the clinic. They will also be written up for publication in journals. The first results should be available in November 2004, and final results by October 2005. If you are interested, copies of the results will be available from the research team.

Who is organising and funding this research?

This research is funded by a Wellcome Training Fellowship grant. Dr Fiona Burns is the person responsible for the study and all the data. Ethical approval for this study has been attained from both the Multi-centre and your local Research Ethics Committee.

Thank you very much for taking the time to consider taking part in this study.

Contacts for further information:

Dr Fiona Burns Ph. 020 7380 9300 ext. 8970

Appendix 6: Consent forms

Headed paper
Version 3 28/11/03

SONHIA

Study Of Newly diagnosed HIV Infection amongst Africans in London

Consent Form
Questionnaire

Patient unique serial number for this study (attach sticker):

Researchers: Dr Fiona Burns, Dr Kevin Fenton, Prof. James Nazroo, Prof. Anne Johnson

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that sections of my medical notes may be looked at by responsible individuals where it is relevant to my taking part in this study. These individuals would only access information which is relevant to this study. I give permission for these individuals to have access to my records.

I agree to take part in the above study

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Researcher	Date	Signature

I decline to take part in this study but I have no objection to the researchers collecting data about my age, gender, country of birth, time in the UK, CD4 count or CDC stage from my records, removing my name and identification from it before adding it to study data.
Agree/Disagree

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Researcher	Date	Signature

SONHIA

Study Of Newly diagnosed HIV Infection amongst Africans in London

In-depth Interviews

CONSENT FORM

Researchers: Dr Fiona Burns
Dr Kevin Fenton
Dr James Nazroo
Prof. Anne Johnson

Unique serial number for this study (attach sticker):

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I do / do not agree to the interview being tape-recorded and transcribed.

I agree to take part in the above study

Name of Patient	Date	Signature
Researcher	Date	Signature

Appendix 7: Quota matrix for in-depth interviews

Primary quotas

Age	Male	Female	Total
18-24	1-3	1-3	2-6
25-34	5-7	5-7	10-14
35-45	5-7	5-7	10-14
45+	5-7	5-7	10-14
Residence in UK			
<5 years	15-25		20-24
5+ years	15-25		20-24

Secondary quotas

Partnership	Male	Female	Total
Partner – not living together	5-8	5-8	10-16
Partner – living together	5-8	5-8	10-16
No current partner	5-8	5-8	10-16
Region of origin			
Lower prevalence (<5%) Northern Horn of Africa Benin Madagascar Chad Mali DR Congo (Zaire) Senegal Ghana Sudan	5-8	5-8	10-16
Higher prevalence (>15%) Namibia Botswana Zambia Zimbabwe Mozambique South Africa	5-8	5-8	10-16
Medium prevalence Ethiopia Nigeria Rep of Congo Burkina Faso Tanzania Uganda Cote d'Ivorie Kenya	5-8	5-8	10-16
Recruitment site			
Central London teaching	5-10		5-10
District General	5-10		5-10

Primary quota controls

Sex and age

Male 18-24
Female 18-24

Male 25-34
Female 25-34

Male 35 +
Female 35+

Residence

Under 5 years

5 years and over

Secondary quota controls

Partnership status

Male – single
Female – single

Male – Partner (co-habiting)
Female – Partner (co-habiting)

Male – Partner non co-habiting
Female- Partner non co-habiting

Region of Origin

Male - Lower prevalence
Female - Lower prevalence
Male - Higher prevalence
Female - Higher prevalence

Male -Increasing prevalence
Female -Increasing prevalence

Recruitment site

Central London teaching
District General

Appendix 8: Topic Guide for in-depth interviews

2. Introduction.

- This study, named 'SONHIA', is about how African people living in London view HIV, their experiences with health services and how this influences when people test for HIV. It is also hoped that it will help with understanding where and when African people in the UK are acquiring their HIV. Very little is currently known on this topic.
- This study will help determine the factors associated with late presentation of HIV disease so that in the future we can target resources to better meet the African communities health needs.
- Brief outline of interview

Explain: Timing (anticipating 90 minutes)
Confidentiality
Tape recording – not compulsory, obtain verbal consent (written consent already obtained)
Check if any questions before begin

8. Personal Circumstances.

Could we start by you telling me a bit about yourself?

- age
- who lives with respondent (relationship), children
- employment/ last occupation or other activities/and partners
- how long lived at current residence/ owned or rented

- Time spent living in the UK and other countries
  - How long lived in UK
  - Where born
  - Other countries lived/ went to school
  - Parents: occupation/ migration history
  - Siblings: ages/ differences in migration history

9. Personal and Community Attitudes.

Now I would like to ask you about what or who motivates you and important influences in your life.

- What do you hold most dear/important?
- What do you most fear?
- What, or who, provides your support network
- Who do you trust
- Your experiences of living in the UK – authority/ racism
- Role of religion – influence on illness; HIV testing; attitude of church to HIV
- Role of the African community – support; attitudes to HIV; how people react when someone diagnosed HIV positive; differences between the UK and home
- Immigration
  - Visa - issues outstanding/ attitudes of those encountered/ stress involved/ HIV status and immigration – influence on testing?
  - Solicitor/immigration advisor – experience/ advice given

10. Learning about HIV.

We have spoken a little about what influences and motivates you. Now I would like to focus on HIV and your experiences in learning about it.

- How first found out about HIV
  - Age
  - What learnt/discovered
  - Views and feelings at the time/of the experience

- What sort of things were learnt
  - Context
  - Timing
  - Most important
- Other sources of information on HIV/AIDS
- What was learnt about HIV/AIDS

- Influences on learning and attitudes about HIV
- Influence on attitude within your community by being an STD
- Who did you tell when you were diagnosed HIV positive
  - their response
  - attitudes and behaviours of people you told – family; friends; partner.

11. Awareness of HIV

There is a lot of attention on HIV in Africa. I am interested in knowing your views on how much awareness there is about HIV in your community here in the UK.

- Perception of risk amongst your friends; partners
- Experiences: own; partners; others
  - explore risk behaviours/practices
  - cultural practices that may help transmission
  - condom use, prevention measures
- Awareness of symptoms and signs of HIV prior to diagnosis.
- Sources of treatment
  - Knowledge of different places/services available/ who runs them
  - Awareness of sources of treatment/testing/advice and information
  - Experiences/past use
  - Preferences – testing; care (specialist; hospital; GP; other)

12. Health Services & Service History

Thinking about your own experiences with health services – both here in the UK and abroad - I would now like to find out about your perceptions of these services.

- Perception
- Access
- Referral process
- Utilisation of services prior to the UK
  - Prior hospitalisation – where/when/experience
  - Primary Health Care – experience/ referral process
  - HIV testing raised?
- Utilisation of Services within the UK
  - Prior hospitalisation – where/when/experience/maternity
  - Primary Health Care – experience/how long had GP in UK/referral process
  - HIV testing: issue raised / barriers to uptake
- Sexual health history – prior sexually transmitted infections, where treated.
- Testing - prior test/ why then/ experience/ peers

13. HIV Treatment options

There are various treatments now available for HIV. I would now like to focus on these. I'll start by asking have you ever heard of HAART or combination therapy?

- Understanding and awareness of HAART/combination therapy
  - ever heard of it prior to testing
  - what does it mean or suggest
- Extent to which treatment options have influenced HIV presentation
  - decision making – factor in testing decision
  - perception in the community
  - ante-natal
- Belief in and utilisation of other forms of therapies/healing: traditional; herbal; faith

14. Improvements to Services and Information

Finally I would like to get your opinion on how we can improve the services and information available on HIV and HIV testing

- Effective forms of encouragement – to test.
- Improvement to information available on HIV – form and content
- Improvement to Services available – type, location, availability.
- Who should be targeted – age, type required.

Thank interviewee – check if any questions or issues raised by interview.
Reassure re confidentiality
Provide contact details
Invite them to be sent summary of research findings and inform how the results of the study will be disseminated.

Appendix 9: Collaborators & key workers

The study of newly diagnosed HIV infection among Africans in London was possible due to the collaboration and generous assistance of the following people.

Archway Sexual Health Clinic	Dr Eva Jungmann Denise Thorburn Johanna Baruah Patricia Whyte
Central Middlesex Hospital	Dr Gary Brook Munyaradzi Chikohora
Charing Cross Hospital	Dr John Wright
Chelsea & Westminster Hospital	Dr Anton Pozniak Dr Ann Sullivan Richard Stack
Homerton University Hospital	Dr Jane Anderson Nicky Hickey Lorraine Muromba
Mortimer Market Centre	Dr Patrick French Nina Panahmand Elizabeth Kirkpatrick
Newham University Hospital	Dr Ade Fakoya Cheryl Tawana
North Middlesex Hospital	Dr Jonathan Ainsworth Anele Waters Fiona Young
St. Bartholomew's & Royal London Hospital	Dr Chloe Orkin James Hand Sarah Manney
St. Georges Hospital	Dr Tariq Sadiq Simone Ghosh
St. Mary's Hospital	Dr Harpal Lamba Andy Hughes
University College Hospital	Dr Rob Miller Peter McKenzie

Victoria Clinic	Dr Nneka Nwokolo Anthony Kerley
Watford District General Hospital	Dr Pat Munday Michelle Slinn