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The Padare Project

**Assessing health-related knowledge,
attitudes and behaviours of HIV-positive
Africans accessing services
in north central London**

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Executive Summary

HIV infections continue to rise in the UK, and are of particular concern within African communities resident in England. Various services run by the statutory and voluntary sector have been set up to help meet the increasing demand for HIV related support and care amongst this population. The boroughs of Camden and Islington in north central London are home to various support groups and informal support networks as well as community and statutory led HIV medical and social service providers. However, despite the epidemiological increase and development of HIV-related services in the district, there is relatively limited data on HIV-related knowledge, sexual attitudes and practices amongst Africans living with HIV in the boroughs, as indeed is the case in the UK. Similarly, their access to HIV-related services within the district remains relatively undocumented.

To help meet this need, Camden and Islington Health Authority funded the Padare Project. The aims of this project were to develop the methodology and collect preliminary data regarding HIV related knowledge, attitudes and practices (KAP) amongst HIV positive Africans accessing services in Camden and Islington. To assess the feasibility of collecting KAP data amongst this population, qualitative and quantitative methods were used in a synergistic fashion, allowing a Padare methodology to emerge in line with the real lives of HIV positive African and providers in the district. The Padare methodology was closely linked to user-consultation with HIV-positive Africans who played a key role in defining and developing the research questions and the eventual survey tool. The questionnaire covered various topics that included demographic information, HIV infection, service use, disclosure, discrimination, contraception and reproductive issues, sexual partnerships, and a range of questions regarding HIV related knowledge, beliefs and behaviours. Following a user-involvement model, the questionnaire was piloted on HIV positive Africans outside London, where they were given a chance to comment on the questions and their wording.

Two hundred and fourteen respondents were recruited over a three-month period in 2002. They were all recruited within statutory and community based services in or around Camden and Islington. There were more females (73%) than males (27%) who completed the survey questionnaire. The recruitment procedure may well have influenced this gender profile, as most respondents were recruited in mixed gender support groups or women only support groups. There were no men only support groups that were located in Camden and Islington.

The majority of the respondents were born in Zimbabwe, Uganda, Zambia and Congo. Although these communities were not specifically targeted in the recruitment process, the 1997-2000 Camden and Islington HIV Prevention Strategy did identify these same groups as in need of intensive health promotion interventions. Most of the respondents were aged between 25 and 39 years (74%), an age range that is clearly associated with relationship formation and childbearing, and hence HIV-specific issues around mother to child transmission. Only 21% reported a current residential post-code from within the boroughs of Camden and Islington, which supports the notion that services within the district are accessed by African community members from a wide range of London boroughs.

Most of the Padare respondents (89%) reported that their sexual partners were usually of the opposite sex (80% of men and 93% of women). The remaining 20% of the men reported same sex partners, with no men reporting both sexes. Of the women, 5% reported same sex partners with 2% reporting partners of both sexes.

Slightly over half (53%) reported having learnt of their HIV status within the last 2 years, whilst 28% had been diagnosed in the last 3-5 years, 9% in the last 6-7 years and 9% in the last ten years. They were accessing a range of services in the district that ranged from HIV clinics to social support.

Religious beliefs played an important part in adhering to HIV-related medication, more so for women (56%) than men (44%); however, 21% believed that prayer cured HIV whilst 13% were unsure whether this was the case. A quarter (26%) did not know whether one could be cured of HIV in the UK, whilst 20% were unsure about the meaning of *undetectable viral load*, and 17% were sure or at the best uncertain that *resistance* meant that they could not transmit HIV to their partner. Just under a third (30%) reported that they did not expect to use condoms forever. Almost half (40%) believed that it was difficult to use condoms with new sexual partners. Most respondents reported that they trusted health care professionals to provide information on living with HIV and preventing (re)infections; however, elders and peers were also identified as credible sources of such information.

Of the 74% who reported penetrative sex in the previous month, 40% reported either occasional or no condom use. Sixty-one percent reported having had unprotected sex with one or more partners in the previous year, whilst 33% had not used condoms with their most recent sexual partner.

The Padare project has shown that it is feasible to engage HIV positive Africans in the collection of data regarding their sexual attitudes, practices and access to HIV related services. Involving HIV positive Africans in the development and ownership of the project was important in sustaining the research process. The inter-borough movements in accessing HIV related services suggest that it is appropriate to conduct a pan-London or pan-England Padare project; respondents accessed services with minimum regard for their geographical locations.

The data from this study are preliminary and caution must be made when generalising across to all Africans living with HIV in London. However, a number of tentative conclusions can be made. HIV positive Africans accessing services in Camden & Islington report a number of significant primary and secondary risk behaviours; while these are in line with other samples of HIV positive people accessing services in the same area (e.g. gay men in the SHARP study), they are still of concern. They do appear to represent a reduction in some aspects of risk behaviour relative to community based samples of African people of unknown HIV status in central London (e.g. Mayisha study). However, they still represent levels of behaviour that place many of them and their sexual partners at risk of HIV/STI's. Similarly, the Padare data suggest small but significant inaccuracies in HIV related knowledge in this population.

On the basis of this data, it is recommended that a larger study be undertaken to assess the levels of HIV related knowledge, attitudes and behaviour, and that this be incorporated in to the national HIV Behavioural Surveillance programme. It is also recommended that prevention interventions be aimed at HIV service staff to help them ensure that HIV positive Africans are fully aware of the meaning of technical notions such as 'drug resistance' and 'undetectable viral load'. Peer interventions for youth, and interventions directed at community and religious leaders to help improve the accuracy of HIV related information held within older community members are also recommended

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Most of all we would like to thank all those participants who filled out the questionnaire, and through doing so, disclosed intimate aspects of their lives in the hope that this would result in better care and services for the African communities living with HIV in the UK. We thank you for time taken to complete the questionnaire as well as sharing your experiences at the Padare spaces.

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1 The aims of this report

The aim of this report is to identify risk factors associated with HIV transmission amongst a sample of HIV positive respondents from the African communities accessing HIV-related services in the London boroughs of Camden and Islington. To examine these risk factors, this report will:

- Map the inventory of HIV services targeting HIV positive Africans in Camden and Islington and service utilisation amongst the Padare respondents
- Describe the demographic characteristics of HIV positive respondents who took part in the Padare Study
- Examine their reported knowledge of HIV transmission
- Examine their reported sexual attitudes
- Map their reported sexual behaviours
- Explore the implications of the respondents' HIV related knowledge, attitudes and reported behaviours for health promotion
- Make recommendations based on the findings of the Padare study

2 Introduction

Demography of Africans in London

It is very difficult to define who qualifies to be called an African. The notion of 'Africa' raises images linked to a continent and its people. The word is used to refer to a group of people who identify themselves as 'African'. Within this report, 'African' is related to a sense of belonging that emanates from the complex interplay of 'place of birth', cultures, group and personal histories. Such interplay's contribute to the diversities and differences found amongst this population.

The total number of Africans in England and Wales remains relatively unknown as the 1991 census, which informed the demographic profile of this population is currently out of date. The profile of the London population is shown in Table 1 below:

Table 1: London population by ethnic group (1000's)

	1996	2001	2006	2011
Black Africans	272	313	361	402
Other	204	249	295	338
Other Asian	145	156	169	179
Chinese	66	71	75	79
Bangladesh	115	140	160	180
Pakistani	120	144	163	180
Indian	403	446	469	486
Black other	107	128	142	154
Black Caribbean	327	350	355	356
White	5,310	5,266	5,230	5,220

Source: Demographic Round 1999:

Key features of the London African population indicate that black Africans in 1996-2001 were the third largest ethnic group after those of Indian or black Caribbean ethnic groups. However, projections show that the African population in London is on the increase. In 2006, it is projected that black Africans would be the second largest ethnic group after those of Indian ethnicity. The implication of this population increase is that health care services may well notice a raise in the numbers of African clients accessing various services.

The Epidemiology of HIV and AIDS in the UK

According to the Communicable Disease Surveillance Centre, by the end of 2002 there were 49,477 people who had been cumulatively diagnosed with HIV in England and Wales; of those, 14,221 (29%) had been assumed to become infected through sex between men and women (CDSC, 2002). However, for the year 2001, 53% of all new infections were presumed to have occurred through sex between men and women. Of the 2,444 new diagnoses assumed to have occurred through heterosexual transmission in 2001, 71% were in people from Africa or were associated with exposure there. Of the 9,167 HIV infected people accessing treatment centres in the

UK in 2001 who were probably infected heterosexually, 24% were of white ethnicity; 62% were of black African ethnicity.

Other key points emerging from the epidemiology show that:

- The focus of HIV infections in England is in London
- There are reported increases of HIV amongst Africans outside London

In response to the increase in the reported HIV cases, a range of services have been developed. These include HIV clinics, registered community-based agencies and informal networks that offer social support to Africans affected by HIV and AIDS.

HIV-related services in north central London

In Camden and Islington, there is a spectrum of services currently on offer to Africans living with HIV and AIDS. These services include those provided by Social Services, the Primary Care Trust and Community-based organisations or self-help groups. These services range from the formal statutory services, the health care services, registered charities and informal networks. There are three main clinics offering HIV related services in Camden and Islington and these are the Mortimer Market Centre, the Archway Sexual Health Clinic and the Royal Free Hospital. The Mortimer Market Clinic and the Archway Sexual Health Clinic were the two clinics where the Padare respondents were recruited. The range of HIV-related services are summarised in Table 2.

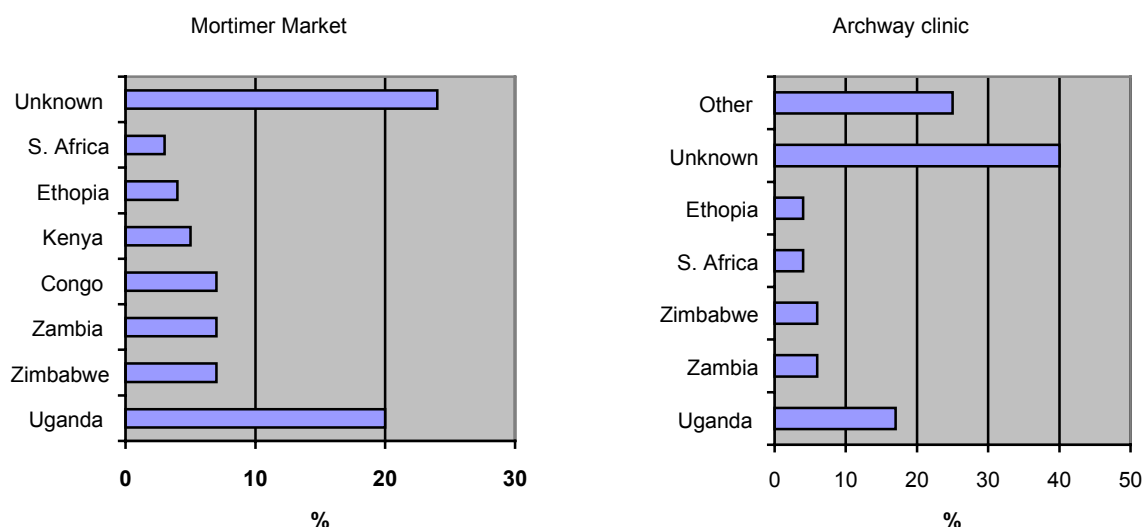
Table 2: HIV related services in Camden and Islington

Primary Care Trust/clinics	Voluntary	Social Services	Informal
Mortimer Market Centre	London Lighthouse	Islington Social Services HIV Team (iCARE)	Peers networking amongst themselves
Archway Sexual Health Clinic	Positively Women		
	Chalk Farm Oasis		
Royal Free Hospital	Simba Community Alliance	Camden Social Services HIV Team	
	Islington Zairian Refugee group		
	African Swahiliphone refugee Project		
	Chalk Farm		
	Ethiopian Health support Association		

Service Utilization: HIV and Sexual Health Clinics

The Mortimer Market Centre (MMC) and the Archway Sexual Health Clinic (ASHC) offer HIV and sexual health medical services. Data from the Mortimer Market Centre show that in September 2002, there were 291 African patients accessing services at that clinic. There were more females (n=185) than men (n=106). Africans (n=54) were also accessing services at the ASHC, with more females (n=34) than males (n=20). African clients accessing services at MMC and ASHC were born in various African countries as shown in Fig. 1.

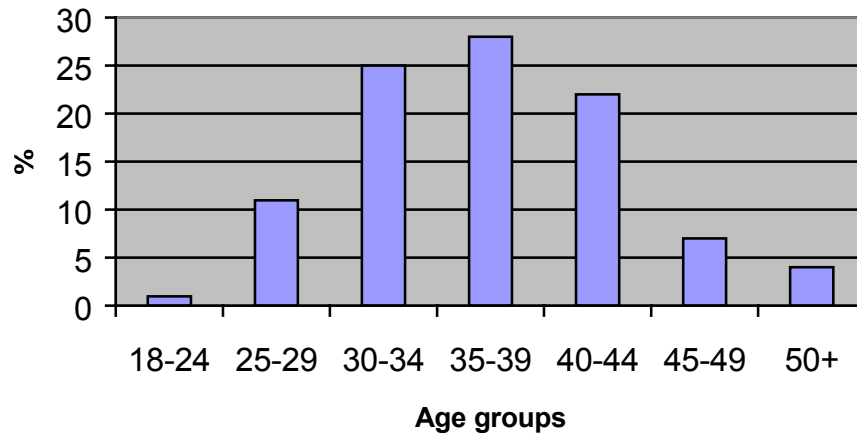
Fig 1: Nationality of Africans accessing services at the Mortimer Market and Archway Sexual Health HIV clinics



Most African clients accessing services in these clinics were aged between 30-39 years. Figure 2 provides an outline of the age profile of the African attendees at Mortimer Market and Archway clinic.

Most clients were between the ages of 35-39, followed by those aged between 30-34, 40-44, 25-29 and 45-49. Few were between the ages of 18-24 and above 50 years. This age profile has implications for health promotion initiatives: the age group of clients is predominantly comprised of people for whom sexual partnership and childbearing are important. This would suggest that health promotion targeting this population should be intensified as far as reducing the risk of re(infection) and/or mother to child HIV transmission.

Fig. 2: Age groups of African HIV clinic attenders at Mortimer Market and Archway Sexual Health



However, not much is known about the risk factors that place these Africans accessing services in the London boroughs of Camden and Islington at a greater risk of contracting HIV. The Mayisha project developed the methodology to access information on these risk factors using community based self-report behavioural surveillance methodology (Chinouya, Davidson and Fenton, 2000). The Padare project was developed to ascertain such information from HIV positive African people, using a community and clinic based research initiative exploring the sexual lifestyles of positive Africans accessing services in Camden and Islington.

The Padare Project

The word 'Padare' refers to traditional spaces where intimate issues, including sexual matters were discussed in a number of African cultures. All matters discussed at a 'padare' were confidential and were never to be discussed in a trivial fashion outside the Padare spaces. The word 'Padare' was as a way of recreating 'traditional' non-gendered spaces in industrialised setting for creative problem solving regarding sexual health matters and HIV in particular.. The ethos of the 'dare' (namely confidentiality and discussion of sexual health matters) led to the project being named 'Padare'. The name 'Padare' was appropriate, as 'tradition' is never frozen in time. The concept and ethos of the Padare was revisited in London and recreated as a non-gendered confidential space for sharing experiences of living with and being affected by HIV. People living with HIV were engaged in the study, sharing their experiences of living with the virus and giving them an opportunity to make recommendations regarding service delivery. This was in line with national policy documents and frameworks that encourage the concept of consumer involvement.

The Policy Frameworks

The first national sexual health strategy was developed around the principles of the National Health Service Plan (Department of Health, 2000). The National Health Service plan set out a sustained investment that aimed at improved efficiency, value for money as well as a more patient centred approach. Taking the principles of the National Health Services Plan, within the context of sexual health meant representation by key stakeholders in decision-making, partnership and narrowing the health [sexual] divide.

The sexual health strategy calls for a reduction in the rates of transmission of HIV and other sexually transmitted infections as well as the prevalence of undiagnosed HIV and other sexually transmitted infections (Department of Health, 2002).

In its National HIV and Sexual Health Strategy Implementation Action Plan (DOH, 2002), the Department of Health called for better support for people living with HIV as well as engagement of HIV positive people in the development of policy and services. In response to the National Sexual Health Strategy, the African HIV Prevention Framework (NAT, 2002) and the Social Care Frameworks (African HIV Policy Network, 2002) developed the African HIV prevention Framework. The HIV prevention framework calls for a sound evidence base for the effective HIV prevention interventions that would work towards the set national target of a 25% reduction in the rates of newly acquired infections by 2007.

Reviewed literature that informed the development of the African HIV prevention Framework (Chinouya and Reynolds, 2001) found major gaps regarding our ways of knowing about Africans affected by HIV and these gaps were:

- The sexual health promotion needs of HIV positive Africans are unknown and subsequently, there is a need to explore the sexual practices and HIV knowledge amongst this population.
- HIV is still a stigmatised condition amongst this population
- Poor clinical post-test monitoring
- Little is known about the disclosure patterns amongst this population
- Living with HIV cannot be dismissed from a social context that is marked by marginalisation, stigmatisation and racism

3 The Padare Methods

The Padare research methods were based around a user involvement model in the development of research tools (the survey questionnaire) and the research process (i.e. the recruitment of participants).

Aims and Objectives

The Padare project aimed to assess the feasibility of exploring HIV-related knowledge and sexual behaviours amongst black Africans living with the virus and accessing HIV-related services in the London boroughs of Camden and Islington. The primary objective of the project was to develop evidence-based interventions informed by the experiences of Africans accessing HIV-related services or resident in the boroughs. The specific objectives of the project were:

- To assess HIV-related knowledge, attitudes and practices (KAP) amongst this population
- To explore knowledge related to use of combination therapies and their understanding of medical terms (viral load, resistance)
- Disclosure of HIV status to sexual partners
- To collate and disseminate the methodology
- To make evidence based recommendations on how the sexual health promotion needs of HIV positive Africans accessing services in the London boroughs of Camden and Islington can be met

The Padare project was conducted in inter-related phases that included:

- Mapping HIV service providers
- Developing the questionnaire in close consultation with providers and service users
- The survey

The Padare Mapping Phase

The mapping exercise was important as it provided a framework of stakeholders namely the local providers and consumers of HIV-related services as well as the spectrum of services offered. The mapping phase informed the research process, as these stakeholders were essential in developing the survey questionnaire as well as informing the research process including the recruitment methods.

To help develop the mapping framework a list of HIV service providers and consumers in Camden and Islington was constructed using the local AIDS directory, AIDS newsletters and local undocumented networks. The directory of services, though exhaustive, however at times failed to capture the latest developments within the boroughs. Most of the latest development missed by written forms of communications included:

- New community-led projects or community groups that were set up after the documentation of the written materials about local services

- Social housing for Africans moved to the borough due to the Dispersal programme under the Immigration Act
- Informal support networks of people living with the virus

To fill in the gaps identified above, the researchers worked with local consumers and providers mapping these developments, with the stakeholder's narratives shaping the researcher's pathways into these 'new communities'. Taking on board the new communities and developments, a list of stakeholders from the statutory, voluntary and unregistered service providers were then constructed. The list was then categorised into the following:

- Advocacy services
- Drop-in services
- Complementary therapies
- Medical services
- Social services
- Support (groups) services
- Translation services
- Informal networks

Informed by this list, stakeholders were contacted, made aware of, and then encouraged to engage in the project. To get their 'voices' in the Padare processes, a steering group was set up.

The Padare Steering Group

From a list of stakeholders, a sample was drawn and used to set up a steering group. The steering group had ten members and included representatives from statutory services, community-based groups, academics, a person living with HIV, researchers and commissioners. The role of the steering group was to:

- Oversee the project and give expert guidance
- Help in developing the questionnaire
- Monitor and evaluate the research process

Other Padare Stakeholders and Partners

There were other people or Stakeholders who were key to the Padare project but were not part of the Steering group. These were also briefed and consulted to give commentary regarding the project, its aims and objectives as well as the methods used.

Briefing stakeholders took many forms to include telephone conversations, group discussions, site visits and informal conversations. It was also commonplace to use observational methods to assess the feasibility of introducing the Padare concept at various settings where HIV related services were provided.

Interestingly, most providers when contacted were aware of the Padare project, as they had been consulted before the research commenced. The Padare partners had been briefed about the project during the Camden and Islington health promotion forum meetings. Depending on the services they offered, providers suggested various ways they could be involved to include:

- Questionnaire development

- Recruitment and re(creating) the Padare concept in their premises
- Questionnaire distribution to people who dropped in to access their services

The Padare partners suggested that a Padare Survey questionnaire be developed and tabled for consultation. A framework of questions based on previous surveys was developed, with questions specific to the project added on.

Developing the Padare Survey Questionnaire

The questionnaire captured information on demographics, migratory history, service utilization, management of HIV, sexual practices and beliefs about sex, disclosure and child bearing. A French version of the questionnaire was also constructed.

Including stakeholders in the development of the questionnaire enabled them to have control of the type of questions that were asked and the use of a language that reflected their lives.

HIV positive Africans outside the research area were also asked to comment on the questions intensively. This allowed the questionnaire to be 'new' when presented to service users in the research area. The development of the questionnaire was cyclical, allowing questions, themes and language to emerge as the research progressed.

The Padare questionnaire was piloted with HIV positive Africans living outside London. There were key lessons learnt during the piloting phase and these included:

- It is feasible to pilot and develop a research tool (i.e. the questionnaire) with HIV positive Africans outside the focal research area .
- Africans identified with project name 'Padare' as they felt it captured the ethos of the project in particular confidentiality, talking about sexual matters as well as other intimate issues.
- Talking about sex appeared to be less stigmatised within Padare spaces
- The ethos of a Padare removed the 'strangeness' often associated with talking about sex in ungendered informal settings.
- Children were conspicuous by their absence from the Parade spaces.

These lessons were very important and taken on board throughout the research process.

The Padare Recruitment Process

Padare respondents were recruited in various settings that were informed by the social mapping exercise. These settings included support groups, sexual health clinics, The Padare 'walk in' space at iCARE, community-based agencies, drop-in centres and homes.

In general, African clients accessing services in Camden and Islington welcomed the opportunity to be involved in the Padare project. They felt the importance of including their experiences and views in service development.

Recruitment in Support Groups

Before recruitment commenced in support groups, it was very important to gain access from the support group workers. Aims and objectives of the project and the contents of the questionnaire were discussed with the workers. Support group workers informed members about the project and a date and time would be set when recruitment would take place.

People in support groups were generally keen to complete the questionnaire. Each member completed their own questionnaire and a French version of the questionnaire was made available for French speakers. Overall, most respondents were able to complete the questionnaire unaided. They were able to read and answer the questionnaire within thirty minutes and often reported that they had come to the group on that particular day to complete the questionnaire. Key lessons that emerged from the support group include:

- In support groups all the participants completed the questionnaire as the day was specially set aside for the project.
- Participants invested a lot in the token of appreciation. They often reported that the token of appreciation would go a long way to meet their daily needs.

The issue of geographical boundaries was of less importance to some of them. Though recruited in the London boroughs of Camden and Islington, some participants were not aware that they were accessing services in the London boroughs of Camden and Islington. They often asked the researcher '*what borough is this?*' Some also asked '*where is Camden and Islington?*'.

Recruiting in Clinics

Access to the clinic was negotiated with nurses and doctors. They often set the dates for recruitment to match with HIV clinic dates when African clients had appointments booked. In most cases the maximum number of clients booked in each clinic was usually less than ten.

Recruiting participants in clinics proved more time consuming and difficult, compared with support groups and community-based agencies. The recruitment had to 'fit in' with the daily clinic routines. The researcher had to be skillful and be able to 'fit into' this routine whilst at the same time be pro-active, diplomatic and sensitive in approaching clients.

Researchers field notes show that her observations indicate that compared with support group recruitment, there was limited time for completing the questionnaire and respondents were more concerned about confidentiality and appeared more distressed. When asked to comment on these observations, some medical professionals commented that in clinics, people have to face the reality of living with HIV. It is in clinic settings that respondents were informed about the ways they were responding to medical treatments with details of their prognosis discussed.

Clinic professionals often also assisted with the recruitment. This involved them approaching clients to take part in the study.

The Padare 'Walk in Space' at iCARE

A Padare 'walk-in' space was created at iCARE. This involved people coming to iCARE (where the project was based) on Thursday afternoons to complete the questionnaire. An advertisement of the Padare walk in space was placed in the iCARE newsletter. This newsletter was placed at the iCARE reception desk, and also sent to individual clients or support groups, clinics and community-based agencies targeting Islington African residents. Participants often came to the iCARE walk-in space with the advertisement. At times social workers based at iCARE told their clients about the project or presented their clients with the flyer advertising the Padare walk-in space.

Recruiting in Community-based Agencies

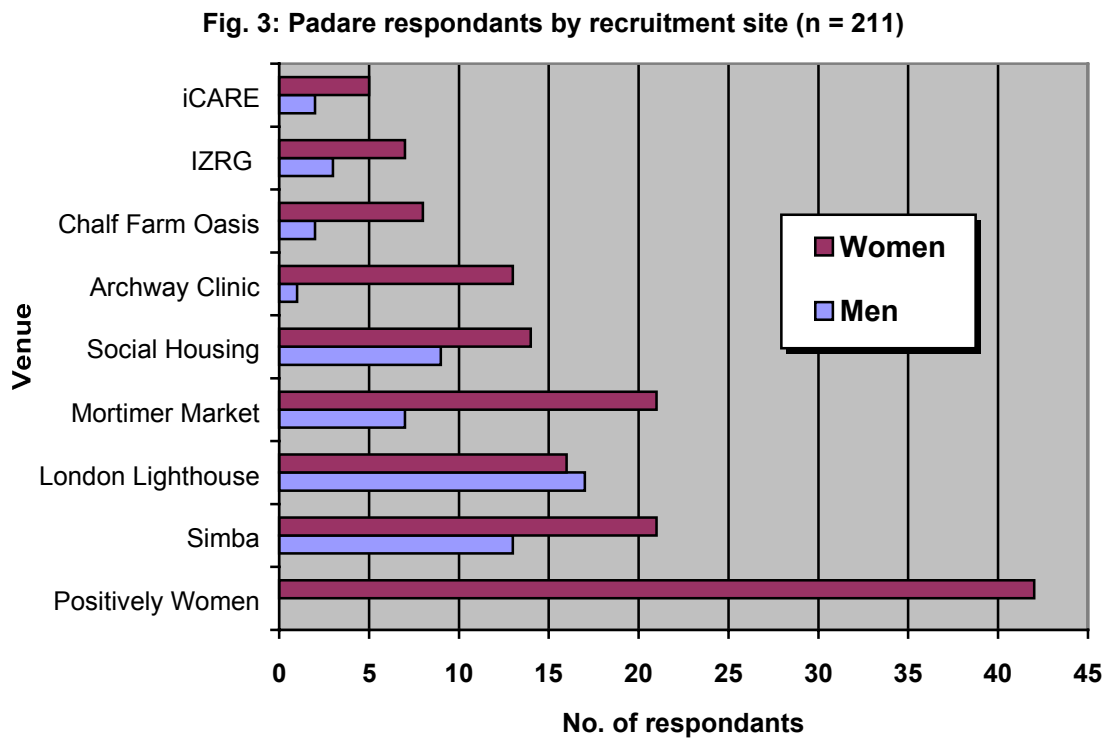
Five volunteers were involved in the distributing the Padare questionnaire in various community-based settings. The volunteer reported a range of experiences in recruiting participants. These experiences varied and were categorised into positive and negative experiences. These experiences are outlined in Table 3.

Table 3: Volunteer recruiter feedback from CBO recruitment

Positive comments	Negative comments
Questionnaire was straightforward	Questionnaire too long
Plain English easy to understand	Question were too 'personal'
The £10 token of appreciation was a good incentive	Stigma
The questionnaire made people reflect on their lives, identifying areas where they could have been at risk of transmitting or being re-infected by a sexually transmitted infections	At times the questionnaire evoked unpleasant memories

4 Results

Two hundred and fourteen men and women living with HIV agreed to participate and subsequently completed the Padare questionnaire (see appendix 1 for a copy of the questionnaire). The participants were recruited in HIV clinics, community based agencies, the Padare 'walk in space' at iCARE, support groups and social homes for people dispersed through the immigration and asylum Act. The number of respondents recruited from each site is shown in Figure 3.



There was a clear gender difference across the total sample, with more women (73%) than men (27%) completing the questionnaire. The recruitment sites may well explain the gender distribution of the Padare respondents. The majority of the women were recruited in support groups namely positively women, Simba Community Alliance, and the London Lighthouse. It was observed that more women than men attended these locations during the recruitment phase. Intuitively, the distribution of male and female respondents may well reflect the gender bias in accessing services or service development. More women than men are targeted for interventions in Camden and Islington. During the recruitment phase there were more 'women only' spaces (Positively Women, Chalk Farm Oasis) compared to those targeting African men living with HIV and/or AIDS.

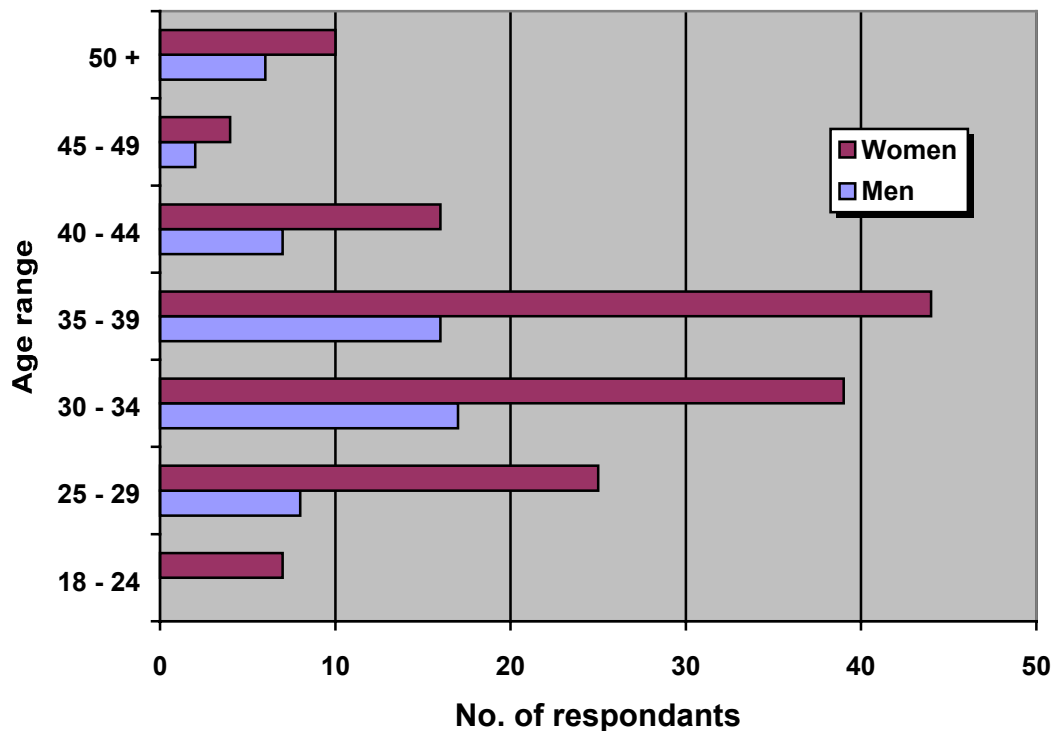
Residency

Respondents were asked about their residential postcodes so as to get a picture of the geographical distribution of African HIV service consumers in the boroughs. When asked to provide the first half of their postcode, only 21% of the Padare respondents reported a residency post-code that was within the Camden and Islington boroughs. A further 12% provided postcodes from within the Haringey and Hackney and Southwark, Lambeth and Lewisham boroughs. This could suggest that a pan-London approach might well be more appropriate in developing research methodologies targeting this population.

Age

Respondents were asked to indicate their age group. Results show that almost three-quarters (74%) of the respondents were aged between 25-39 years (Figure 4). Thirty percent of the respondents were aged between ages 35-39, 28% between 30-34 years, 17% between 25-29 years. Twelve percent were aged between 40-44 and 6% were 50 years or older. Few (2%) were 18-24 and 2% were between 45-59. Thirteen of the respondents did not respond to this question. Data shows that most of the Padare respondents were drawn from an age profile for which relationship formation and childbearing were part of an important aspect of their lives. This has important implications for mother to child transmission and indeed transmission between sexual partners.

Fig. 4: Age distribution of Padare respondents

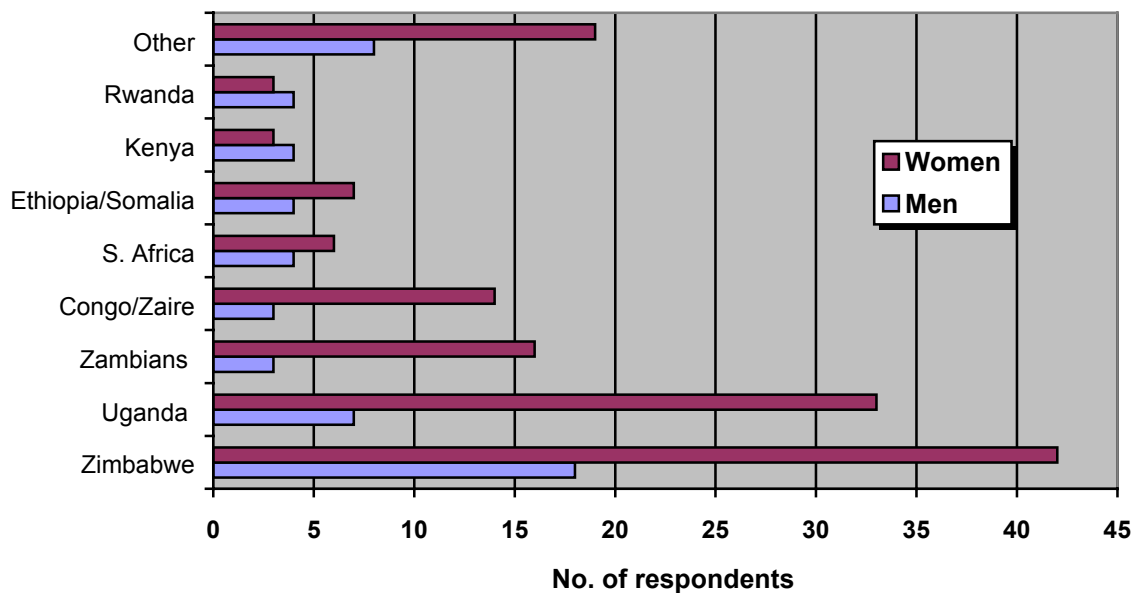


Country of Birth

The Padare respondents were asked 'in which country were you born?' Their answers show that the respondents were born in various African countries as shown in Figure 5.

The respondents were born in various African countries with the majority born in Zimbabwe followed by those from Uganda, Zambia, Congo and South Africa. The majority of the respondents' countries of birth coincide with the countries that have the highest HIV rates reported in the world.

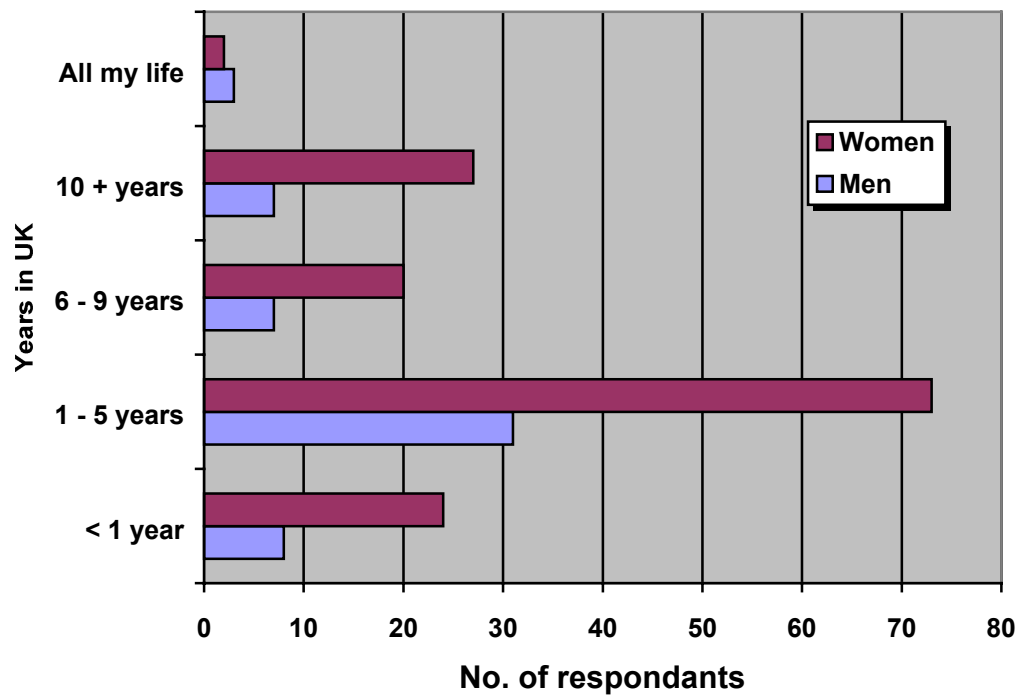
Fig. 5: Self-reported country of birth



Length of stay in the UK

Their length of stay was explored (see fig. 6). Results indicate that most of the Padare respondents (67%) had arrived in the UK in the last five years whilst 13% had been resident in the UK in the last 6-9 years, with 17% resident for ten years or more (Figure 6). A few (3%) were born in the UK. This indicates that Africans accessing services in the London boroughs of Camden and Islington were more likely to be drawn from the migrant population. Migrant communities are at greater risk of poor health and vulnerable to HIV/AIDS. This vulnerability is reflected among the Padare respondents' socio-economic circumstances in conjunction with living with a stigmatised condition.

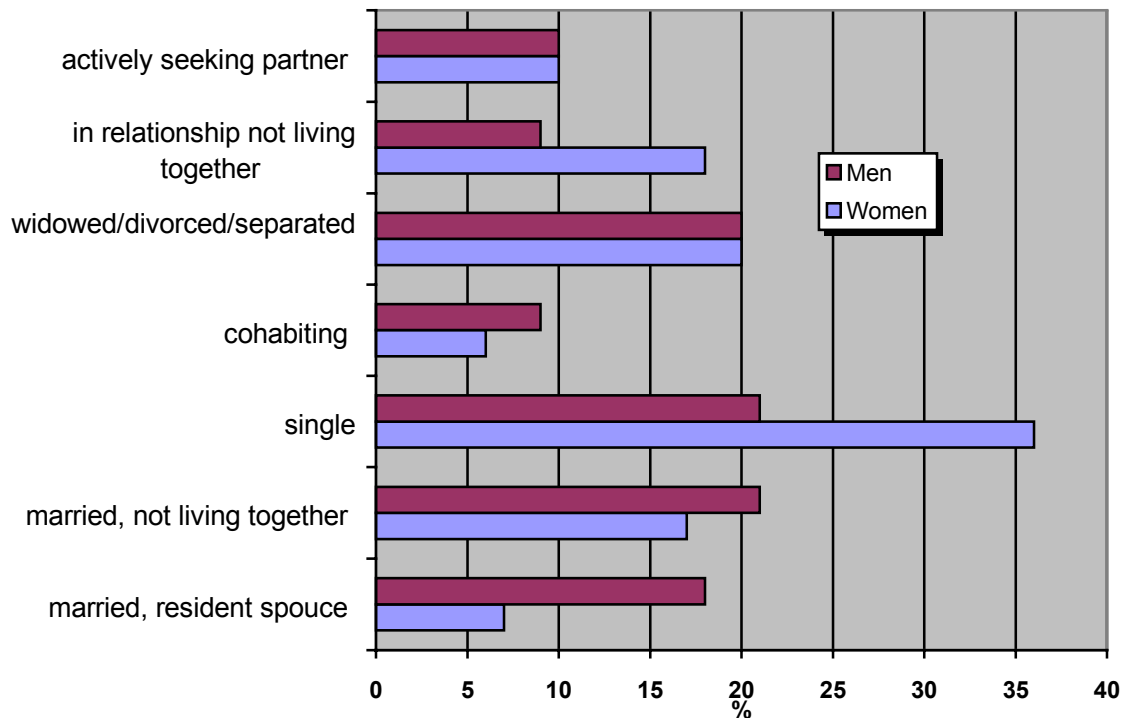
Fig. 6: Number of years living in UK



Relationship Status

Respondents were also asked their marital status and the results are shown in fig 7 . Padare respondents were more likely to be in a non co-habitant relationship. Thirty-six percent of the Padare female and 21% of the male respondents were single and had never been married, 20% of the females and 20% of the males were widowed/divorced/separated, whilst 17% of the female and 21% of the male respondents were married and their spouses were non-resident. Eighteen percent of the Padare females and males (9%) reported that they were actively seeking a partner. Fewer Padare respondents had a co-resident spouse as 7% (females) and 18% (males) were married and living together, or were cohabiting (6% females and 9% males).

Fig. 7: Relationship status of Padare respondents



Self perceived health

Respondents were asked how they perceived their health given their positive HIV diagnosis. Most respondents reported their health favourably with 77% of the male and 76% of the female respondents perceiving their health as 'excellent' or 'good'. Almost a quarter of the male (23%) and female respondents (24%) reported their health negatively (i.e. not so good or poor). This could also be reflective of the recruitment process as people who perceived their health favourably were more likely to have attended the social venues (e.g. support groups) where the respondents were recruited.

Religion

The Padare respondents belonged to a spectrum of denominations with the majority (65%) reporting that their religious beliefs were strong or moderate (30%). A few (5%) reported that they did not have any religious beliefs. These findings indicate that for most Padare respondents, religion played an important part in their lives.

Socio-economic circumstances

Most respondents had received some formal education with proportionately more women (10%) than men (5%) reporting primary/elementary education or secondary (women = 41% and men = 30%) as the highest achieved. Proportionately more male respondents (63%) than women (48%) reported college/university education as the highest achieved. Men (2%) and women (1%) reported 'Other' educational qualifications as the highest achieved.

Respondents were asked 'which of the following best describes what you were doing in the last 6 months?' and the results are tabulated in Table 4.

Table 4: Activities in the last 6 months

	Male respondents (%)	Female respondents %
Full time college	18	17
Full time employment	15	8
Unemployed and registered for benefits	42	39
Unemployed and not registered for benefits	14	18
Part-time employment	2	8
Unable to work (long term illness/disability)	9	10
Total (%)	100	100

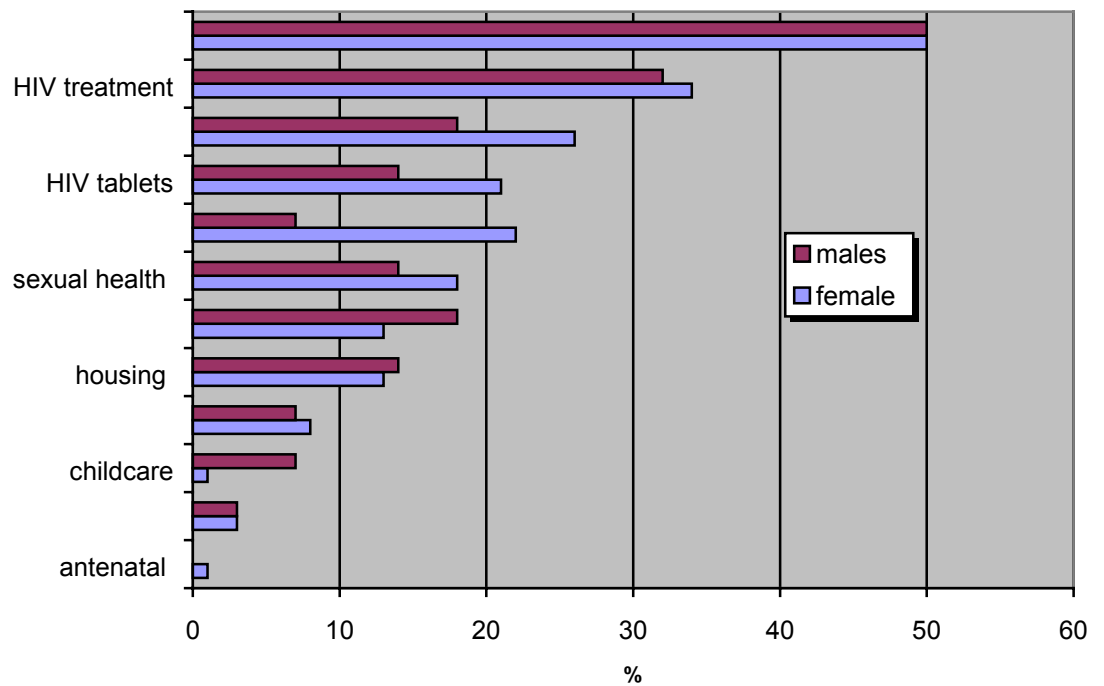
Most (42% males and 39% females) Padare respondents were registered for benefits, or studying (18% males and 17% females) in part-time employment (2% males and 8% females). Fourteen percent of the males and 18% females were unemployed and not registered for benefits. Some (9% males and 10% females) were unable to work due to an illness/disability. These findings suggest that despite their high educational levels, the Padare respondents had limited access to economic resources and poverty characterised their lives. Due to poverty and other pressing needs, the presence of HIV may be less prioritised.

Service Utilisation

Respondents were asked when they were diagnosed with HIV. More than half the sample (53%) had known their HIV status in the past two years whilst less than a third (28%) had known between 3-5 years ago. Ten percent had known their diagnosis between 6-7 years ago and 9% in the last ten years.

Respondents were asked 'what are you doing to manage HIV?'. Respondents used a wide range of strategies. At times these were in combination with other strategies and these included taking anti-HIV tablets (77%) or relying on nutrition (41%), religion (33%), complimentary therapies (31%), herbal medicines (4%) or traditional healers (1%). There were some (4%) who reported that they were doing nothing to manage the virus. These results show that the Padare respondents were active participants in the management of their health and used various strategies to manage the virus. Respondents were asked 'please tick the services that you are currently getting from Camden and Islington because of your HIV diagnosis?' The Padare respondents were accessing a range of services in Camden and Islington and their gendered distribution in accessing services is shown in Figure 8.

Fig. 8: Service utilisation by Padare respondents



There were gender variations in service utilisation. Though more women accessed antenatal services, more men reported the use of childcare services than women. Men were more likely to be accessing housing and dietary services than women.

When asked how long they had been accessing services, less than half (44%) had been accessing HIV-related services for longer than a year whilst almost a third (34%) had accessed the services for less than a year. Few (21%) reported that they had never accessed services in Camden and Islington. Some of the people who reported that they had never accessed services in Camden and Islington were recruited in Camden and Islington support groups but were not aware that they were within the district.

Disclosure

Respondents were asked “Have you told anyone about your HIV positive diagnosis?”, Of the 201 responses to this question, 79% of the men and 86% of the women said yes (79%). Respondents were further asked who they had told. Results showing the significant other who had been told of their positive diagnosis is shown (table 5)

The results above show that respondents were more likely to tell a professional person such as GP or social worker.

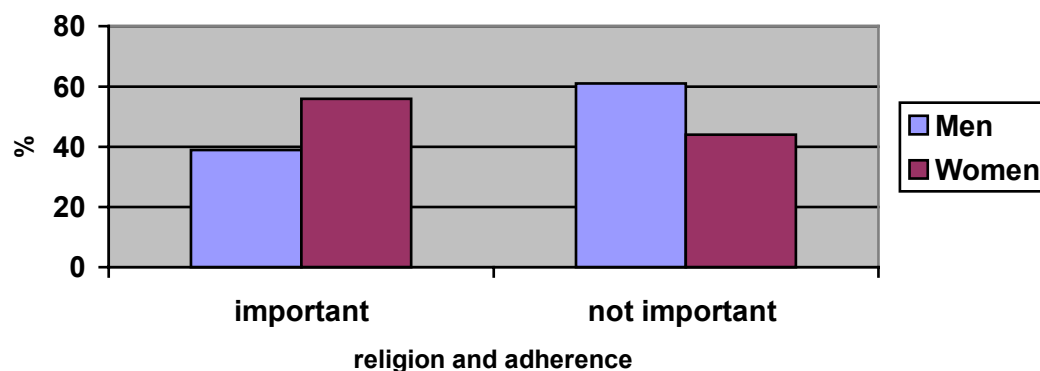
Table 5: Who has been told of their positive diagnosis

	Men (%)	Women (%)
Mother	27	34
Father	18	15
Brother	32	30
Sister	39	51
Partner	32	33
Friend(s)	45	47
GP	61	66
S/Worker	61	64
Kids	1	13
Others	5	7

Religion and adherence

As noted earlier in this report, religion played an important part in their lives. Respondents were also asked the importance of religion on adherence. The results are shown in Figure 9:

Fig. 9: Importance of religion to medication adherence



Religion was reported as important in taking the medication as prescribed. There were marked gender differences in reporting as more females (56%) than males (44%) reported that religion was important in taking the medication as prescribed. The implications of these results are important as health care workers may well need to be aware of the importance of religious beliefs on the lives of HIV positive Africans and be able to locate religious beliefs as an important variable in taking the medication as prescribed.

HIV-Related Knowledge

The Padare survey questionnaire also aimed at exploring the respondents' knowledge of HIV transmission, treatment and prevention issues. Respondents were given a set of

statements, which they had to agree or disagree with. Table 5 summarises the response from the Padare respondents.

Table 6: Padare summary responses to HIV-related knowledge questions

Statement	True %	False %	Don't know %
One can get cured of HIV in the UK	16	74	10
An undetectable viral load means I cannot pass HIV to someone else	8	80	12
A pregnant woman taking HIV tablets can effectively reduce the risk of passing on HIV to her unborn baby	75	10	15
Resistance means my partner cannot catch HIV from me	7	83	10
Prayer can cure HIV	21	66	13
Complimentary therapies can cure HIV	6	73	21

About a quarter (26%) of the Padare respondents were not sure if one could be cured of HIV in the UK as some (16%) believed that one could get cured of HIV whilst 10% did not know. A majority (75%) believed that one could not get cured of HIV in the UK. There were no marked gender differences in their levels of awareness as 15% of the men and women (16%) believed that one could get cured of HIV. Health promotion interventions need to build on this level of awareness regarding HIV treatment in the UK.

Some respondents (8%) thought that an 'undetectable viral load' meant that they could not pass HIV to anyone whilst 12% were not sure about the answer. A majority (80%) thought that the statement was false. There were some marked gender differences in their reporting as 10% of the women and 2% of the men believed that an undetectable viral load meant that they could not pass HIV to someone.

Fifteen percent of the Padare respondents did not know that a pregnant woman taking HIV tablets could effectively reduce the risk of passing on HIV to her unborn baby whilst 10% reported that this was not true. However the majority (75%) reported that a pregnant woman taking HIV tablets could effectively reduce the risk of passing on HIV to her unborn baby. These findings suggest that health promotion should continue to raise the levels of awareness regarding the risk of vertical transmission and the use antiretrovirals.

Seventeen percent of the Padare respondents were not certain of the implications of 'resistance' as 10% did not know the meaning of 'resistance', and whilst 7% believed that 'resistance' means that my partner cannot catch HIV from me. The majority (83%) of the respondents did not agree with the statement 'resistance means my partner cannot catch HIV from me'.

Although a majority of the Padare respondents (66%) did not believe that prayer cured HIV, almost a quarter (21%) believed that prayer cured HIV and 13% were not sure. There were slight gender differences in their beliefs as proportionately more women

(23%) than men (14%) believed that prayer could cure HIV and 13% of the women and 11% of the men were not sure.

Some respondents (21%) were not sure of the role of complementary therapies as a cure for HIV and others (6%) believed that complimentary cured HIV. Most (73%) respondents did not agree with the statement that complimentary therapies cured HIV.

Attitudes towards prevention

The Padare respondents were presented with a set of attitudinal statements to explore beliefs regarding condom use, disclosure and HIV. Table 7 captures some of the Padare respondents' reported beliefs regarding condom use, disclosure and HIV.

The beliefs regarding disclosure suggest that most (67%) of the Padare respondents believed that they expected someone to tell them about their HIV status whilst a few (15%) were not sure and 18% disagreed with the statement.

Further, more than half (55%) of the Padare respondents were not sure they would use condoms for ever, whilst less than a third (30%) agreed with this statement and 15% disagreed.

Nearly half the Padare respondents (40%) reported that it is difficult to use condoms with a new partner, (55%) were not sure and 5% did not agree with the statement.

Table 7: Summary of Padare respondents beliefs regarding HIV

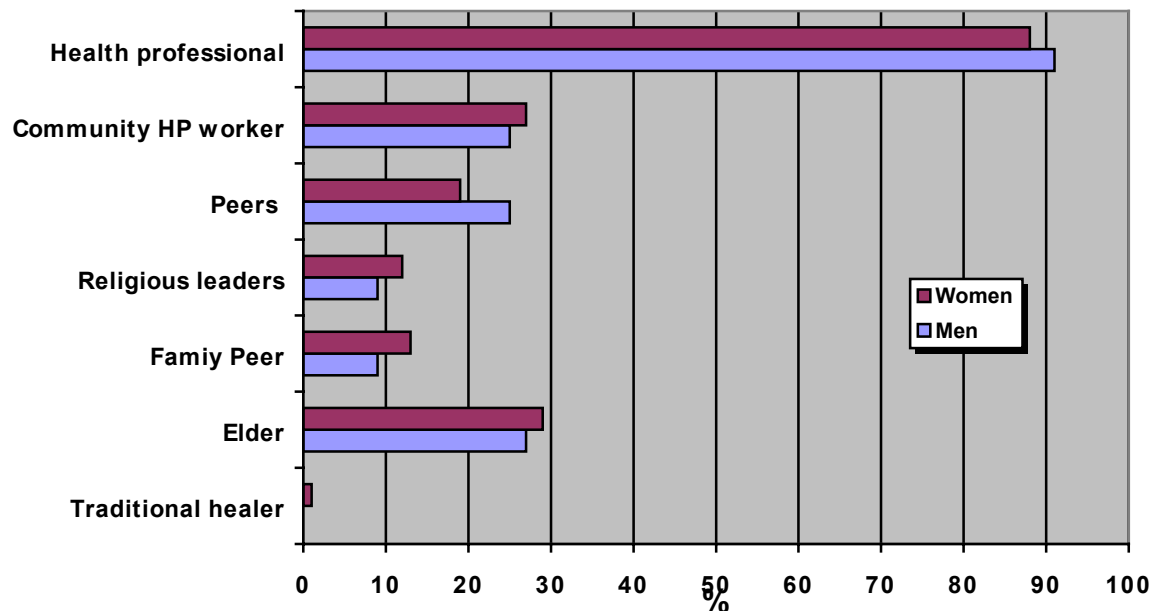
Statement	Agree (%)	Disagree (%)	Not Sure (%)
I'd expect someone to tell me their HIV status before we have sex	67	18	15
I'd expect to tell my partner about my diagnosis before we have sex	72	15	13
I don't expect to use condoms for ever	30	15	55
It is difficult to use condoms during sexual intercourse with new a partner.	40	5	54
Most people who are important to me do not think I should use condoms with new partners	12	5	82

Credible sources of information

The Padare respondents were also asked 'if you were to receive information from someone about HIV (how to live with HIV and how to protect yourself and others from HIV) which of the following would you trust most'. The respondents had a list of persons to select from and the results are shown in Fig. 10.

Health care professionals were the most trusted people to give health promotion information, then community health workers as well as peers. Slightly more women than men also reported religious leaders as most important in disseminating sexual health promotion information. Traditional healers were less trusted to give information. Similar proportions of people felt that elders, peers and community health promotion workers were a credible source of information

Fig. 10: Source of credible HIV health promotion



The implications of these findings are important, as health care workers (i.e. nurses and doctor) have to play a major role in imparting information regarding living with HIV as well as protecting others from the virus. The competency of nurses and doctors in Camden and Islington to take on this role in a systematic way is unknown and it may be that service providers may well need to build the health promoting capacity of their health care professionals.

Sexual Behaviour

This section of the report examines the respondents' reported sexual behaviour. In particular, the report examines sexual orientation, sexual partnerships, condoms use and pregnancy/reproduction.

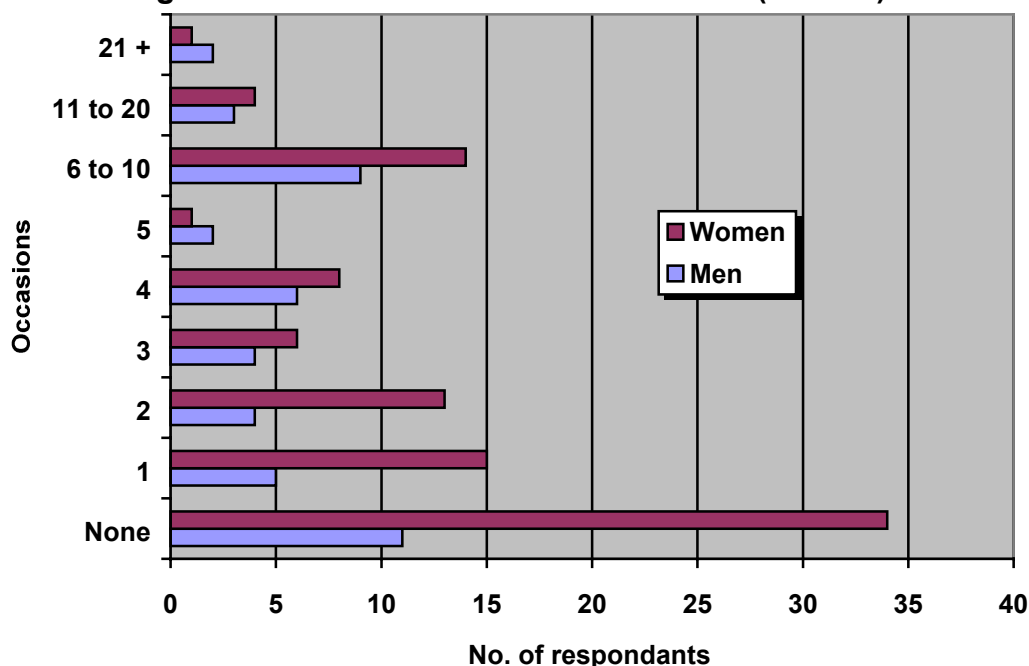
The Padare respondents were asked the biological sex of their sexual partners in the last year. Of the 178 who responded to this question, 89% reported that their sexual partners in the last year were of the opposite sex (80% of the men and 93% of the women). The remaining 20% of the men reported same sex partners, with no men reporting both sexes. Of the women, 5% reported same sex partners with 2% reporting partners of both sexes. These are important findings as the needs of homosexual and bisexual African men and women are unknown.

Respondents were then asked about their sexual behaviour over four different time spans; their most recent partner, partners in the previous 4 weeks, the previous six months, and the previous one-year.

Previous 4 weeks

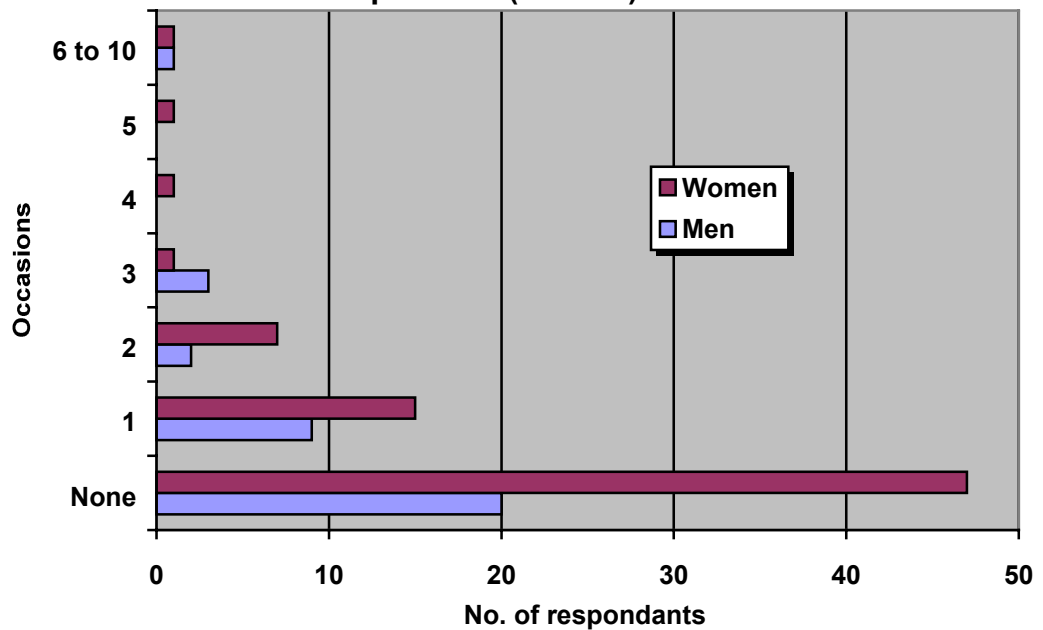
When asked on how many occasions in the last four weeks had they had sex (vaginal, anal or oral intercourse), of the 150 who responded (70%), 24% of the men and 35% of the women reported no occasions of sexual intercourse, with 11% of the men and 15% of the women reporting one occasion. The remaining 65% of the men reported sex on two or more occasions, with 50% of the women reporting sex on two or more occasions (see Fig. 11).

Fig. 11: Occasions of sex in last 4 weeks (n = 150)



When asked how many of these occasions of sex in the last four weeks were with a new sexual partner, 57% of the men and 64% of the women reported that none of these occasions was with a new partner, 26% of the men and 20% of the women reported that there was one new partner, 6% of the men and 9% of the women reported two new partners, with 11% of the men and 5% of the women reporting that they had sex over the previous 4 weeks with 3 or more new partners (Fig. 12)

Fig. 12: Occasions of sex in last 4 weeks with new partners (n = 112)

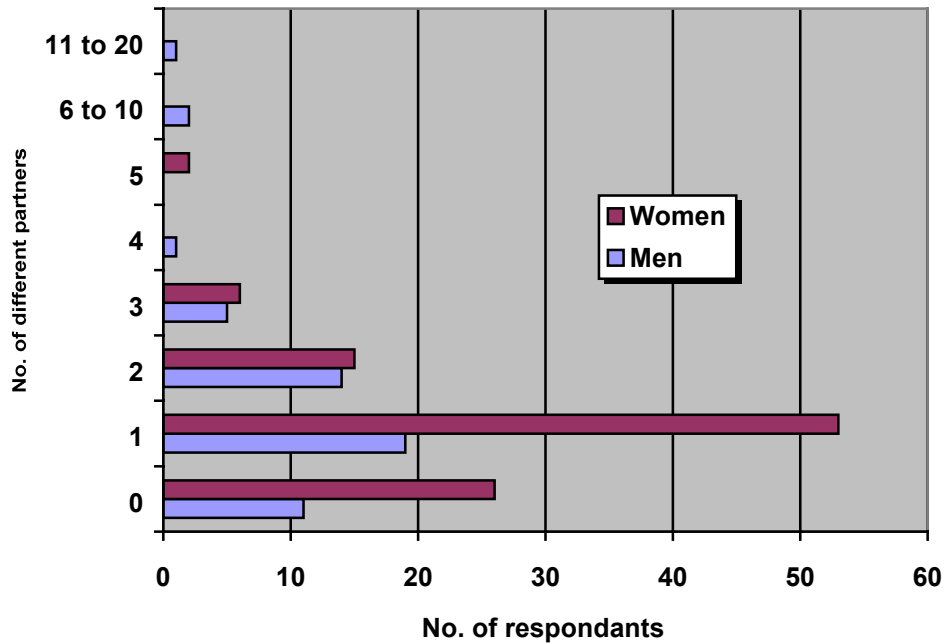


They were then asked if they had used condoms on any occasion when having sex in the last 4 weeks. A total of 176 responded to this question, with 45/176 (26%) reporting that they had not had sex in the previous 4 weeks. Of the remaining 131, 60% reported condom use on every occasion, 21% reported condom use on some occasions with 19% reporting no condom use on any occasion. Thus, 40% of the respondents reported occasional or no condom use if they had been sexually active in the previous 4 weeks; however, this dropped to 29% if you include all the people responding to this question, as 26% had not been sexually active.

Previous 6 months

When asked how many different partners they had had sexual intercourse with in the previous 6 months, 161/214 participants responded (75%). Of these, 21% of the men and 25% of the women reported that they had no partners, 36% of the men and 52% reported one partner, 26% of men and 9% of women reported two sexual partners, with 17% of men and 8% of women reporting 3 or more different sexual partners in the previous 6 months (Figure 13). When asked how many of these partners were new partners, of the 145/214 that responded, 44% of the men and 53% of the women reported that none of these were new partners, with 31% of the men and 34% of the women reporting that one of these partners was new.

Fig. 13: No. of different sexual partners in last 6 months



Respondents were asked how many of these partners in the previous 6 months were new; of the 145 people who responded to this question, 44% of the men and 53% of the women said that none of the partners in the previous 6 months were new, with 31% of the men and 34% of the women reporting that only one of those partners was new, and the remaining 25% of men and 13% of women reporting that two or more of those partners in the previous 6 months were new partners.

Last year

Respondents were asked if they had ever had sexual intercourse without using a condom in the last year. Of the 169 who responded to this question (79%), 37% of the men and 41% of the women reported that they had sexual intercourse without a condom. The remaining 61% of men and women reported that they had used condoms on all occasions in the past year.

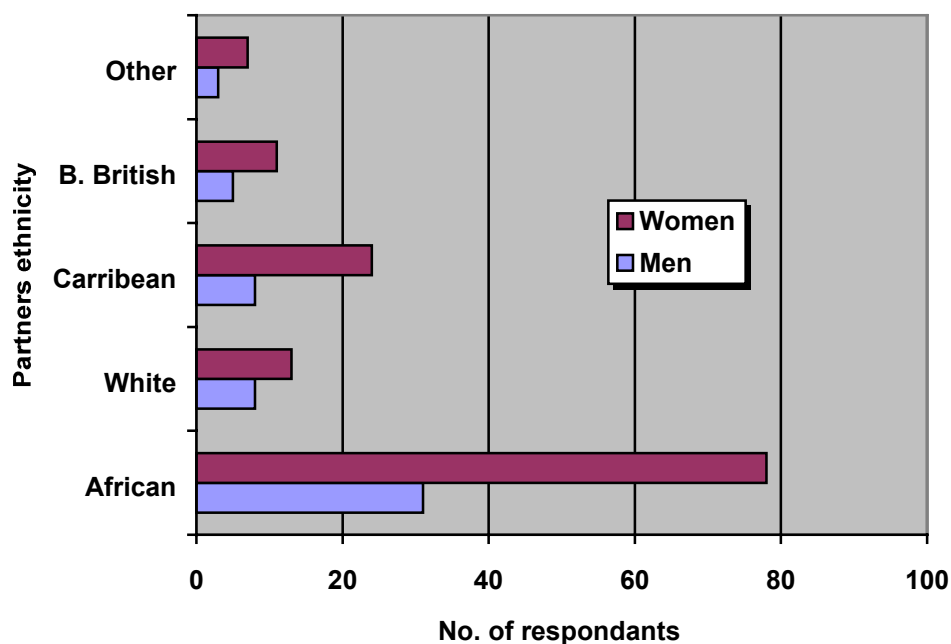
When asked with how many different partners they had sex with in the previous year without using a condom, 32% of the men and 42% of the women reported no condom use with one partner, and 30% of men and 19% of women reporting no condom use with two or more partners in the previous year. Approximately 40% of the men and women did not report unprotected sexual intercourse in the previous year.

Most recent partner

Respondents were further asked “thinking of your most recent partner: was a condom used on that most recent occasion?” Of the 184 who responded to this question (86%), 27% of the men and 35% of the women reported no condom use when last having sex. When asked if their most recent partner was a new partner, 29% of the men and 34%

of the women reported that it was the first occasion. When asked what kind of relationship they had with their most recent sexual partner, 22% of both men and women reported a casual relationship with that partner, with 29% of men and 22% of women reporting that they were married to their most recent sexual partner, and the remaining respondents reporting that their most recent sexual partner was their regular partner.

Fig. 14: Ethnicity of most recent sexual partner (n = 193)



Fifty-six percent of men and 59% of women reported that their most recent sexual partners were Black African, with 15% of men and 10% of women reporting that their most recent sexual partner was white, 15% of men and 18% of women reporting their most recent partner as Carribean, and 9% of men and 8% of women reporting that their most recent partner was Black British (Figure 14).

Reproduction and Pregnancy

Respondents were asked about pregnancy intentions and outcomes after their positive HIV diagnosis. Overall 6% of the respondents reported that they themselves had conceived or had made a woman pregnant since diagnosis. Padare male respondents (12%) were more likely to report having been involved in conception, with 4% of women reporting that they had become pregnant since the time of their diagnosis.

Respondents were also asked if they or their partners had had given birth since the time of their positive HIV diagnosis. Overall, 15% of the Padare respondents reported that they or their partners had given birth since the time of the diagnosis. Female Padare respondents (18%) were proportionately more likely to report having a baby since the time of diagnosis than their male counterparts (6%).

4 Discussion

The Padare Project aimed to develop a methodology for assessing sexual health risk factors in HIV-positive members of central London's African communities. It aimed to assess the feasibility of obtaining such information from both formal and informal statutory and community based organisations and structures, and in turn, to provide preliminary data that helps inform the Primary and Secondary prevention needs to service providers and the communities themselves.

The sample size of 214 represents participants from a number of different communities; it is difficult to generalise on the basis of such a heterogeneous sample. The findings however provide some initial indications of sexual behaviours and attitudes among this target group. Further work needs to be undertaken to validate the findings by comparing with other sexual behaviour surveys and through more detailed investigation.

The data collected and outlined in this report suggest significant levels of need in the HIV positive section of central London's African communities. The data suggest that there are small but significant gaps in HIV-related knowledge within this target population. It also suggests significant levels of sexual behaviour that places both the individual living with HIV and their sexual partners at risk of transmitting HIV and other STI's. In itself, this data suggests that greater efforts need to be made in addressing these needs. Before providing recommendations to this effect, it would be appropriate to place the current data in context and in to perspective relative to other target groups.

Comparison of Padare data with other target groups

Rates of sexual activity and sexual partnerships can also be compared to other relevant data. The Padare HIV positive African community sample indicated that 76% of men and 65% of women reported sex on one or more occasions in the previous 4 weeks, while the NATSAL 2000 data suggest that 72% of men and 76% of women from the general population had engaged in penetrative sex in the previous 4 weeks. The NATSAL general community data (n = 11,161) also suggest that the median number of occasions of sexual intercourse in the previous four weeks was 4 (99 PCT of 28) for both men and women (mean of 6.4 and 6.5 respectively). The SHARP data (n = 413) indicated that HIV positive gay men in central London have a median of 2 sexual partners over a four week period, although there was considerable variation in this aspect (range 0 – 55). Our Padare data suggest a median of 1 *new* sexual partner in the previous 4 weeks (range 0 – 36) for HIV positive Africans, but unfortunately we did not collect data for overall numbers of sexual partners (old and new) for this same time span.

Our data suggest that a significant number of people from London's African communities who are living with HIV, engage in sexual behaviour that is of significant risk to themselves and their sexual partners. However, the 27% of men and 35% of women from the Padare project who reported unprotected sexual intercourse with their most recent sexual partner, can be compared to the Mayisha sample that reported rates of 56% for men and 58% for women, drawn from a sample of 748 people of unknown HIV status from African communities accessing social venues in central London in 1999. While the Padare rates are of concern, they do nonetheless suggest a marked reduction in this indicator of risk behaviour compare to a general African community sample.

Similarly, the rates of unprotected penetrative sex with any partner over the previous 4 weeks of 29% for the Padare sample should be compared to the 1999 SHARP data which suggested that 21% of a sample of 260 HIV positive gay men in central London reported unprotected anal intercourse with a new partner in the previous month, while the 2000 NATSAL general population data suggested rates of inconsistent condom use over the previous 4 week period of 10% for women and 15% for men. It has always been the case that HIV and STI clinic attenders report rates of sexual risk taking activity higher than those from the general population. However, it would appear from our data that HIV positive Africans in central London do not engage in sexual behaviour that is significantly more at risk for themselves or others, compared to other HIV positive populations such as gay men. Rates of sexual risk behaviour need to be gathered from other target groups such as HIV positive heterosexuals from populations outside of African communities to further clarify this issue.

Results also indicate that at times Africans access services with limited understanding of the benefit of such services. Some believed complimentary therapies cured HIV. Health care providers may well need to position the meanings of 'complementary therapies' within the cultures of these populations, in particular their use of language.

Caution

A study of this nature may have many potential sources of bias, including selection bias (due to recruitment from social venues); participation bias (due to respondents reluctance or willingness to participate in a survey of this nature); and reporting bias (difficulties in reporting true behaviours due to memory or social acceptance). As the Padare sample was recruited from a mixture of venues, systematic differences may exist between those who attend these venues and those who did not (e.g. age and economic power). Further, the sample may be skewed towards respondents who were more open to talk about sexual matters. Respondents could also have been embarrassed by completing questionnaires on private matters (sexual lifestyles) in public venues thus biasing the sample to those who felt at ease to talk about sex, or leading to under reporting of risk or unconventional sexual lifestyles.

Caution should therefore be taken in generalising these findings to the overall population of HIV positive Africans living in London. The study participants were recruited in venues mostly visited by Africans who had connections with the London boroughs of Camden and Islington. Their attitudes and lifestyles may differ from other Africans who chose not to attend these venues or have no connections with the boroughs.

5 Recommendations

The Padare project aimed to collect KAP data amongst a sample of HIV positive Africans accessing services in the London boroughs of Camden and Islington. The feasibility of collecting this information was also to be assessed. This section of the report outlines the implications of some of the key findings in relation to health promotion and future work.

Recommendation 1: *It is recommended that the Padare data be further analysed, especially in the light of the UK census data and the NATSAL ethnicity data, both of which are soon to be released.* The Padare data needs to be placed in to context relative to how representative the participants were of London's African communities, and relative to nation-wide community based sexual behaviour data for all African communities obtained through NATSAL.

Recommendation 2: *It is recommended that a pan-London or England-wide Padare Project be carried out.* The Padare project has shown that it is feasible to conduct a sexual behavioural study with HIV positive Africans accessing services in two London boroughs. The blurred geographical boundaries in accessing HIV related services indicate that African clients access services with minimum regard of these boundaries. A larger study should be undertaken to assess the levels of HIV related knowledge, attitudes and behaviour across all of the areas in the UK where significant African communities reside, and that this be incorporated in to the national HIV Behavioural Surveillance programme.

Recommendation 3: *It is recommended that a collaborative approach be further developed to conduct such a project.* People living with HIV, service providers and researchers need to work collaboratively in developing and designing the research process and the eventual tools. Importantly, people living with HIV should feel that the research is of benefit in the short and long term. Service providers are also key to the research process. It was through collaborative work with service providers that access to this population was made possible. The research capacity of service providers should be built upon.

Recommendation 4: *It is recommended that particular note be made of the role of religion and religious leaders in influencing African community knowledge and attitudes regarding HIV and its management.* The Padare respondents were active participants in the management of their health and they bring along various complex issues that affect their interpretations of medical care. Religion played a major factor in adherence to medical prescriptions. Health care professionals need to be aware of this important fact; more research is needed to explore the ways in which religion may play a positive role in health behaviour. However, more health promotion work and education needs to be invested in understanding the relationship between prayer and HIV cure. The role of religious and community leaders in health promotion is vital within sub-groups of HIV infected African communities. It is recommended that specific resources be allocated towards a system for supporting such leaders in providing clear and accurate information regarding HIV and its treatment

Recommendation 5: *It is recommended that service providers be made aware of potential confusion around concepts such as 'resistance' and 'undetectable viral load', and take care when explaining such issues to HIV positive Africans.* It is clear that clinicians need to be very careful when discussing issues such as resistance and undetectable viral load. Specific training around this issue is recommended.

Recommendation 6: *It is recommended that health promotion service providers review their prevention programmes and increasingly incorporate factors relevant to members of the African communities who are already living with HIV.* Health promotion interventions in Camden and Islington have used models that include condom distribution in various settings. However, the Padare data suggest that condom use involves much more than making condoms available, and health promotion may well need to invest more on interventions that deal with personal risk assessment and changing attitudes

Recommendation 7: *It is recommended that peer interventions be aimed at younger members of the African community who are HIV positive.* Preliminary analysis of the Padare data suggest that there are a sub-group of HIV positive Africans who consider their peers as the most credible source of information regarding primary and secondary prevention. The use of contemporary music, dance and theatre need to be explored as effective vectors for conveying health promotion messages

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6 Appendices