

VOICES FOR THE FUTURE

A report by
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Needs Assessment of black and
Minority Ethnic Communities in
Brighton & Hove East Sussex in
relation to sexual health and
HIV/AIDS

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1. Executive Summary

This report provides findings and recommendations based on needs assessment and gap analysis of HIV prevention, support, treatment and care services for people from Black and Minority Ethnic Communities. The project itself started in July 2002 and ended in June 2003. Qualitative method was mainly used in the process of data collection and analysis.

The main goals of this research were: (a) to identify the health service needs of Black and Minority Ethnic Communities in relation to HIV/AIDS; (b) to determine the gaps in prevention, treatment and care services by conducting a literature review, and collecting qualitative data focused on perceived utility and appropriateness of existing services from service providers and HIV affected clients; (c) compile a summary report and recommendations and feed recommendations back into the community; and (d) develop a package of recommended resources around HIV and undertake awareness raising training with the communities and HIV organisations.

What follows are some of the key findings and recommendations from the survey.

HIV service users - people living with HIV

Key findings

- The overall finding is that the unmet need and unmet demand is not that huge.
- With the exception of the large unmet need of receiving advice in the filling and monitoring their asylum applications, of having more family oriented drop in centre specifically for minority ethnic communities, and culturally appropriate emotional support and a link worker who identifies with them, other gaps are small.
- The difference between what services are perceived to be needed and what services are asked for (“articulated need”) indicates a gap between what people believe they need and their expectation of receiving a service. They may not ask because they do not know or perceive they are ineligible, feel that they have no access, or do not know who to ask in order to obtain the service.
- There is a lack of peer advice or information sharing for people from these communities living with HIV. All advice and support is mainly from professional health workers.
- Individuals’ fears regarding confidentiality are particularly strong when they have not yet trusted the service provider. But as soon as they win the trust of the service provider, this fear is reduced.
- Some of the people living with HIV do not utilise the services provided by AIDS service organisations. Some of these individuals do not feel comfortable with particular organisations because of their principal client populations.

- Services from treatment and care providers seem to be more appreciated by the users than compared to prevention and support. At least they gave more positive feedback about these services. Their narratives were also most likely to correspond with the service provider's responses.

Key recommendations

- There should be clear and simple information on all available services for HIV positive people from the Black and Minority Ethnic Communities.
- Since the number of people from Black and Minority Ethnic Communities being diagnosed HIV positive is on the increase, support services specifically tailored for these communities should be in place.
- A trained and experienced part-time or full-time support/link worker (particularly someone from the communities or anyone who has a proven long-term experience of working with the communities on issues around HIV) should be employed. This post could be hosted by one HIV agency and undertake to liaise with other agencies on matters of Black and Minority Ethnic Communities.
- There should be more attention paid to the vulnerability of asylum seekers and refugees living with HIV. It is often so that asylum seekers living with HIV do lose sense of direction due to their inability to manage with the problem of being asylum seekers and HIV positive at the same time.
- There should be more contact with key workers such as nurses and support workers, from areas where there are large Black and Minority Ethnic Communities, particularly in London.

HIV Knowledge and Awareness - individuals and community groups

Key findings

- There is evidence to suggest that people from Black and Minority Ethnic Communities have some knowledge of HIV. But this knowledge was acquired prior to their arrival in the UK.
- They do not have up to date information about HIV simply because there is not well co-ordinated prevention outreach work being undertaken in Black and Minority Ethnic Communities.
- Access to appropriate sexual health and HIV services by Black and Minority Ethnic Communities is very low, thus the need for more appropriate information dissemination techniques.
- Language could be a problem in accessing services, but does not appear to be an issue that requires urgent attention. This is because most of the respondents prefer receiving information in English.
- There is no existing agency that has tailored their service to meet the needs of Black and Minority Ethnic Communities in terms of using a potential worker from the Black and Minority Ethnic Communities.
- People from Black and Minority Ethnic Communities prefer seeing their GPs rather than any other health agency for issues related to sexual health and HIV.

Key recommendations

- While individuals and community groups in this study have varying degrees of general knowledge about HIV/AIDS, their lifestyle and sexual behaviour still has to be studied in order to have a holistic idea of targeted prevention work.
- Black and Minority Ethnic Community based organisations (which already have rich networks within the community), that are interested in providing culturally specific HIV information and education should be supported and funded to do so.
- General Practitioners could take a cue from this finding and broach the subject with their patients, since from this study GPs are those most likely to be approached by these communities on issues around sexual health and HIV.
- There should be more seminars, forum, workshops, etc designed and offered to every ethnic community group/entity (Community Experts, Community Leaders, Student Group Leaders, Community Providers, etc.) with the intention of supporting and facilitating positive behavioural change. These should be varied, targeted and tailored to the intended audience group and cover a range of topics relating to HIV/AIDS.

Service providers – HIV and general service agencies

Key findings

- HIV serving agencies in the area of study are experienced and committed to providing standard services to all clients. However, many have not received appropriate training on understanding and tailoring services to Black and Minority Ethnic Communities.
- Most of the HIV agencies liase very well with others. This is clearly shown in their common views to service provision.
- None of these agencies is vigorously working in collaborative partnership with any community groups or organisation from the Black and Minority Ethnic Communities on service development.
- Collaborative partnership with agencies working on immigration and asylum issues is needed.
- Most of the staff working in HIV serving agencies is white.
- There is no clear mechanism for assessing the impact of their prevention work among Black and Minority Ethnic Communities.

Key recommendations

- More funding must be made available from the local authorities for a concerted, focused, community-involved campaign using effective methods to get basic, accurate and consistent HIV/AIDS prevention, care and treatment information to Ethnic Minority Communities in Brighton, Hove and East Sussex.
- Clearer mechanisms for monitoring number and ethnicity of clients, particularly for the GPs is needed. This will enable a sensitive approach to service development
- There should be cultural awareness training for AIDS service organisations staff. This must be backed up with great desire to put the

outcome of the training into practice; one service provider commented on her own change of attitude when she learned where and from what circumstances people were coming.

- Providers should develop an appropriate style of emotional support that is not based on a western style of counselling. Most Africans usually do not want to talk about how they are feeling. They want to know in what way they are practically supported. This view was held by the service users and agreed on by service providers.
- Providers should recruit more staff and volunteers from the Black and Minority Ethnic Communities.

2. Introduction

Brighton & Hove and East Sussex has about 1000 people living with HIV, and a large number of this population are gay men. Recent statistics are showing an increase in numbers of persons from Black and Minority Ethnic Communities diagnosed with HIV and accessing HIV services. Although many of these services have been developed to respond to all HIV related cases, these services have developed predominantly in relation to access of gay men as main client group.

This report hopes to raise the level of awareness of Black and Minority Ethnic Communities on issues around sexual health and HIV and the services provided in these areas; to identify the gaps in the services provided for people from these communities who are living with HIV; to provide information to health care providers on how they can better serve these communities; and to raise awareness of the Black and Minority Ethnic Communities and of the ways their ethnic minority status impacts on their health and the receipt of health care and support.

In reading this report, you will find out that the design of the needs assessment and the basis for arguments for action are not based on traditional statistical data collection and analysis. This does not mean to undervalue statistical data collection and analysis. In fact the absence of clear statistical data on Black and Minority Ethnic Communities in Brighton & Hove and East Sussex prior to the research seems to suggest that the issue of health and other needs have not received adequate attention by the health care providers.

It is also important to note that this report does not in any way claim to represent the views and needs of all the Black and Minority Ethnic Communities living with or affect by HIV. However, the voices and experiences of all respondents who participated in this assessment are duly represented.

This report will, in a simple and readable form, present the beliefs and experiences of the individuals and communities of Black and Ethnic Minorities around HIV and also the views of the service providers. Chapters 3-6 in this report will give us full details of the aim and objectives, demography, and method engaged in data collection and analysis. Chapter 7 will deal with the issues of knowledge and awareness of HIV and outlining the views of the individuals and communities. Chapter 8 will focus on the views of service providers, while chapter 9 will be dedicated to the views of people living with HIV about ease of access to services. Each of the last three chapters has a conclusion, key findings and recommendations. Chapter 10 finally concludes the whole report.

2.2 Literature review

This review is based on published literature, electronically published data, public documents and 'grey' literature. It covers HIV related projects among Blacks and Ethnic minorities from the period 1995 to 2002.

Some of the literature is gathered from the University of Sussex Library, Brighton and Hove Primary Care Trust Health Promotion Library, Camden and Islington Library, King's Fund Library, National Centre for Social Research, Medical Foundation for Aids and Sexual Health, London Enfield and Haringey Health Authority, National AIDS Trust, Sigma Research.

In order to access the grey literature, calls and visits were made to various agencies, mainly outside the Brighton area, most of whom were African HIV agencies in London. These agencies included Positively Women, Positive Futures, Lewisham on Line, London HIV Strategy Group, Slough Primary Care Trust (African Team), Ugandan HIV Community Organisation, African HIV Policy Network, UBUNTU (an African community initiative consultant agency), Zion Community Health and Resource Centre (African team), Manchester, African Community Involvement Association, London, HIV/AIDS Association of Zambia etc.

Other information used in this review was gained from attending different seminars, like "Asylum Seekers; Human Rights Day", "Seminar Day of the African HIV Research Forum", "African Men Seminar" etc. Much information was gleaned from the papers presented in these seminars. ***(Please see the appendix for the full literature review, which will be found separate from this report)***

2.3 Key issues learned from the review

Eighteen reports were reviewed, and each provided me with insight into different projects, achievements and the unmet gaps in services provided around HIV and sexual health for people from Black and Minority Ethnic Communities, particularly from sub-Saharan Africa. The full review report is found in the appendix. But here are some relevant issues learned from the review.

- Data from the UK epidemiology shows that HIV has disproportionately affected people from minority ethnic backgrounds, and Black Africans were highly affected.
- Issue of primary HIV prevention was predominantly addressed in most literature.
- Studies on treatment, care and support for people from Black and Ethnic minority groups were limited, and usually treated as a sub-topic, as was information on groups other than Sub-Saharan Africans.

- Issues around men who have sex with men from these communities, particularly black men, were less discussed in the literature, but are becoming a very important topic in HIV studies.
- Most literature pointed out that not enough prevention work has been designed to reach the heterosexual African men. There has been less support from the statutory and voluntary sectors on this matter.
- Community involvement in planning and implementing HIV services were seen as lacking in the literature

3. Aim and Objective of the Project

This project is designed to assess the needs of Black and Ethnic Minority Groups in Brighton & Hove and East Sussex with regard to HIV and sexual health. The major objectives of this project are: (a) to identify the health service needs of Black and Minority Ethnic Communities in relation to HIV/AIDS; (b) to determine the gaps in prevention, treatment and care services by conducting a literature review, and collecting qualitative data focused on perceived utility and appropriateness of existing services from service providers and HIV affected clients; (c) compile a summary report and recommendations and feed recommendations back into the community; and (d) develop a package of recommended resources around HIV and undertake awareness raising training with the communities and HIV organisations.

4. Brief Look at Ethnicity

The largest ethnic group in Brighton and the whole of East Sussex is white. In Brighton & Hove, whites constitute about 94.3% of the whole population. This is higher than the national average, using which is 90.92% in England and Wales, but slightly below the South East average of 95.1%. Eighty-eight percent of the population of Brighton & Hove stated that they are white British, while 1.6% stated that they are Irish, and 4.6% described themselves as other white. (Office of National Statistics, Census 2001)

A recent census shows that the population of non whites in Brighton & Hove has almost doubled since 1991. Currently, non-whites constitute about 5.8% of the total population of Brighton and Hove. A break down in percentage of the population in terms of the non-whites shows that people of mixed parentage are 1.9%, Asian or Asian British 1.8%, Black or Black British 0.76%, Chinese 0.53%, and other 0.68%. (Office of National Statistics, Census 2001)

5. Premise on Which the Project is Based

The project is based on the premise that the number of HIV positive people from Black and Minority Ethnic Communities is increasing in this area, and this has led to more people from these groups seeking access to services for HIV positive people within the region.

Frequently, the service providers find it difficult to assess the needs of HIV positive people from these communities, and the best way of responding to those needs.

Since countywide assessment of the HIV prevention, care and support needs of Black and Minority Ethnic Communities have never been conducted, Brighton & Hove Primary Care Trust and local authority were concerned that the existing services may not be aware of additional prevention, care and support needs or barriers to services experienced by their clients from the Black and Minority Ethnic Communities. This is why the local health authorities have recruited a person to focus on this needs assessment.

6. Overview of Method

Data for this project was collected consistent with the goals and objectives set forth by Brighton & Hove Primary Care Trust (health promotion monitoring and evaluation), Brighton & Hove Social Care and Health, and Brighton Body Positive.

The first stage was a review of available literature on HIV within the context of Black and Ethnic Minority groups in the UK. This review is based on published literature, electronically published data, public documents and 'grey' literature. It covers HIV related projects among Blacks and Ethnic minorities from the period 1995 to 2002.

There was also strong liaison and collaboration with a number of HIV agencies working in the related field, particularly, HIV agencies working in West Sussex and London. This enabled an understanding what HIV projects have been carried out among these areas and how they could help assess the needs of the population concerned in this particular project.

The second stage was the survey itself comprised of key questions derived from similar projects in other parts of the UK and focusing on similar areas of targeted information.

Once developed, the questions were reviewed by an Advisory Group and were supported by piloting interviews of selected members of the communities and service providers. The Advisory Group for this project are group of independent people from the HIV sector and Black and Minority Ethnic Communities to provide impartial professional support to the worker.

One to one interviews were conducted within the key populations such as students and others who were not captured in the focus groups. The focus groups were groups of 6 individuals from Brighton & Hove and 4 individuals from Eastbourne and Hasting. They were all people from Black and Minority Ethnic Communities living with HIV. They were guided into increasing levels of focus

and dept on key issues deemed necessary in finding what the HIV service needs of the communities are.

Qualitative methods were applied throughout the research. A quantitative approach was only utilised with demographic matters such as gender, age, immigration status and country of birth. At the end the data collected were analysed thematically.

6.1 Community initiatives and participation

A good number of different community groups and organisations within Black and Minority Ethnic groups were consulted prior to the survey. The survey was also advertised in some local newsletters and university advertisement sheets seeking people from Black and Minority Ethnic Communities to help as well as to participate in the research. Many community members gave influential suggestions. There were also a few responses from the university environment which eventually drew one potential research student to assist in the survey. Many who indicated their interest were unfortunately unable to participate due to clashes with other activities.

6.2 Sampling:

Service Users

Because there was no comprehensive demographic data of the Black and Minority Ethnic Communities in place prior to this research, it was difficult to obtain a social mapping of the total population. This has resulted in a convenience sampling of the population. Some participating agencies were asked to determine approximate numbers of clients seen by each organisation during a given weeks period.

There were attempts to involve in the survey a number of HIV positive individuals from the Black and Minority Ethnic Communities who access services. The experience however, is that most of the people who use the services and who were willing to participate in the survey were all Black Africans. These individuals were contacted and were encouraged to participate in the survey.

There is no claim that the eventual participants in the survey represent the total sum of the population actively accessing services in Brighton & Hove, and East Sussex (Eastbourne and Hasting). Due to this small sample, it was not possible to generalise on many of the issues.

Individuals who participated in the HIV knowledge and awareness survey represented a range of different ethnicities and were chosen randomly through outreach contacts on the streets, in coffee houses, shops, on buses and in university and public libraries.

There were a total of 30 individuals from the communities who participated in the survey. 9 of them whom were living with HIV, 4 are community leaders, and 17 were individuals who participated in the knowledge and awareness interviews. £10 was given to each individual living with HIV as a compensation for their transportation and time. All interviewees were resident in Brighton & Hove and East Sussex.

6.3 Modes of contact

Service users:

The tag 'hard to reach' that commonly goes with the ethnic minorities, particularly with the African groups on issues around sexual health and HIV/AIDS work, was seen differently during contacts with them. In fact less difficulty than anticipated was experienced in taking and retaining contacts with these groups. Contacts were made on:

- Personal and flexible time frame which involved extending contact outside working hours, like on holidays and weekends (invite to meals, birthday parties and helping in arranging memorial ceremonies).
- Friendly level which involved a total openness and sharing from both sides. The position of a community worker or a researcher was less significant in this case. There was no one sided narrative, rather both parties were intimately sharing their life stories. This enhanced some commonalities that made both parties work together.
- Social level which involved arranging of social events like World AIDS Day. This event was important in the sense that contacts were extended with other members of the communities and also allowed people that had already met to meet other new people.
- Snowball networking- people that I had met already played significant roles in connecting me with other people. In fact the amount of commitment from the first contacts cannot be overemphasised.
- Encouraging community participation- communities were approached with a convincing message that it is about time that we influence the decisions made on our behalf, particularly on issues around sexual health and HIV. This was an empowering message that drew quite a lot to the project.

6.4 Difficulties encountered

- Some of the community members approached were either too busy or unemployed. Some of the unemployed needed monetary compensation which unfortunately was not guaranteed due to limited funding for this project.
- Some community groups, especially of Islamic background, were not so willing to participate in the research. For example, one leading agency that works with Black and Minority Ethnic Communities needed an internal pre assessment in order to find out whether there is the need for a sexual health and HIV needs assessment with the communities that they are

working with. This is a fair suggestion considering the political and religious background of the people that they are working with. However, such conditions limited my access to the communities.

- Some of the respondents sometimes doubted paper research. They think that it does not answer their immediate needs.
- Sometimes there is a sense of dryness in the research when it could not promise the respondents (the infected and affected) immediate changes in some modes of service provision.
- It was difficult to separate support work from the research. The research time was divided with support time given to clients who participated in the survey as well as to people referred to the project by some service providers who misunderstood the remit of the project.

6.5 Service providers

Most potential agencies serving these communities were visited or contacted by phone or email to inform them of the Needs assessment/gaps analysis project. Generally, responses from most of these agencies were overwhelming. There was a general indication of awareness of the project from most of them. There was also overt confirmation that it was about time for such a project. The survey interviewed almost all the HIV/AIDS organisations serving the county.

6.6 Difficulties encountered

There were essentially no huge difficulties contacting and collaborating with the HIV service organisations in the survey. Almost all the sample for interviews from the service providers responded very well.

The only unfortunate issue was the difficulty in reaching the General Practitioners. It is acknowledged that their busy schedules were a barrier to their participation in the survey. Nevertheless it was discouraging that out of 34 General Practitioners contacted for this survey by more than one means (letter, emails phone calls), and sometimes with repeated contacts, only 8 replied to letters or returned phone calls. Only 6 GPs eventually responded to the interviews. But those who responded were very helpful in providing needed information.

Ironically the GPs were the 'hard to reach' in this survey. This is a reverse of the initial assumption that the targeted service users are 'hard to reach'.

Dear Ogo Chime,

Our practice provides general medical services to all patients registered with us without discrimination. We do not have time or resources to offer extra services outside NHS provision.

Regrettably the Doctor does not have time for interviews or questionnaires.

.....

- A reply sent from a surgery

7. Knowledge and Awareness of HIV/AIDS and Available Services

Individuals: Background of Respondents

In all 12 females and 6 males were interviewed for this study which focused mainly on awareness and knowledge of HIV/AIDS and the services available. The average age of respondents was 30 with a range of 18 to 43. This age falls within the highest HIV/AIDS prone group, according to global statistics on the disease (UNAIDS Fact Sheet 2001). Therefore, it could be justified using this group for the study.

All respondents defined their sexuality as heterosexual. This also confirms the observed pattern of sexuality and mode of transmission of the disease in non-western countries according to the world report on HIV/AIDS (UNAIDS Fact Sheet 2001). Only two of the respondents (a male and female) had been born in the UK. The rest had moved to the UK from elsewhere. Varying in years, 6 of the respondents had moved to the UK in 2002, 3 in 2000, 2 in 1999, 1 each in 1987, 1990, 1992, 1994, and 2001. In sum, most of the respondents were recent residents in the UK.

7 of the respondents were of African background (5 from sub-Saharan, 2 from the horn of Africa and 1 from North Africa). Others were 2 Afro-Caribbean, 1 Latin-American, 2 from Russia, and three from Southeast Asia, and 1 from the Middle East.

Table 1. List of countries of Respondents

Bangladesh	Iraq	Zimbabwe	Nigeria
Pakistan	Somalia	Tanzania	Morocco
Japan	Eritrea	Gambia	Brazil
Jamaica	Barbados	Russia	Uzbekistan

The employment status and the types of employments the respondents had varied greatly from unemployed through floor attendant to student. Almost half of the respondents were students. The people who are in employment are either self-employed or are working as care assistants or in a restaurant. It is very possible that people in other kinds of employment were not reached due to the nature of sampling used in the survey. But results from this sample suggest that there are limited high-paid job opportunities for these communities in this area.

None of the respondents identified him or herself as an asylum seeker or refugee. Often it is assumed that the number of asylum seekers in Brighton & Hove is rapidly increasing. The large number of students in this survey seems to suggest that a good number of people from the communities who have moved into Brighton & Hove and East Sussex have come to study. A number of

language schools and universities in the area have attracted most of these students.

7.1 Main issues of the study

Respondents were asked 13 questions each to assess their knowledge and awareness of HIV, available HIV services, and the ease with which they felt able to access these services or recommend them to a friend or relative if needed. The questions looked at religion, culture, language and confidentiality as possible factors that might either enable them to respond and address the issues around HIV or become a barrier to their awareness and access to services.

7.2 Culture and religion

It was important to ask the respondents about the part culture and religion play in their lives, and to what extent these factors influence or restrict their attitudes towards, and access to sexual health awareness information. Culture in this context refers to values, belief and practices. Most of the respondents felt that culture and religion were very important in their everyday lives, but not in anyway a barrier to openness on sexual health issues. This is not an unpredicted finding. While culture and religion play an important role in Asian and African societies and in the lives of the people from these places, western education and multiculturalism have had a softening effect on their approach to sexual matters (see Fenton et al. Exploring Ethnicity and Sexual Health, 1997)

7.3 Languages

Most of the respondents spoke at least one language apart from their native languages. These other languages had been learned to improve respondents' communication and interaction with the environment in which they found themselves. Thus these other languages were learned as an adaptive strategy. It is not surprising therefore that most of the respondents felt that language was very important and essential in order to work, study and generally as a key coping strategy for survival.

"Now that I am living in England English is becoming more important. Generally language is part of a culture, so I see English important to use" - Individual from Black and Minority Ethnic communities
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This finding was also consolidated by most respondents' assertion that they communicate better with the people and the officials in the English language. This is an important observation and could then be argued by implication that information geared towards these communities should to a large extent be in the English language. Most of the respondents also felt that they have good access to the information on the services in their area. However, it is important to note that this does not represent the general view of the total Black and Minority Ethnic Communities living in the area of study.

7.4 Knowledge and awareness of HIV/AIDS

When asked questions around knowledge and awareness of HIV, all the respondents overwhelmingly agreed that they have all heard of HIV/AIDS and most of them have known about it for more than ten years. Most of the respondents mentioned the media as their main original source of information on HIV/AIDS although others said they first heard of it from infected people, teachers and AIDS council groups.

Respondents also mentioned that they know that HIV/AIDS is mainly transmitted through unprotected sexual intercourse, sharing of needles, blood transfusion, vertical transmission (mother to child) and infected body fluids. This is a confirmation that the respondents had some tangible knowledge of HIV/AIDS.

It appears that the respondents to the study had some knowledge of HIV/AIDS. This is clearly shown when asked to indicate which other information they required on HIV/AIDS. Most of them said that they felt they had enough information already on the issue. They confirmed this position by indicating that they would provide support and care for positive people and advise them to seek help from professionals. The only concern here is that a couple of the respondents still retain the myths around HIV/AIDS, believing that HIV can only infect gay men or people who have sex with prostitutes, and also that people who are HIV positive should be isolated.

7.5 Knowledge of and access to available services

Most of the respondents had little or no knowledge of specific HIV services where they could either go or advise someone else to attend. Only two of the respondents have heard of the HIV/AIDS treatment directory. Due to the stigma attached to HIV some of the respondents think that HIV services are not for them, and are therefore not very willing to openly seek information about HIV. Some think that these services are for gay men or men who sleep with prostitutes.

Most of them however said they would be interested in receiving printed information on HIV/AIDS services in either English or other languages like Arabic, Bengali, Hindi, Swahili, French, Ndebele, Shauna, Titirgina, Ahmaric, Portuguese, Urdu, Spanish, Wolof, Japanese and Russian . This indicates that they would not reject credible HIV and sexual health information if someone were to approach them.

On being asked if respondents would be comfortable inquiring about HIV/AIDS issues from their GPs, community groups, religious groups or HIV organisations, most of them preferred to do so with their GPs.

7.6 Community groups

Community group leaders were interviewed in this survey because their views and insights as leaders are crucial and will act as a consolidation to the

information given by some community individuals. Four Community Groups, namely Chinese Community, Society of Nigerians, Somali informal Group and Mosaic (Black and mixed parentage group) participated.

They all shared the same concerns over the long silence in the discussion of issues around sexual health and HIV/AIDS in their communities. They think that this is an issue that should be addressed in the communities. But one important and challenging question they all posed was 'how would that be done and what is the culturally appropriate way of doing so and still maintaining the trust of the people'?

Usually such issues are not commonly discussed among the groups because there is a degree of sensitivity around sexual matters, particularly HIV. The mixture of different sexes and ages in their gathering and the environment in which they gather make it even more difficult to have such sensitive discussions. Interestingly they did not see sexual matters as necessarily taboo, but only that some members could prefer discussing it individually.

"I think it is very difficult to go deeply into the issue if you don't have the trust of the people. This is a very sensitive issue to discuss in our culture. We have to build this trust with the people through our education"
-Community Leader

"Sexual discussion is not necessarily a taboo, but it is difficult issue to discuss openly in our culture especially in the men's meeting. It is also difficult to discuss when both sexes are gathering. Sexually transmitted infections are usually part of women's discussion but not among men. This is not supposed to be so though"
-Community Leader

Findings show that two of the community leaders do not know of any particular HIV and sexual health service agency in the area. Though they know that such agencies exist, they do not know what they are called or where they are based. Most of them said that they have rarely used or referred their members to any of these services, even though there had been the need sometimes. They usually refer members to the General Practitioners or to the Hospitals. One major reason is that they do not know exactly what kind of services these HIV agencies provide, particularly whether their services will be sensitive to the cultural needs of their communities.

However, most of them acknowledge the need for HIV prevention messages as well as the need to involve the communities in the programme. They also showed their willingness to integrate such activities in their agenda if they would be briefed and funded to do so.

"Community groups and members should be contacted directly on issues that will help them come open to discuss issues on sexual health... Most of our members know about HIV but because information about services are high jacked by the health officials, member groups seem reluctant to relate to them"
- Community Leader

For information and messages around HIV and sexual health to be well communicated to these communities, community group leaders must be involved from the onset. Health service providers must be flexible in their approach towards HIV prevention information for these communities. The need for capacity building cannot be overemphasised. Communities must be consulted and where possible empowered by granting them small funds to design and disseminate information leaflets that are culturally appropriate.

7.7 Summary and conclusions

Findings from the study show that to a large extent the Black and Minority Ethnic Communities interviewed had some knowledge and awareness of HIV/AIDS issues. They have knowledge of the disease, its causes, prevention but not a particular HIV serving body where to seek medical help when the need arises. What they require now is printed material on where to access these HIV/AIDS services. It also emerged from the study that most respondents are comfortable with information communicated to them in the English language although some of them would not mind having such information in their native language or other second language they are familiar with (see 7.5).

Most of the respondents also felt that they would be more comfortable talking to their GPs about HIV/AIDS issues. Community groups also voiced their interest in incorporating HIV and sexual health activities into their agenda if they would be supported.

In conclusion, it appears to a large extent, that Black and Minority Ethnic Communities have some grip on the issues of HIV/AIDS. What needs to be done is to consolidate this position by designing more a focused and well co-ordinated programme on HIV/AIDS for the communities incorporating some or all of the findings of this study.

7.8 Key findings

- There is evidence that suggests that people from these communities have some knowledge of HIV. But this knowledge was acquired prior to their arrival to the UK.
- They do not have the up to date information about HIV simply because there is not a well co-ordinated prevention outreach work among them.
- Access to appropriate sexual health and HIV services by these communities is very low, thus need for more appropriate information dissemination techniques.
- Potentially language could be a problem in accessing services, but does not appear to be issue that requires urgent attention. This is because most of the respondents prefer receiving information in English.
- There is no existing agency that has tailored their service to meet the needs of these people in terms of using a potential worker from the communities.

- People from Black and Minority Ethnic Communities prefer seeing the GPs than any other health agency for issues related to sexual health and HIV.

7.9 Recommendations:

- While individuals and community groups in this study have varying degrees of general knowledge about HIV/AIDS, their sexual behaviour and lifestyle issues that could impact those behaviours should still have to be explored in order to have a holistic idea of a targeted prevention work.
- More updated and clear information about HIV and current services available in the area must reach the communities. Service providers should clearly list in their information leaflets some specific tailored activities for the communities. This is because continued misinformation in the community about HIV/AIDS will lead to a continuing rise in the rate of infection.
- Black and Minority Ethnic Community based organisations (which already have rich networks within the community) that are interested in providing culturally specific HIV information and education, should be supported and funded to do so.
- Information needs to contain a clear message that HIV and AIDS are preventable and treatable: using well-known local community members in advertisements and getting them involved in creating the messages leaflets and getting them out.
- There could be more seminars, forum, workshops designed and offered to every ethnic community groups/entity (Community Experts, Community Leaders, Student Group Leaders, Community Providers, etc.) with the intention of creating positive behavioural change. These should be varied, targeted and tailored to the intended audience group and cover a range of topics on everything around HIV/AIDS.
- More focused HIV prevention information particularly one to one outreach work could be intensified among the student groups. Many of the students tend to live in isolation and often find it very uncomfortable to relate to services around HIV.
- The community could have a full array of HIV/AIDS services that are offered in general health environments and in community convenient locations.
- General Practitioners could take a cue from this finding and broach the subject with their patients. From this study GPs are most likely to be approached by individuals from these communities on issues around sexual health and HIV.

8. HIV/AIDS Services and Other Service Providers in Brighton & Hove and East Sussex

Table 1 is a SOPHID data for the year 2001. It shows the HIV positive people by Ethnic group by Primary Care Trust, or the local authority, who were receiving NHS care for HIV/AIDS. The Ethnicity data is not complete because there are a large number of unknowns, particularly for Brighton clinic.

Table 2 shows a list of service providers interviewed in the survey and the numbers of Black and Minority Ethnic Communities they report seeing over the last year 2002-2003. They were categorised according to the services they provide.

Table 1. HIV positive people by Ethnic group by PCT. SOPHID data for the year 2001

	White		Black Caribbean		Black African		Black other		Indian/Pakistani/Bangladeshi		Other/mixed		Not Known		TO TA L	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M/ F	
Bexhill & Rother PCT	9	2	0	0	0	0	0	0	0	0	0	0	0	3	1	15
Brighton & hove PCT	113	4	1	2	4	4	2	1	0	0	3	0	468	33	633	
Eastbourne Downs PCT	38	2	1	0	1	7	0	0	0	0	1	0	3	1	54	
Hastings & St. Leonards PCT	18	4	1	0	1	2	1	0	0	0	0	0	2	0	29	
Sussex Downs & Weald PCT	17	3	0	0	1	0	0	0	0	0	0	1	24	5	51	

Table 2. Service Providers and number of Black and Minority Ethnic persons seen in the last 1 year on issues around HIV and sexual health

<u>Prevention and Support</u>	
1. Brighton Body Positive	10
2. Open Door	46
3. Terrence Higgins Trust (South)	30
4. UNISEX	25

<u>Care and Support</u> 1. Community Team HIV/AIDS 2. HIV/AIDS Mental Health Team 3. Department of Clinical & Counselling Psychology HIV/AIDS 4. Special Team, Adult Social Care 5. Representative at Lawson Unit, Elton John & HIV Pharmacy	20 2 3 35 0
<u>Treatment and Care</u> 1. Sexual Health Clinic Eastbourne 2. Hasting Sexual Health Department 3. Claudi Nicole Centre/Lawson Unit 4. Sussex Beacon Nursing Home 5. Elton John Centre 6. General Practitioners	20 unsure of the figures 90 10 10 34(by 3 GPs with monitoring mechanism)
<u>General Advice and Support</u> 1. Asylum Seekers Team Brighton & Hove 2. Asylum Seekers Team East Sussex 3. Brighton & Hove Migrant Helpline 4. Black and Minority Ethnic Community Partnership 5. Brighton & Hove Citizen Advice Bureau HIV Project	6 0 2 20 9

It is very clear from observation as well as from service providers' responses that Brighton, Hove and East Sussex are fortunate to have good HIV and sexual health services compared to other neighbouring counties. This is evidenced in the number of clients from outside the county accessing HIV services. Although confidentiality may contribute to people from other areas accessing services in Brighton, Hove and East Sussex, that does not discount the quality and credibility of the services they provide.

All the 13 HIV specialist services (from prevention to care, treatment and support) demonstrated their commitment to provide reputable services to the entire communities. They have a wide range of services within their working remits. Some of them even extend their services beyond their remits.

Except for most of the general-practitioners, all the HIV/AIDS organisations in this study have mechanisms that monitor the ethnicity of their clients and also which takes into account their age and gender. They all have had at least 2 persons from Black and Minority Ethnic Communities who have accessed or are still accessing their services. Sexual Health Clinics experience the largest number of service users from the Black and Minority Ethnic Communities on issues around sexual and HIV. For example in the past 1 year, one of the clinics has seen 90 people with HIV related cases.

What this indicates is that people from Black and Ethnic Minority Communities are increasingly becoming active users of some HIV services. Whether these communities are finding these services easy to access was the other crucial question.

8.1 Easy access to services

Service providers were asked the kind of services they provide, to ascertain if these services also embrace the needs of the communities. Major services listed are:

- General medicine
- HIV pre/post-test discussion
- Same day testing
- Fast track services
- HIV support drop in
- One to one counselling
- Support for newly diagnosed
- Information about financial grant,
- HIV treatments
- In/out patient care
- Respite services
- Home nursing
- Health education for patients and carers
- Signposting and referral
- Mental health services
- Psychological assessments
- Individual led assessments.

Most of the services are quite general and are for all groups of people irrespective of their gender or ethnic background. However, the study shows that people from Black and Minority Ethnic Communities are not using the services as the service providers have anticipated.

"I have been surprised how few people from Black and Minority Ethnic Communities have registered with us. My perception some years ago when we began is that we will have more proportion of people from these communities." - Service provider

One service provider thinks that not enough communication and information dissemination about services that they provide is in place and that this limits easy access to services. In other words, more clear information about services would attract people to use their services.

8.2 Difficult requests

Service providers were asked if there is any request from the communities which they are unable to meet. All maintained that they would try to meet every request and would refer to another agency if they could not. However issues around

asylum, immigration applications, housing and personal assistance like shopping could be difficult requests that would not be met by many service providers.

8.3 Language

Most service providers have never experienced language as a barrier in relating to their clients. Although they agree that language could potentially be a problem, they have not had any particular case to prove that. They all said that most of their clients from ethnic minorities speak quite good English. If there was to be a problem with language, most service providers said that they can easily access interpreters or translators in the Trust or from other interpreting services, and this could usually take a day or two. The languages that they mentioned that they can easily access interpreters to are French, Arabic, Urdu, Bengali, Portuguese and Spanish.

Most of the information leaflets available in the organisations are in English, which is probably because all the clients read and understand English well enough. However, they do sometimes order from other agencies information translated into languages other than English such as information in French.

It would be difficult to make a conclusion based on this finding. This is because, as already asserted, the number of people from these communities accessing services is on the increase. It could therefore be possible that the need for other languages would increase as well. What could be said therefore is that language at the time of this survey has not been a big barrier for these communities in accessing sexual health and HIV services.

8.4 Culture

Understanding of cultural difference is an issue that all service providers think is crucial in their services for Black and Minority Ethnic Communities. Apart from agencies that specifically work with Black and Minority Ethnic Communities, such as Asylum seekers team, migrant helpline etc., all other organisations acknowledge their limited knowledge of some cultures within these communities. Training on cultural awareness, especially of Africa for all the staff was seen as very important. Other important areas for cultural awareness mentioned by providers are:

1. Attitude to sex and sexuality in different cultures and religions
2. Gender (questions such as why African women are more likely than African men to access services, for instance)
3. How people from other cultures understand health promotion
4. Culturally specific attitude towards health and medication
5. Culturally specific experiences of illness and symptoms, and culturally specific ways of communicating about illness
6. Information on HIV in Africa

8.5 Confidentiality

Confidentiality was highlighted by service providers as an issue that can make service provision problematic. In most cases service providers would not know when it is appropriate to refer their client to another service provider. Furthermore, this can limit access to some available services, one of the providers claimed. A good number of studies conducted by other researchers in this field find this to be the case (see Access All Areas, 2002; Capital Assets, 2000; Project Nasah, 2003 etc.)

“Clients seem to be embarrassed and ashamed of their condition, and many times they have the feeling of not being accepted, they think that letting other people into their lives would be an embarrassment.”
- Service provider

8.6 Gender and sexual identity as a potential barrier?

The issue of gender and sexual identity become very crucial in this survey due to epidemiological statistics of HIV in Brighton & Hove, and also due to the long history of HIV service development in the area. HIV services in this area have had gay men as predominant service users. Newer statistical evidence shows that there is becoming an increasing mixture of ethnicity (mainly Africans) and heterosexual men and women accessing to services in this area in the past few years. Hence it is important to see if this increase in the number of service users outside the gay community is reshaping the service provision and delivery.

Three of the providers did not see gender or sexual identity of client as a big barrier in providing services to these communities. This view was mainly from the HIV prevention and support organisations. The argument from these providers was that their services try to embrace all people irrespective of their gender and sexual identity. Only one service provider in this category thinks that gender and sexual orientation of client could sometimes limit his or her access to service. This provider argues that this problem exists and that denying its existence would not help the situation.

“There is a perception in the Black and Minority Ethnic Communities that our organisation is for gay men. There is also the fear, and expectation, in these communities that white English society are racist. On the other hand, there may be a suspicion among service providers and our gay male clients that these communities are homophobic. So there is a cycle of fear and suspicion going on. The only way to tackle this is to first acknowledge its existence. Pretending it is not there won't help the situation.”
- Service provider

Most service providers from care and support agencies agree on the barrier that gender or sexual identity of a client could sometimes bring in service provision. Their experience of such cases, made them feel conscious and sensitive to individual needs, and helps them in tailoring service with more specification.

“Personally I have not been engaged with African men as a woman, especially on issues of sexual health. I am aware there are issues where gender could affect service provision. But we try to have equitable services.” - Service provider

One interesting finding here is that those service providers who have not experienced gender and sexual identity of users as a barrier are the organisations that are assumed by some outsiders to be gay male dominated organisations with predominantly gay male service providers and service users.

What seems to be the case here is that either the current workers in these organisations do not believe gender of a service user to be a barrier for them when providing services to these communities, or they are re-structuring their services as to have a balanced representation of gender, for example by arranging few activities for women and employing more female workers.

8.7 Provision of referrals

All the service providers said that referrals (i.e. a definite passing on of a client to some specific service providers) are an efficient way to improve service delivery and help clients get services they may not provide. Referrals create bridges for collaboration between agencies and can help eliminate gaps in service. However, some providers said that referral is not working as well as it should. Some providers seem not to be referring as often as they should. One reason is confidentiality which they claim some users are very concerned about.

8.8 Significant barriers

Service providers were asked to outline the significant barriers in delivering effective services to the Black and Minority Ethnic Communities. To a very significant level the barriers that they mentioned were the same. The main factors identified by all service providers were: poor information dissemination about the HIV services to the communities; difficulties in dealing with some of the asylum seeker's issues and issues around confidentiality. The fear of racism and the sexual orientation of the service provider as a potential barrier were only mentioned by three HIV prevention and support organisations. A summary of these significant barriers follows:

1. Information about services is not clear enough and is not well disseminated to the communities.
2. There is still the perception that some organisations are for gay men.
3. There is fear of racism from the communities.
4. There is suspicion from some organisations that some people from Black and Minority Ethnic Communities are homophobic.
5. Drop-in services are used by predominantly white gay men.
6. The staff and volunteers are mostly white.
7. Confidentiality is seen as a problem in referrals.
8. There is a shortage of staff.
9. No funding to recruit worker from Black and Minority Ethnic Communities.
10. Difficulties applying for grants for asylum seekers from the grant giving bodies.

11. Difficulties in working with other agencies, especially on issues around asylum.

8.9 Self evaluation and future services

Irrespective of all these barriers most service providers believe that people from the communities who have used their services so far have responded well; although it is still up to the individual to come up with comments and complaint, which they encourage them to do so through users satisfaction form. There were a few example of cases were some service providers claimed that users have come to thank them for their good services.

“If they need to go to hospital they will prefer to come here. They have openly said that several times. One African woman has said that she was surprised the way she was touched and treated kindly by the white nurses. We can see that their confidence grow whenever they come here.” –Service provider

All the service providers interviewed expressed interest in providing continuous services for the communities for one reason, because it broadens their service users outside white and gay men. They also think it is crucial to identify the needs of Black and Minority Ethnic Communities and respond to the challenges of providing services for them. But how this complex and challenging service would be balanced was not clear in their responses.

One of the new coming activities in Terrence Higgins Trust South for example as was intimated by the area manager would be a family oriented service for African women. Though this post will be based at Eastbourne, it will be covering Brighton & Hove area as well. Another area of service development is the merging of the HIV care and support groups into one team. This as was told by the newly recruited manager would make the care and support services more efficient and possibly better their services to Black and Minority Ethnic Communities.

“We will integrate as a team in the future, and there could be some other services from this which would benefit the communities” - Service provider

Generally, it was impressive to observe the amount of confidence service providers have in the standard of services that they provide for the communities. Even though they try to work within their remit because of lack of resources, some providers said that they have sometimes gone beyond their remit to provide better services for Black and Minority Ethnic Communities. Services such as blood sampling, free food packages, making international phone calls from office etc, were some of the services that these agencies would not provide otherwise. They acknowledged the increasing number of people they see from these communities and accept that it could influence the shape of future services.

As the number of people from Black and Minority Ethnic Communities that we see are increasing, we need to monitor the gaps in the services we provide. It may mean employing a person from the communities as a worker. We need to be flexible. – Service provider

8.9.1 Conclusion

There is number of agencies providing services and programs for persons affected by HIV/AIDS in Brighton & Hove and East Sussex. The people working in these services indicate that while they are generally satisfied, more could be done to provide services that are culturally sensitive, gender mixed, provide clear information, educationally sound, and reflect the needs of targeted populations.

8.9.2 Key Findings

- HIV agencies in the area of study are experienced and committed to providing standard services to all clients. However, many have not received appropriate training on understanding and tailoring services to the communities of study.
- Most of the HIV agencies liase very well with others and this is clearly shown in their common views on service provision.
- None of these agencies is working in collaborative partnership with any community groups or organisation from the Black and Minority Ethnic Communities on service development.
- There is not enough collaborative partnership with agencies working on immigration and asylum issues.
- Most of the staff working in HIV agencies is white.
- There is no clear mechanism for assessing the impact of their prevention work among Black and Minority Ethnic Communities.
- Only one HIV prevention and support agency makes account of some of the clients concern.
- Until the end of this project calls were being received from many service providers asking me whether there is any service in place for the newly HIV diagnosed Africans. What this implies is that they have not been able to meet the needs of these communities.

8.9.3 Key recommendations

1. More funding must be made available from the local authorities for a concerted, focused, community-involved campaign using effective methods to get basic, accurate and consistent HIV/AIDS prevention, care and treatment to Black and Minority Ethnic Communities in Brighton, Hove and East Sussex.
2. Clearer mechanisms for monitoring the number and ethnicity of clients, particularly for the GPs. This will enable a continuous and sensitive approach to service development
3. Anti-discriminatory and cultural awareness training for HIV service provider staff. This must be backed up with a greater desire to put the outcome of the training into practice; one service provider commented on her own change of attitude when she learned where and from what circumstances people were coming.

4. Providers should develop an appropriate emotional support that is not based on western styles of counselling. Most Africans usually do not want to talk about how they are feeling. They want to see where they are practically supported. This was the view of some African people who participated in the research as well as the view of a service provider from the prevention and support group.
5. Recruit more staff and volunteers from the Black and Minority Ethnic Communities. One way of doing this is by working strongly with Black and Minority Ethnic Community Groups (see 7.6 for some community groups), and encouraging them to inform their members of volunteering opportunities. Also contracting few hours to one potential Black and Minority Ethnic Community groups to help in some HIV service development.
6. Develop a steady working relationship with other non-HIV Black and Minority agencies such as the asylum teams.
7. Rethink on services to provide more flexibility to meet the need of the communities through being sensitive to the findings in this report. Also rethink that Black and Minority Ethnic Communities may not always be 'hard to reach' as usually assumed. They are probably 'hard to find', but not hard to reach when you have got what it takes to meet their needs.
8. There must be more support for service providers; as one said "everything is left for us with less resources"

9. Services as Perceived by Service Users (people living with HIV)

Background of respondents

Table 3. A background of respondents (Gender, age, sexuality, ethnic background, whether born in UK and date of arrival if not born in the UK).

1	2	3	4	5	6	7	8
Female	Male	Female	Female	Male	Female	Female	Male
32	34	35	33	35	31	46	49
Hetero	Hetero	Hetero	Hetero	Hetero	Hetero	Hetero	Hetero
Zimbabwe	Burundi	Zimbabwe	Zimbabwe	S-Africa	Zambia	Zimbabwe	Zimbabwe
No	No	No	No	No	No	No	No
2001	1997	2000	1999	2001	2002	1999	2000

Method: One to one interviews and three sessions of focus groups were conducted as a means of gathering information about the experience of using HIV services for HIV positive Black and Minority Ethnic Communities.

There were a total of 8 respondents made up of 5 females and 3 males. Their age range was between 31 and 49. All the respondents identify as heterosexual. The respondents were of mainly Southern African background. None of the respondents was born in the UK. All of them have been in the UK for at least a year before the onset of this study. The actual time of moving into the UK varies from 1997 to 2002.

9.1 Access to services

The study found out that all of the respondents have access to at least one HIV care and support service. The number of services ranged from one to six. Almost all of them used their first service in London which they found ethnically diverse and less tense to access. It is also worth noting that all of them have at one time used HIV services within their locality of abode. Even though some of the respondents said they had initial difficulty in accessing HIV facilities, they agreed that to a large extent, they found the services relatively easy to use. This is in agreement with the view of the service providers.

They mentioned that they found these services to be beneficial because they meet people there who have similar problems. They found staff in various organisations helpful which make them to feel at home in their services. In fact, to them, these were the factors which mainly influenced their choice of a particular HIV service.

9.2 Language

The study found out that most of the respondents have little or no difficulty in understanding HIV service information in English texts except for some scientific jargon. They believed however, that if the information was to be in their local language or if they had access to a trustworthy interpreter the services could be more useful. Shuna and Ndemele were the only mentioned languages.

9.3 Culture

There was a split in opinion as to whether cultural difference between oneself and the service provider could be a barrier to accessing services. Whereas some felt that culture was not a real barrier, others felt it was a real problem which could be solved if service providers made a conscious effort to understand the culture of their clients.

Women were more likely to experience the need for more knowledge and understanding of African cultures from the service providers.

One respondent explained why adequate knowledge and understanding of their culture by the service providers could enhance better services:

“...for example when my son with HIV related illness passed away, I did not feel that I needed counselling, but I was advised to go for it. All I needed and asked for was that someone could please send my mum over. I talked to some people who talked to some organisations that helped to bring my mum over. Even though my mum couldn't come, my aunt came and it helped me a lot. What I am saying is not that counselling is not good, but that at that particular time I needed my mum, a relative and someone outside health providers. I was really grateful that they understood my need at that particular time. – Service user

Very few of the respondents felt that there were terms or topics used in HIV which were culturally inappropriate, but if that was the only way of explaining their symptoms for appropriate medication to be administered then they did not really mind. None of them was able to give any example of such terms because they thought they were not very big issues.

All the respondents suggest that having someone who is from their cultural background as an additional worker in HIV services would be beneficial to them

9.4 Gender of service provider as a potential barrier?

Interestingly men were more likely to respond openly to services provided by another gender (women) and gay men. All the men think that gender and sexual identity of the service provider does not matter to them in as much as it is a human being like them who could help them with their problems. Except on few cases where these male respondents had to use sexual terms, women service providers, or one who is a gay man, has not presented a big barrier to them accessing services.

Women were more likely to find the gender or sexuality of service providers, or fellow service users, a cause of unease

“One thing that I experienced was that most services are only used by gay men. We find it difficult to open up discussion with them. They seem to be on their own and less interested in talking with us. Sometimes we feel excluded.” - Female service user

This, they emphasised, has nothing to do with being homophobic, but a fear that they might not be understood because they do not know what is expected of them in terms of how to relate to some gay men in a drop-in.

9.5 Confidentiality

Although confidentiality could be seen as a big issue and one which in some cases has become a barrier in both providing and using of service, it was not noticeably so by the users. For example when asked whether they would be comfortable using an interpreter from their national and cultural background if there would be the need, respondents express willingness to do so in as much as the person is trained to do so. For them the issue of confidentiality is only a problem when the service provider has not gained the user’s trust, and wants to get another person involved.

One provider thinks that from experience confidentiality is not that as big an issue as is it is thought to be.

“We assume that because of confidentiality many African clients living with HIV do not want to meet each others. But this has been proved false. It is the other way round. Once they get over the common barrier, they are very happy to meet with other folks. Most of them like it when they could chat with other patients of the same African background.” – Service provider

9.6 Immigration and Living conditions

It is important to emphasise that immigration status and asylum seeker status are not interchangeable terms. Immigration status here is used in a general sense which covers people with work permits, student visas, residence permits, as well as people who are asylum seekers. Though all the respondents in this survey were asylum seekers, there were other HIV positive people from Black and Minority Ethnic Communities who were either born in the UK or have residence permits or student visas, and who were in contact with the researcher but were not willing to participate in the survey. It would therefore be a mistake to assume that all HIV positive people from Black and Minority Ethnic Communities are asylum seekers and to make policies accordingly.

Two of the respondents felt that their status as asylum seekers is a barrier to accessing services while most felt that it was not a major problem. Generally it is unlikely that service users would be denied access to HIV service due to their immigration status, whether as a student, person with work permit or an asylum seeker.

However, for the asylum seekers in this survey, their residency status is still the top priority. All the respondents in this survey were of African background and for almost all of them their legal status was still undecided.

They describe often feeling depressed about their legal status as immigrants, and in particular how they would cope with their illness if they were denied the right to stay in the UK.

"I think that our status as asylum seekers affect the whole situation. It would be slightly different situation if our papers are intact and refugee status granted. Sometimes as an asylum seeker I feel embarrassed to ask for any help. I don't know what the policy is on asylum seekers receiving any HIV benefit. – Service user

Living conditions for these people living with HIV could be much easier if appropriately assisted on the issues around immigration and housing, particularly in giving valuable advice and support until their immigration decision is finally made.

Giving them some volunteering opportunities where they could receive some financial compensation could alleviate the isolation and loneliness often experienced by people in this situation, and their fears about the future. It would also be a big step in restoring their self-esteem.

9.7 Treatment issues

Half of the respondents are on combination therapy. Those who are on medication were very positive with the services, but were at the same time unwilling to discuss the matter at length. Even though they are very pleased with the medications, it was likely that the side effects of the drugs, their uncertain immigration status, their access to money via work or benefits and other essentials for everyday life are their greatest worries. For all respondents

treatment issues were a lower priority than practical day to day living, like housing and having enough money to buy foods and clothing.

One said that she would not have gone on medication if she would have had options. She mentioned that though medication helps, it however brings more problems to her daily life. The side effects of the anti-retroviral drug are so much for her to cope with. For example, since she has started her medication, she has been continuously depressed and her social life has been limited. She has not been able to visit friends or invite her friends over to her home.

Interestingly all the respondents who are on medication, and who have been admitted into the HIV nursing centre, described their experience as encouraging. To a certain degree HIV treatments has been the most favourable HIV service that they have used. This is an experience in the study that would need further investigation, as to why they have had a positive experience using those services. There is a need to suggest here that medication itself is not the only reason why they have liked their services, but the general approach of the staff towards their needs.

9.8 Childcare, transportation and opening hours

The majority of the respondents have their children living outside the UK and so did not have problems with childcare, even though it came out strongly from the study that the service providers do not provide any childcare facilities or services.

Most of the service users have little or no transportation problem accessing HIV services. They said that there have not been many difficulties since they are not living very far from drop-in centres. It was only on few cases that two of the service users encountered some difficulties in getting to treatment appointments. They would like to be helped in such situations.

Exactly half of the respondents had used services outside the Brighton and Hove and East Sussex area. These were found to be mainly in London area. Their experience of using services in this area was overwhelmingly positive. For example they claimed attended to by people who are well trained to deal with complex issues of African cultures.

9.9 Insufficient information and fear of being stigmatised as beggars

Most respondents said that the information that they receive about general services for HIV positive people, like benefits is not sufficient. They think that some information is not simple enough to explain certain things for them without help from a service provider. Moreover they see it as very frustrating asking for clarification of the same thing repeatedly. The worst nightmare for them is begging for information to be given to them.

"I must say that there are some workers who want to help us when we come up with the issue, but sometimes we don't have the courage to do so. This is primarily because we are afraid of being seen as people going to what does not belong to them." - Service user

"I used to take my HIV related disabled child by train to many places. I was paying for all the costs until I was told of the right that I have to transportation help. It seems that when they see that you are black, they tend not to bother going further to these needs. It seems as if it is only when you have got a white person to call on your behalf that things start to go better." - Service user

All except one respondent felt they were happy with the opening hours of HIV agencies.

9.9.1 Service Improvement suggestions

On suggestions about future improvement of HIV services for the users, these were some of the recommendations given by the respondents:

1. Incorporation of more women activities into services
2. Employment for HIV positive people
3. More black representation on employment of service providers
4. Services should be provided taking into consideration the cultural diversity of users.
5. Giving transportation assistance when clients have not enough money
6. Assisting as much as possible on their immigration issues

9.9.2 Summary

In summary, respondents feel that they have adequate access to services for HIV. Most of them have ease of access in lieu of transport to drop-in centres though it could be a problem sometimes. Some of them use three service providers which suggest their willingness to explore the services available. These providers are mainly in East Sussex and London. They think that services in London which they have sometime used take a better approach to issues concerning African clients.

Respondents understand information given by services providers in English although they would have preferred if it were translated or interpreted in their own language. They feel the services provided for them are very beneficial. What they would want to see happen is the employment of a person from Black or Minority Ethnic background as part of the staff, understanding African culture into their dealing with clients and also to develop a more human approach to understanding personal concerns of clients such as housing, and immigration status application processes.

9.9.3 Outcome from the focus groups

In the three focus groups sessions for this survey, participants were more free and vocal with their opinion about HIV services for them. Topics related to their experience of services, gaps in services and expectations were covered. All overwhelmingly appreciate the general standard of HIV services in Brighton, Hove and East Sussex (Eastbourne and Hasting). Many told impressive stories of friendly reception and treatment given to them in some hospitals and nursing homes.

What they wish to see done by the service providers and local health authorities in order to make services more accessible are:

1. To help where necessary in monitoring the process and progress of their asylum applications.
2. To allow them to see the same HIV doctor irrespective of their status as asylum seekers. They are usually shifted from one doctor to another because of their asylum status. Each new doctor fails to have an update of their complications.
3. They would like to have a drop-in were they do not feel too inferior or unable to express their emotions as much as they would. For example, free internet access could be in somewhere else than places where you are very tensed about relating to other people.
4. Basically they would need someone who understands the complexity of their problem and who could work with them without seeing them as different people.

9.9.4 Some key findings

- With the exception of the large unmet need of immigration, drop in centre that is more family oriented, culturally appropriate emotional support and a link worker who identifies with them, other gaps are small.
- The difference between what services are needed and what services are asked for (“articulated need”) indicates a gap between what these people believe they need and their expectation of receiving a service. They may not ask because they do not know or perceive they are ineligible, or do not know who to ask for in order to obtain the service.
- There is a big lack of peer advice or information sharing for people from these communities living with HIV. All advice and support is mainly from professional health workers.
- Individuals’ fears regarding confidentiality are particularly strong when they have not yet trusted the service provider.
- Some of the users do not utilise the services provided by HIV service organisations. Some of these individuals do not feel comfortable with particular organisations because of their principal client populations.
- Services from treatment and care providers are more appreciated by the respondents compared to that of support and prevention services.

9.9.5 Recommendations

1. There should be clear and simple information on all available services for HIV positive people from these communities.
2. There could be more communication network with other key workers like nurses and support workers from areas, like London, where there are

- large Black and Minority Ethnic Communities. This will enable the sharing of experience and good practices.
3. Since the number of newly diagnosed HIV positive people from these communities is on the increase, service specifically tailored for these communities should be in place.
 4. A trained and experienced part-time or full-time support/link worker (particularly someone from the communities or anyone who has a proven long term experience of working with the communities on issues around HIV) should be employed to work in one HIV agency. The person will be liaising with other agencies on matters of minority ethnic communities.
 5. Efforts should be made to register and address the views of women using HIV services. There is a sense of uneasiness witnessed in them which could affect their chances of using services. Service that empowers them would also benefit the other members of the communities, especially in secondary prevention.
 6. There should be more concern about the vulnerability of asylum seekers and refugees living with HIV. This will entail more staff training on issues around asylum seekers and refugees.
 7. Involve people living with HIV from these communities in the implementation of some services.
 8. Creating a forum whereby a peer support system is possible for people from these communities. Often they need to talk with somebody from their background who is living with HIV about the experience of living with HIV in a foreign country.

10. Concluding Remarks

From the experience of conducting this needs assessment, if we have to go beyond merely interpreting stopping HIV/AIDS there are only three general arenas of actions where we need to concentrate our efforts. These are:

- Preventing new cases of HIV/AIDS through the generation of knowledge and service that improves the effectiveness of efforts to reduce the incidence of high-risk behaviours which facilitate the transmission of HIV
- Promoting knowledge and service about how to enhance the quality of life of people living with HIV/AIDS
- Implementation of knowledge we have gained or can obtain on issues related to prevention and to improving the lives of men, women and children who are already infected.

Respondents in this survey sacrificed their valuable time and knowledge to give information that is now written in this report. What is contained here is not all the information and views from the respondents, but those views that help in attaining to the objectives of this exercise. As with any interpretation of information collected in needs assessment, the viewpoint of the interpreter

influences the selection of the information to analyse, the methods of analysis, and conclusion. This report has tried to give voice to the experience of some Black and Minority Ethnic Communities and their particular HIV and sexual health needs.

The findings and recommendations outlined are designed to help in the future HIV work and services with these communities.

11. Appreciations

Service Providers and individuals who contributed in0 the research

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Dr P. Moore, Quaside Medical Practice Newhaven, Brighton

Dr R. Baker, Brunswick Surgery

Dr R.G de Souza, 120 Stanford Avenue Surgery Brighton

Dr Z. Warwick, Claude Nicole Centre/Lawson Unit Brighton

Guido Tapia, Elton John Centre Brighton

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Paul Whitehead, Brighton & Hove Migrant Helpline

Perry French, Terrence Higgins Trust South

Peter Mustow, Society of Nigerians in Sussex

Rahel Otieno, Institute of Development Studies Sussex

Richard Fitzpatrick, HIV/AIDS Mental Health Team Brighton

Rob Davis, Brighton & Hove Social Care and Health

Samuel Boakye, University of Sussex

Tony Pippen, Brighton Body Positive

Ursula Smith, Brighton Body Positive

12. List of agencies contacted during the survey

National Centre for Social Research

London Charities Evaluation

London, Enfield & Haringey Health Authority

African Community Involvement Association, London

HIV/AIDS Association of Zambia

Medical Foundation for AIDS and Sexual Health

British Medical Association

National AIDS Trust

East London Health Library

Kings Fund Library/Bookshop

African HIV Policy Network

London HIV Strategy Group

London Regional Specialised Commissioning Group

Lewisham Online- HIV Co-ordinator

Zion Community Health and Resources Centre, Manchester (African Team)

Sexual Health Promotion Specialist, Slough NHS Primary Care Trust (African Team)

Ubuntu (An African Community initiative consultant agency)

Health Promotion Library, St Pancras Hospital, London

African Health promotion Specialist, Camden Primary Care Trust

Positive Futures, African HIV researcher

Terrence Higgins Trust, African Team, London

Mid-Sussex Body Positive, Crawley

Mid-Sussex Primary Care Trust Sexual Health and HIV Team

13. References

Literature used in the review

A. McMunn, R. Mwanje, K. Paine & A. Pozniak: An Assessment of Factors Relating to Health Promotion & HIV Prevention for Ugandan Communities in Southeast London, April 1997

African Forum in Redbridge and Waltham Forest: Capital Assets, A community research intervention, November 2000

African Men's Seminar, How can men make a difference in HIV prevention?
St Pancras Hospital London, 11 September 2000

Akina Mama wa Afrika: Working with Men for Change Gender and HIV Prevention in the African Community in the UK, Conference Report, 24 April 1996

C. Bhatt: Positive Responses, A local HIV Action Strategy for African Communities, April 1997

C. Bhatt, C. Phellas, & A. Pozniak: National African HIV Prevention Projects, Evaluation Report for the Department of Health and Enfield & Haringey Health Authority, January 2000

C. Bhatt: Responses, A local HIV Action Strategy Policy for African Communities, Pages 53-64, April 1997

C. Bhatt: HIV & Black Communities 2, Primary and Secondary HIV Prevention Issues for African Communities, A Report of HIV Working Group, 1995

C. Ndofor-Tah: The West African HIV Prevention Initiative, Maximising Community Participation, 1999

Camden & Islington Health Authority: HIV Prevention Strategy, Working with African Communities in Camden & Islington, 1997-2000

D. Mukasa (Ed): Informing Policy: Issues for African communities affected by HIV

G. Elam, K. Fenton, A. Johnson, J. Nazroo, J. Ritchie: Exploring Ethnicity and Sexual Health, 1997

G. Lucas: Positive Changes, A review of progress on African HIV prevention in Enfield and Haringey, 1997-March 2002

K. Balogun: Access All Areas, A study of the accessibility of Positive Futures services for people from Black and Ethnic Minorities, June 2002

K. Fenton, B. White, P. Weatherburn and M. Cadette: What are you like? Assessing the sexual health needs of Black gay and bisexual men, 1999

Office of National Statistics, Census 2001

P. Henshaw: Adherence Issues from a Cultural Perspective, Paper presented in Asylum Seekers: Human Right Study Day, 1st November 2002

P. Weatherburn, W. Ssanyu-Sseruma, F. Hickson, S. McLean and D. Reid: Policy Paper No. 1, November 1999

Project Nasah, An investigation into the HIV treatment information and other needs of African people with HIV residents in England, February 2003

Report of the 1ST National African Communities, HIV Primary Prevention Conference, St Pancras Hospital Conference Centre London, 9th & 10th March 2000

UNAIDS Fact Sheet, 2001

14. Appendix 1

Questions for people living with or affected by HIV/AIDS

1. What is your gender? (male/female/transgender)
2. How old are you?
3. How do you define your sexuality?
(heterosexual/gay/lesbian/bisexual/unsure)
4. What is your ethnic background; where are your geographical roots?
5. Were you born in the UK?
6. If you were not born in the UK, when did you move to the UK?
7. Which HIV services, e.g. clinics, helplines, community groups, are you currently using or have used in the past year?
8. Do (or did) you find these services easy or difficult to use? (Discussion or comments)
9. What influences your choice of services from HIV agencies?
10. Do you see the gender of a service provider as any barrier to accessing services from their agency?
11. To what extent does the use of English language affect your access to services?
12. Do you have problems reading and understanding HIV service information in English texts?
13. Do you think it would improve your knowledge and access to services if information were to be translated into your local language?
14. Have you ever been offered the option of using an interpreter in any situation where some important English concepts were not clearly understood?

15. If the English language is a barrier, would you feel comfortable having someone that understands your local language to interpret for you?
16. Are there terms or topics (e.g. sexual terms) used in HIV services which you think are culturally inappropriate?
17. If yes, in what ways do they affect your use of services?
18. Do you think that cultural differences between yourself and service providers are a big barrier to accessing services?
19. If yes, could you outline some areas of cultural incompetence from the service providers?
20. Are you happy with the opening hours of HIV agencies?
21. What other opening hours would you suggest that would make your access to services easier?
22. Do you have children?
23. Do you have problems arranging childcare whilst using services?
24. Do any of the services provide childcare while you are using their services?
25. Have you experienced transportation difficulties when accessing services?
26. Have you used any other HIV services outside East Sussex?
27. If yes, which services?
28. Do you think that your immigration status is a barrier to accessing services?
29. Have you had a housing problem?
30. Have you received information from any of the HIV agencies on where to get help on housing issues?
31. In your view how can future HIV services be improved for people from ethnic minority communities?
32. What issues about your general condition do you feel that service providers have not understood yet?
33. Are there any other areas that you would like to give us information about?

Questions for the Prevention and Support providers

1. What is the name of your organisation?
2. Which area of East Sussex do you cover?
3. What kind of services do you provide?
4. Who uses the services that you provide?
5. Do you have any mechanism for monitoring the ethnicity of the client?
6. Does your monitoring take into account age and gender?
7. How many people from the Black and Ethnic Minority Communities have you seen in the last year?
8. If you are unsure of the numbers, could you estimate the percentage?
9. What is the composition of your staff in terms of ethnicity?
10. When specifically providing HIV/AIDS support/information, what number or percentage of these individuals is identified as being from Black and Minority Ethnic Communities?
11. What kind of support/ prevention information do you provide?
12. Do you think that they have responded well to the support and prevention information given to them?
13. Do you provide any other services outside what your organisation stands for?
14. If yes, what are those services?
15. Do you have separate facilities for women and men in your organisation?
16. Are there facilities for one to bring his/her child along whilst accessing services (e.g. a crèche)?

17. Do you see language as a barrier in providing effective services for the BMEC groups?
18. Do you have any information about your services translated into any other language other than English?
19. Do you have interpreters in your organisation?
20. Do you have access to translation services?
21. Do you have access to interpretation services?
22. Does gender of a service user affect the way you would provide service to him or her?
23. Does nationality of a service user affect the way you would provide service to him or her?
24. If any, what are those cultural issues that you need training in order to provide better services to these communities?
25. Is there any indication from your service users (BMEC) that they have liked the services that you have offered to them?
26. Which requests is your organisation unable to meet in delivering HIV/AIDS services to the BMEC groups?
27. What are the most significant barriers for your organisation in delivering effective services around HIV/AIDS for the Black and Ethnic Minority Community?
28. What other HIV/AIDS services do you believe your organisation needs to provide in order to effectively meet the needs of BMEC groups?
29. Could critically tell us whether you enjoy providing continuous services to these communities?
30. Is there any area that you would like to give us more information about?

Appendix 2

Literature Review Report

A review of some available publications with regards to HIV services among Blacks and Minority Ethnic Communities in the UK.

1. INTRODUCTION

This project is designed to assess the needs of Black and Ethnic Minority Groups with regard to HIV and sexual health. One of the main objectives is to find out the attitudes of people from these communities towards HIV, the ease with which they can access the services available to them in Brighton, Hove and East Sussex and their experience of using these services. The number of HIV positive people from all these groups is increasing in this area, and this has led to more people from these groups seeking access to services for HIV positive people within the region.

Frequently, the service providers find it difficult to assess the needs of HIV positive people from these communities, and the best way of responding to those needs. The first stage, however, is a review of available literature on HIV within the context of Black and Ethnic Minority groups in the UK. This will enable us to know what HIV projects have been carried out among these communities and how it could help assess the needs of the population concerned.

What will follow is a review of the projects; of their objectives, of the methods used and of the outcome of each project. There will then be a summary of the recommendations made in these projects.

2. METHODOLOGY

This review is based on published literature, electronically published data, public documents and 'grey' literature. It covers HIV related projects among Blacks and Ethnic minorities from the period from 1995 to 2002.

The bibliography at Brighton Bodypositive mentioned certain literature which was relevant to this review. However, some of this literature is not easily accessible for reasons such as not having yet been published. Steps to access this literature

were mainly taken with the help of contacts made during the induction period. Most of the people contacted were helpful, either by providing the sought material or by suggesting ways in which it could be accessed.

There was an attempt to find some of the literature at University of Sussex Library, Brighton and Hove Primary Care Trust Health Promotion Library, Camden and Islington Library, King's Fund Library, National Centre for Social Research, Medical Foundation for Aids and Sexual Health, London Enfield and Haringey Health Authority, National AIDS Trust, Sigma Research etc. Use of some of the above libraries proved to be problematic without membership. However, the Health Promotion Interlibrary was able to access and lend out some of the literature.

In order to access the grey literature, calls and visits were made to various agencies, mainly outside the Brighton area, most of whom were African HIV agencies in London. These agencies included Positively Women, Positive Futures, Lewisham on Line, London HIV Strategy Group, Slough Primary Care Trust (African Team), Ugandan HIV Community Organisation, African HIV Policy Network, UBUNTU (an African community initiative consultant agency), Zion Community Health and Resource Centre (African team), Manchester, African Community Involvement Association, London, HIV/AIDS Association of Zambia etc. Valuable material was accessed through these contacts.

Other information used in this review was gained from attending seminars at two events, namely "Asylum Seekers; Human Rights Day" and "Seminar Day of the African HIV Research Forum". Some of the papers presented were highly informative and useful.

Of all the above information, most predominantly addressed the issue of primary prevention of HIV/AIDS. Studies on treatment, care and support for people from Black and Ethnic minority groups were limited, and usually treated as a sub-topic, as was information on groups other than Sub-Saharan Africans, hence this review focuses mainly on primary prevention among Black Africans. The areas that this review fails to focus on (namely ethnic minority groups other than those from Sub-Saharan Africa) and issues of treatment, care and support could perhaps be discussed in a future meeting. Issue around gay men from minority ethnic community, particularly black gay men, is becoming very important topic in HIV studies and is considered in this project.

1. PREVENTION

1. AN ASSESSEMENT OF FACTORS RELATING TO HEALTH PROMOTION & HIV PREVENTION FOR UGANDAN COMMUNITIES IN SOUTHEAST LONDON

April 1997

By Anne McMunn, Roy Mwanje, Katie Paine & Anton Pozniak

Project

This was a research project commissioned in 1996 by NHS Ethnic Health Unit to evaluate current HIV prevention outreach being carried out by African organisations in southeast London.

Aims

The aims of this project were:

1. To understand the health needs of the Ugandan community in southeast London, particularly in relation to HIV/AIDS.
2. To learn how to provide health services and health promotion to this population more appropriately and accessibly, particularly in relation to HIV/AIDS.
3. To provide baseline information to be used in a pre-test/post-test outcome evaluation.

Key Objectives

1. To explore reception of health promotion information on a wide range of topics, particularly HIV/AIDS.
2. To measure knowledge of HIV/AIDS and of safer sex.
3. To explore perceived gender inequities in negotiating and practicing safer sex.
4. To describe the health promotion and the HIV prevention methods used in Ugandan community based organisations through a detailed case study.

What the project was dealing with and the processes

This project started from the premise that no published information on HIV prevention among African communities in the UK existed. It also argued that while interviewers had collected information from community organisation providers, no one had yet collected information from the community members themselves.

To bridge these identified gaps, the project conducted a cross-sectional survey of Ugandan communities, another cross-sectional survey of African HIV service providers in the voluntary sector as well as qualitative evaluation of current community-based HIV services for London's Ugandan community.

Community Survey

Sampling: The initial sampling frame was through the Membership lists from three Ugandan community organisations, and snowballing was then used to reach Ugandan immigrants who were not members of the community organisations. Recruitment of respondents was carried out by phone contacts, post contact and snowball referrals. Telephone was the most successful technique for recruiting respondents although snowball referral was quicker and easier.

Questionnaire: There were mainly 'open ended' qualitative questions to provide rich supplementary explanations. To ensure content validity, the questionnaire was developed in consultation with 14 Ugandan key informants, many of whom work in the HIV field.

Data Collection & Analysis: The project recruited Ugandan interviewers through the Ugandan Community Relief Association who were trained by two of the researchers. Interviews were conducted face-to-face and usually in respondents' homes. Quantitative and qualitative data were analysed using frequency distribution and content analysis respectively.

Results

Knowledge of HIV/AIDS, transmission, prevention, condom use and testing

The survey found out that a very high number of the community members knew what HIV was, and also the main routes of transmission. There was also surprisingly good knowledge in the communities regarding prevention and testing. Men seemed to have more knowledge of the differences of HIV virus and the routes of transmission than women.

Gaps in HIV primary Prevention Activities

Gaps mentioned by the respondents are:

- Heterosexual African men are not being reached
- A need to reach young African people
- A need to reach black people who are not considered high risk, such as Somalis, West Africans, Caribbean, Asians and South Africans.
- People are not using condoms and there is a need for primary prevention generally, including analysis of risk-taking behaviour.
- Primary prevention projects are not reaching groups from northern, western and eastern Uganda. The communities should work to close the political, ethnic differences and lack of information in local languages.
- Religion and fatalism in the culture were also seen as big barriers.
- Health promotion literature was seen as culturally inappropriate.

Success of the Project

Being one of the pioneering health promotion and HIV Primary prevention surveys of African community organisations and community members, this project succeeded in many areas. It raised awareness of the factors that must be given due attention if HIV prevention among African communities is to have more impact. This study is very useful because it not only produced results on the difficulties of reaching African communities, but it outlined useful information that the community already knew about HIV primary prevention. This was very important for subsequent work within these communities.

The method that this project used in data collection was very strategic. The idea of consulting some of the community members to develop the questionnaire was an excellent one.

Major difficulties

- Much of the information from the organisations' membership lists was out of date due to movement within the Ugandan community. There were incorrect telephone numbers and incorrect addresses. This inhibited their contact with most members.
- The second difficulty was the existence of political and ethnic rivalry within the Ugandan community. Ethnic groups who were not contacted at the onset of the project were not willing to co-operate. As a result of this, certain sections of the community were somewhat under and over-represented in the sample.

Key Recommendations:

- Need to look at whether what appears to be the 'new use of condom' is a result of new patterns of condom use in Uganda, or of education and awareness work being conducted by African community organisations in London, or mixture of the two.

- Resources should focus on tailored interventions around specific risks as well as capitalising on the 'converts' to influence social mores and those not yet 'reached'.
- African organisations should distribute information to people in their community to help dispel the fear of stigma for people who are HIV infected.

2. HIV PREVENTION STRATEGY 1997-2000

Working with African Communities In Camden & Islington

By Camden & Islington Health Authority

Project:

HIV prevention strategy was designed as a result of the need for a strategy to guide HIV prevention work with African communities, this being the second largest social group in the UK affected by HIV and AIDS. Camden & Islington, with the Department of Health's Evolving Strategy strongly supported this project after identifying people from African countries with high HIV prevalence as a priority for proactive HIV prevention. Even though primary prevention work had been going on in this community, there was still a need to address secondary prevention guidelines and to provide a basis for consistency in the prevention work as a whole.

Strategy group:

The strategy group consisted of individuals from the statutory sector, voluntary sector and African communities.

Aim:

To produce a strategy for health promotion aimed at reducing the rate of HIV transmission among targeted African communities in Camden and Islington.

Strategic and Specific Objectives:

- To develop and promote inter-sectoral links between statutory, voluntary and community-based organisations working on HIV prevention within African communities.
- To ensure that people from African communities have sufficient knowledge of HIV and modes of transmission, and that they know how to protect themselves.
- To develop and target culturally-appropriate educational resources.
- Evaluate the effectiveness of interventions.

Main Targets:

Black African resident populations in Camden & Islington health district who come from Nigeria, Ghana, Sierra Leone, Uganda, Gambia, Zambia, Zimbabwe, Kenya, Somalia, Eritrea, Ethiopia, Southern Sudan, Zaire, Angola and South Africa. The major targets are men and women who engage in heterosexual sexual relationships, and who are in close link with the countries of origin, for example, by travel or due to having a partner there.

How was this strategy developed and what were its achievements?

Collected demographic and epidemiological data

The strategy looked widely into the epidemiology survey by WHO and came up with statistical figures underpinning the high prevalence of the HIV epidemic in Africa compared to other regions of the world. The data mentioned that heterosexual intercourse is the main route of transmission in sub-Saharan Africa. Data from the UK epidemiology show that HIV has disproportionately affected people from minority ethnic backgrounds, and Black Africans were highly affected.

The strategy produced the demography of black Africans living in Camden and Islington borough. There was a relatively high population of Black Africans in the boroughs, (3% of the total population in Camden and 3.5% of the total population in Islington, from 1991 census). These figures were expected to rise by the year 2001.

The demography indicated that many black African residents are from countries with a high prevalence of HIV.

Identified risk factors:

- The strategy highlights that very little data existed on either the risk behaviours among African communities in this health district or on who may be at a high_risk of acquiring HIV infection, and the degree to which high risk behaviour patterns abroad are maintained while in the UK.
- The majority of heterosexual HIV infection appeared to be acquired outside the UK, mainly from sub-Saharan Africa.
- African communities might be at risk of exposure to HIV infection as a result of increased travel and migration to and from countries of origin.
- Camden and Islington has the largest population of African refugees in the UK. This would be a risk factor since they are coming from a region with a high prevalence of HIV.
- Little information exists of African men who have sex with men and intravenous drug-users. This results in under-representation of these groups in service planning.

HIV prevention work within African Communities in Camden and Islington, 1997-2000).

These are African community organisations funded to do preventive works.

1. Islington Zairian Refugee group (IZRG), targeting members of IZRG.
2. Akina Mama Wa Africa, targeting African women.
3. Ugandan Community Relief Association, targeting Ugandan community.
4. UK East African Women & Children Appraisal Group, targeting Swahili speaking communities.
5. African Churches Council for Immigration and Social Justice, targeting church members.
6. Africare, targeting African Children and families affected by HIV.
7. Zimbabwean HIV/AIDS Forum, targeting Zimbabwean community
8. Somali Welfare Centre, targeting Somali community.
9. Eritrean community (organisation), targeting people from Eritrean community.
10. Positive Care Link, targeting people from sub-Saharan Africa affected by HIV/AIDS.
11. Centrepeace, targeting women.

These organisations worked jointly with the voluntary sector organisations and statutory sectors assisting them in reaching their targets. The major reason for the collaboration of the statutory sector with the community organisations was to avoid duplication and to achieve effectiveness.

All the organisations have relatively different strategic settings for meeting with the communities. Settings such as churches, hired hall, mother tongue classes, social gatherings and hospitals were found to be ideal.

Methods for reaching out to their target groups varies from community to community, but the most used methods were: workshops, drama, group consultation, one day training, advocacy, outreach, networking, referrals, advice and seminars.

The main HIV prevention work for these organisations at that time were, HIV/STDs information and condom distribution, poster campaign, primary care, needs assessment, one-to-one sessions, drop in service, management training in health/HIV issues, nutrition support and World AIDS Day.

Intervention Options

Biomedical Prevention Strategies and Behavioural Interventions

The strategy recommends applying biomedical prevention, like organising comprehensive contact tracing, providing mass HIV antibody test and increasing provision for intensive treatment and care (secondary prevention) to HIV risk populations.

On behavioural intervention the strategy outlined the following:

- Information: Providing basic information about sexual behaviour as it relates to HIV prevention through the use of visual and auditory media, and through newsletters.
- Education: Using health professionals to distribute information, involving seminars, group discussions etc.
- One-to-one intervention: provided by professional workers and volunteers giving information on HIV related matters and services.
- Popular media: making prevention messages more human and less direct by the use of theatre, fiction, music, poetry, song, dance, film etc.
- Behavioural-skills training: helping people to put information about safer sex into practice through the acquisition of behavioural skills aimed at communication, e.g., eroticised condom usage and non-penetrative sexual practices.
- Community/Peer interventions: Using peer education models to inform people about HIV. Islington Council HIV Services and Camden & Islington Health promotion Service have trained a group of peers educators nominated by their community groups from Zimbabwe, Zaire, Somali, and Kenya to carry out peer education in their respective communities.
- Outreach: improving contact and access to the members of the community group who have difficulties in accessing HIV information from the regular places. An example is the Magic Carpet cruising project carried out by the Health Promotion Services in Finsbury Park, and Ugandan community Relief Association promotion of one-to-one work in people's homes.
- Community Group Events: Targeting larger community members through the use of social events.

Evaluation of Behavioural intervention:

The strategy referred to a number of studies evaluating attitudes and sexual behaviour change in a number of African countries like Uganda, Kenya, etc., and in the USA focusing on high risk groups within African-America and Hispanic communities.

The strategy found no reports of a quantitative work on African born communities living outside Africa.

From the evaluation of HIV promotion programmes aimed at a range of other high risk groups (gay men, IV drug-users, etc.), the strategy discovered that the

provision of information is essential, but not enough to bring about significant and long lasting behaviour changes in sexual attitudes and behaviour.

The strategy hypothetically suggested the claim that the influence of group norms over an individual's behaviour is as powerful, if not more powerful, within African communities, when compared with western communities and that peer-based interventions will be required to bring about significant changes in high risk sexual behaviour within in these populations.

Major recommendations by the strategy are:

- Prioritisation: in the following criteria (a) assessing the degree of risk to which individuals or groups may be exposed, (b) assessing the extent of equity, (c) assessing the most appropriate opportunities for prevention, and (d) carefully studying the local demography.
- Emphasis should be given to partnerships and good working relationships with the African communities.
- Prevention should take on board these three levels: (a) primary prevention- concerned with preventing HIV transmission, (b) secondary prevention- concerned with reducing the rate of progression of HIV once transmission occurs, and (c) tertiary prevention- concerned with minimising the avoidable complications of AIDS and AIDS related conditions.
- Personal strategies should be addressed in the context of African cultural and individual diversity taking into account lifestyles, roles, and societal expectations and the influences of the socialisation process into which individuals have been brought up.

3. REPORT OF THE 1ST NATIONAL AFRICAN COMMUNITIES HIV PRIMARY PREVENTION CONFERENCE

9th & 10th March 2000 at St Pancras Hospital Conference Centre London

Prevention Conference:

Participants:

This conference was attended by participants from all over the UK and beyond which included strategists and planners, commissioners, health care staff from clinical services, providers of prevention services, researchers and academics, from both the voluntary and statutory sectors.

Aim:

The aim of the conference was to explore effective ways of developing, implementing and commissioning HIV primary prevention for African communities in the UK.

Key Objective: To raise the level of knowledge of social and cultural factors that put African people at an increased risk of HIV infection, and the way to provide effective HIV primary prevention.

Key issues from the presentations:

The need for diverse approaches so as to address the diverse cultural, religious, national, ethnic and linguistic needs of Africans.

There was the need for investment in research work on African cultures and how it relates to attitudes and behaviours around sex and HIV.

The need for targeted work with African communities was addressed.

The need for a partnership approach to work with African communities was seen as very important.

The conference had numerous presentations that offered an unprecedented opportunity to embrace and challenge information about HIV prevalence among African communities. It also brought into focus the debate on success and failures of HIV prevention work with Africa communities so far.

The conference was evaluated by the attendants as a success, and hoped that it would be held once in every two years.

Key recommendations:

These are four key recommendations very useful to take on board.

- The conference recommended that there should be more behavioural research into what puts African people at an increased risk of HIV transmission for example risk-taking behaviours including cultural attitudes, beliefs and practices, in order to inform intervention.
- They expressed the need to integrate sexual health into HIV interventions at a community level.
- There was the need to include and mobilise religious communities within the existing religious structures and networks in order to maximise their contribution to HIV prevention within African communities.
- African men need to be specifically targeted for HIV prevention in order to facilitate the reduction of HIV transmission within the African community.

4. WORKING WITH MEN FOR CHANGE GENDER AND HIV PREVENTION IN THE AFRICAN COMMUNITY IN THE UK

Conference Report, 24 April 1996

By AKINA MAMA wa AFRIKA (A non-governmental development organisation for African women)

This is a report from a conference organised to deflect the discourse away from 'risk' to a more comprehensive examination of the factors that influence African women's vulnerability to HIV infection. It was also meant to focus the minds of leaders and members of the communities, as well as the statutory sector, on salient points that inform behaviour, belief and practice in the African communities and their implications for effective health promotion work. The conference was supported by Health First/Afrikan Health Forum of Lambeth, Southwark & Lewisham.

Three important lessons from the conference

- The conference addressed gender awareness and sensitivity to the needs of women in general and the needs of women infected and affected by HIV/AIDS in particular. It was clearly stated that if HIV prevention work is going to yield higher and better results, particularly among heterosexual Africans in the UK, it has to be carried out in a gender context and not in single sex focused (usually towards women) that has been the norm to date.
- The conference agreed that given the power imbalance within most African communities, men are in a strategic position to effect change.
- The conference addressed certain social mores which govern the behaviour of young African men and women, the role religious and cultural leaders play in shaping behaviour and change in the communities, and also the gender and power roles in relationships.

- The conference complained that African community organisations are not encouraged to be involved in policy and strategy development around HIV prevention and other issues.
- Finally the conference concluded that HIV/AIDS prevention involves more than the adoption of offensive prophylactic technology. It involves above all, complementary strategies for action that interact within cultural values, HIV infection, the rights of women and widespread implementation of community-based prevention programmes.

The conference was celebrated with success. The only complaint was the low attendance of men. But they agreed to put more efforts into encouraging men to attend the next conferences.

5. AFRICAN MEN'S SEMINAR

How can men make a difference in HIV prevention?

11 September 2000

St Pancras Hospital London

This seminar was organised as a result of the recommendation from the 1st National African Communities Prevention Conference, and also from the outcome of other conferences that raised gender awareness.

Contributions from most men in these conferences were seen as gender insensitive by the women, and therefore unable to influence positive changes on HIV prevention work. The lack of involvement by men in HIV projects was also a concern.

This seminar was therefore, to encourage men in becoming more involved in HIV and sexual health services, particularly on HIV prevention, to bridge the gap of gender disparity in the field and to maximise their knowledge on gender networking.

Key Points from the seminar presentations:

Men have very often been overlooked in work around HIV prevention. There has been less support from the statutory and voluntary sectors.

Negative social environmental impacts on African men in the UK means that they may not be pre-disposed to making important health decisions, both for themselves and their families. It was found that people from African communities are the most highly educated ethnic group in the UK, including white people.

There is no hard data to inform us about what African men in the UK know about HIV, what their attitudes are towards HIV and what their risk behaviour is towards it.

African men need to develop openness in discussions about sex and sexuality and they must be prepared to discuss frankly the myths and realities which surround sex, sexually transmitted infections, reproduction and the importance of having children in African culture.

Key Recommendation

Support to be given to schemes which aim to encourage African men to engage with health agencies, to have concern for their general and sexual health, to speak more openly with each other about sexual matters, to confront the traditional African myths and stereotypes which surround sexuality, to come to terms with the use of condoms and to embrace their responsibility to take an active role in HIV prevention.

A scheme should be established to distribute condoms as widely as possible to African communities to ensure that men and women have easy and reliable access.

6. CAPITAL ASSETS

A community research intervention
by African Forum in Redbridge and Waltham Forest (London)
November 2000

Project Objectives

The survey project was designed both to gather information from the communities and to provide information to them. The information sought was not simply about the participant's information needs but also about the assets they have to address those needs within their own communities.

Methods:

Sigma Research designed the survey, the input and analysis of the data and writing of the report. They also designed the questionnaires but the members of community groups interviewed members of their community. The report of the survey highlighted mainly the issues that related to access to services, but few issues on prevention were reported because it was also the intention of the project to assess knowledge about HIV and preventing infections.

Prevention issues & Recommendation

Given concerns about the prevalence of HIV among Africans resident in London, the communities were asked about their knowledge of HIV and how it could be transmitted.

The finding shows that 68% of the respondents knew the right answers. One in ten of the total respondents were unsure or did not know how HIV was transmitted. 63% knew that HIV is a serious health problem for many Africans living in London.

Basic knowledge of sexual transmission routes of HIV was higher than medical knowledge. And HIV transmission from a woman to her child, either during birth or during breastfeeding, was far less widely known about than sexual transmission.

Women were generally in more need of information about HIV and prevention.

The data suggests that the lack of basic HIV knowledge among African people in London is extensive and there have been few targeted and culturally appropriate interventions that aim to address this need.

It then strongly recommends that consultation needs to take place with the community groups with regards to devising initiatives that will utilise the substantial number of social sites and social networks as an aid to health promotion, especially with regard to HIV prevention.

7. THE WEST AFRICAN HIV PREVENTION INITIATIVE

Maximising Community Participation

By C. Ndofor-Tah

1999

Project and Aim:

This is a report from a pilot carried out on behalf of Enfield and Haringey Health Authority between January 1999 and July 1999.

The project aimed to take health promotion to the West African communities; identify their social venues and programmes, and explore the feasibility of integrating health promotion into their activities.

Programme and Methods:

The programme for this project was developed in 6 stages: (a) development work to identify groups/leaders (b) needs assessment (c) primary HIV prevention intervention (d) evaluation and (e) report writing.

Methods used to address the needs of the project were: (a) literature review (b) Outreach work (c) Networking and (d) Needs Assessment.

Result and Recommendations:

Many groups and leaders were impressed to have the workers in their meetings even though they expressed prejudice towards HIV+ people. In most cases the workers were given longer time than agreed to speak to the community.

It was clearly evident that these communities are in great need of HIV awareness and prevention programmes.

There was great impact from using positive people to address the communities.

It was found that 90% of the respondents were knowingly coming in close contact with a HIV+ person for the first time.

The project has made a great impact in terms of raising and providing information on HIV prevention and transmission.

Key Recommendation:

The approach of identifying groups and leaders, visiting them in their various meetings, and using positive speakers in this project was very cost-effective and rewarding. It was highly recommended that meeting people in their own environment or space with a positive person to explain to them what living with AIDS means put a reality to prevention and brings the issue of HIV more to the forefront for these communities than any seminar could.

8. POSITIVE RESPONSES A local HIV Action Strategy

For African Communities, April 1997

By Chetan Bhatt

This report was for Enfield & Haringey Authority and it was intended to inform local service commissioning and service development policy in order to improve services for African communities.

Method:

This report conducted an extensive demographical and epidemiological survey. It explored the most useful resources available to generate useful data on the general epidemiology internationally, in the UK, and in Enfield and Haringey. It

then mapped out clearly the social and demographic characteristics of the Black African population living in the UK and in Enfield and Haringey. By putting these groups into smaller categories, it was easier to identify specifically the areas of HIV prevention among the African communities that needed attention.

Reports Findings

The report's epidemiological data showed that Enfield & Haringey has among the highest rate of heterosexually transmitted HIV infection in the UK.

Africans particularly people from Nigeria and Ghana, were considered to be at high risk and needed to be included in the HIV prevention strategies.

HIV prevalence data also showed a high rate of prevalence among pregnant women, particularly among pregnant African women.

There has been failures locally and nationally to recognise and identify heterosexual HIV infection.

It identified work with African communities to be at a critical juncture in the Enfield and Haringey district and needed broad organisational and structural attention.

Methods and models used within Enfield & Haringey in primary prevention work:

- A rolling strategy of community development work with mainly local African community groups.
- Event-based primary prevention activities (during World AIDS Day and so forth)
- Funding of posts in African community groups so that workers can undertake direct education work with members of the community in both primary and secondary prevention areas.
- A constant, persistent and tenacious presence of Enfield & Haringey health promotion staff at virtually all local African community-based events.

Key Recommendations:

- It recommended that the health authority investigate areas of opportunistic safer sex and sexual health education.

- It recommended that the Health Authority consider consultations with the locally-based sites in order to initiate a locally-based pilot targeted education exercise
- It recommended that a specialist working team be convened locally to discuss and work through the broader and quite urgent implications of unidentified HIV infection in African communities.
- It recommended that steps must be taken quickly by the health authority in order to ensure that community-based health education in some African communities continues.

9. POSITIVE CHANGES

A review of progress on African HIV prevention

In Enfield and Haringey 1997-March 2002

By Greg Lucas

Aim:

To produce a report which makes recommendations on the strategic direction to be taken for HIV prevention work with African communities, reviewing achievements against targets set out in Positive Responses and which takes account of local epidemiology changes, evidence of effectiveness and new policy initiatives.

Methods

Three different methods were used for collecting data. They were (a) document review, (b) semi-structured interviews, and (c) use of focused groups.

Findings

This document showed that the number of African men and women infected with HIV is increasing at a faster rate than the African population in general is increasing. But there is practically no reliable data on the pattern of infection amongst different African communities within the UK. Given the increasing figures and the fact that there is a serious and growing epidemic in West Africa, West Africans continue to be missed by, or miss, safer sex messages and prevention interventions.

The document reports that there have only recently been studies of the vast diversity of cultural and other factors that influence African sexual behaviour. There is also little clear data linking HIV to deprivation in spite of the fact that the borough of Enfield and Haringey identified as having the highest deprivation scores.

It quoted the emerging themes from the UK studies from other authors, which are:

- The limited role in parental teaching on HIV and sexual health
- The specificity of sexual behaviours and uncertainty surrounding STI transmission risk
- Twice the number of men than women have a new sexual partner when they visit 'home'

It also quoted from other authors four different criteria that could form the basis of adequate responses.

- HIV prevention information: basic information about HIV transmission; sexual risk and sexual practice including perception of condom use; pregnancy and ante natal testing.
- Negotiation skills: to deal with culture and power barriers to maintaining safer sex practices; negotiating safer sex.
- Culturally competent service: easy access to free condoms and lubricants.
- Work to address HIV related discrimination: individual support for those worried about disclosure; women's experience of domestic violence and rejection from home.

Recommendations:

The document recommended the following:

- Basic research into African demography, economic and social well-being linked to health status including HIV
- Joint statutory and voluntary agreements about testing and prevention processes including action research.
- More focused and targeted work with particular groups and populations based on transferable tools to address risk assessment, sexual practice and condom use. For example working with men and working with women, and use of 'traditional' communication methods, and establishing partnerships with religious leaders.

10. NATIONAL AFRICAN HIV PREVENTION PROJECTS
Evaluation Report for the Department of Health and Enfield &
Haringey Health Authority, January 2000
By C. Bhatt, C. Phellas, & A. Pozniak

Project

This is an evaluation report for the first year project commissioned by Enfield & Haringey Health Authority in the period April 1998 to March 1999 for HIV prevention projects in African communities in England.

Whereas this report has been useful in its evaluation of HIV prevention projects among African communities through media, there is no significant difference in the epidemiology and demographic data used in the previous works of the authors.

For this reason few findings from the report will be outlined.

Methodologies used in media HIV prevention projects:

The report undertook a methodological critique of some media preventive project. This evaluation was very systematic and strong in critique. Many African media projects, like African Information on Line, Terrence Higgins Trust (African team) etc., and other non-African independent commercial research organisations were evaluated and given recommendations on where to improve.

Internal structure, particularly the planning body saw need for improvements. For example THT use of focus group in the process of developing leaflets was seen as a good method, but inappropriate method for editorial and content discussions of written material. Nominal groups, and wider detailed peer review was supposed to be more appropriate for those specific tasks.

Other HIV prevention areas:

Future campaigns may need to address impact of proposed dispersal policies, and need to target certain areas, e.g. Manchester and Birmingham.

More prevention work among African teenagers of which there have been little.

Recommendations:

- Feature projects maximise the integral involvement of the African independent sectors.
- Evidenced-based approaches are both explained and prioritised in future interventions
- Feature project works towards creating and demonstrating a coherent symbolic identity in their various campaign materials and activities.
- Outcome measures should be integrated into any future media campaign and each of its components.

EXPLORING ETHNICITY AND SEXUAL HEALTH

BY Gillian Elam, Kevin Fenton, Anne Johnson, James Nazroo, Jane Ritchie
1997

This was a report on an in-dept study of sexual attitudes and behaviours among Jamaican, Black African and South Asian People. It is the first community-based, qualitative survey among ethnic minorities in Camden and Islington Health Authority, and indeed in the UK.

Core Objectives of the study

- To explore sexual health attitudes, practices, and behaviours among selected ethnic minority groups, specifically, South Asians- Indian and Bangladeshi, African Caribbeans- Jamaicans, Sub-Saharan Africans- Nigerian and Ugandan.
- 9. To identify the personal, cultural and other factors that influence sexual lifestyles.
- 10. To provide and understanding of behavioural and cultural norms, related to sex and sexual health behaviour among the minority ethnic groups that will inform current health promotion activities.

Method involved in the study

The study used qualitative survey techniques in identifying a representative sample of minority groups; and collecting accurate information from the groups on this sensitive subject. The qualitative approach made it possible to describe the range and diversity of attitudes and behaviours and personal and cultural histories that have formed them.

Even by using the member of the communities in the interviews, there were number of methodological challenges in this study. It was not possible from the study to provide any statistical statements about the prevalence of different lifestyles not the characteristics associated with them. This let to conclusion suggested by the data to be presented only as hypotheses to be tested.

Factors influencing sexual lifestyles

Many factors were found to influence the sexual lifestyles of individual in the study communities. The most important were gender, religion, acculturation, and individual interest in sexual matters and sexuality

Other literature which were not reviewed in this report but which also has valuable information on prevention were:

**HIV & BLACK COMMUNITIES 2
PRIMARY AND SECONDARY HIV PREVENTION ISSUES**

For African Communities
A Report of HIV Working Group
Compiled by C.Bhatt
1995

WHAT ARE YOU LIKE?
(Assessing the sexual health needs of Black gay and bisexual men)
By Kevin Fenton, Bryan White, Peter Weatherburn and Michael Cadette
Published by Big Up 1999

2. TREATMENT AND CARE SERVICES

It was difficult accessing literature that separately dealt with HIV treatment among African targets. However, there is little literature that discussed treatment and care as a sub-topic. What this indicates is a need for more research in this area.

1. RESPONSES A local HIV Action Strategy
POSITIVE For African Communities, April 1997
By Chetan Bhatt Pages 53-64

Positive response discussed the use of treatment centres by African communities in Enfield & Haringey. Findings suggest that access to HIV Treatments by these communities could be determined by gender, the location of the clinic and the nationality of the user.

Positive response survey came up with two conflicting data about the use of the local clinics by HIV positive people. CDSC claimed that those exposed to HIV through heterosexual sex were less likely to use the local services, compared to gay men, whereas Enfield and Haringey claimed otherwise.

African positive women were found to be using the local treatment sites more than men. It is not clear whether this is because the clinic is perceived to be more gay 'identified' or conversely less 'African identified' than the other clinic outside the district.

Despite the existence of extensive dedicated HIV treatments and services, most service providers have reported seeing a relatively large number of people belonging to one African community (Ugandans), in comparison with any other national linguistic group, and this is consistent with pan London data.

Some suggested reasons for this are:

- Low experience of staff in responding to the complicated life of African HIV positive people.
- Inaccurate perception of treatment centres by Africans due to the mortality of African patients.
- Non-integration of treatment services with other services such as counselling and social services.

Positive response recommends that more research will be needed in this area, but agrees that it is a very sensitive issue to get information from HIV positive Africans, especially from groups that are already insecure about their legal status in the UK.

2. INFORMING POLICY

Issues for African communities affected by HIV

Policy Paper No. 1

November 1999

Edited by Dorothy Mukasa

This is a report document by the African HIV Steering Group intended to inform national and local HIV policy as well as improve and influence HIV prevention work and service access for African communities. The report was based on research conducted by members of this group and covered a range of many HIV related issues, including treatment.

The report did not outline clearly the research sample and the method used for data collection. However, it told of the outcome of the research.

Reasons for less use of treatment services

Clarity

Members of African communities affected by HIV usually have little knowledge of the statutory sector and how it functions, particularly the National Health Service. There is lack of clarity about entitlement to treatment and care from the African communities.

Language

Language barrier creates an imbalance in effective communication and negotiation. In some occasions many African people do not understand the meaning of some terms used in the medical field, but consent to the treatment. Eventually when they have found that they were falling short of their expectations, they pull back from attending services. An example is a lack of understanding of complying with drug prescription guidelines.

Priority

The report records that health issues are not often the top priority for many people. Going to the General Practitioner is usually seen as 'unnecessary'. Many Africans end up in the hospital when their illness has developed to crisis point.

Traditional remedies

Many Africans explore complementary remedies, like traditional medicines for their healing, before resorting to conventional medicine. One reason for this is the general lack of trust in medical providers.

Evaluation

Finally, it lamented the lack of evaluation of effectiveness in reaching those targeted for treatments.

Adherence:

Given the multitude and complexity of issues in African communities relating to treatment, education and information, the report agreed there is very little reason to

believe that adherence rates are any better in this group than among other ethnic minority groups.

Recommendation:

- There could be more evaluation of effectiveness in reaching African communities who are on HIV drug treatments.
- Community-based interventions need to be developed using peer education models that have been successful elsewhere in HIV sector.

2. ADHERENCE ISSUES FROM A CULTURAL PERSPECTIVE

Paper presented in Asylum Seekers: Human Right Study Day
1st November 2002

By Philip Henshaw

Henshaw's paper argued that though cultural factors like religious beliefs could sometimes explain adherence issues, ethnicity is not a good explanatory variable for adherence. He outlined factors associated with low adherence found in many ethnic groups or cultures. These are: (a) pill factors- large numbers of pills, large pills, doses, unpleasant side effects, etc; (b) process factors- change in daily routine, clashes with other priorities, forgetting, etc; and (c) person factors- mental health, psychological well-being, attitudes and beliefs etc.

African communities who responded to his interviews spoke of oppression and poverty via depression as having a major impact on adherence.

Henshaw found that Africans in London hesitate to go for treatment due to these reasons:

- HIV is highly stigmatised – and this leads to secrecy and isolation.
- Fears of disclosure and confidentiality of clinics, waiting rooms, voluntary/support groups.
- Perceived distrust and discrimination against the medical profession.
- Alternative treatment and sources of care.
- Lack of knowledge about anti-retroviral medications and treatment decisions.

Recommendation

There was no specific recommendation in this presentation.

3. ACCESS ALL AREAS

A study of the accessibility of Positive Futures services for people from Black and Ethnic Minorities

June 2002

By Kay'e Balogun

Aim

To offer guidance to Positive Features on the best and most appropriate form of service delivery, in meeting the needs of blacks & minority people living with HIV & AIDS in London.

Method used

The author conducted a quantitative and qualitative survey on a London-wide sample of HIV service users from black & ethnic minorities. These service users were interviewed between March and July 2001 at various Black HIV organisations and mainstream organisations that provided identifiable services.

There were also some informal discussions with workers and staff from service providers and observations of discussions among service users.

Achievement

The report identified barriers, perceived and real, and explored some of the wider issues facing people from black and ethnic minorities and how these affect their ability and /or willingness to access services.

From service-users point of view the barriers are:

- Immigration issues-
- Distance of Positive Feature
- Care for their children while accessing services
- Stigma and Confidentiality
- Ill Health of the client group.
- Lack of self-esteem, self-confidence and assertiveness
- Priorities attached to other issues, such as racial discrimination, isolation, financial difficulties etc.

Poor partnership with other organisations was also identified as a barrier. Many organisations do not know exactly what services Positive Features are providing, hence there were problems with referring people to them.

Recommendations

- Services offered by Positive Features need to be more widely advertised and publicised both within the partnership and to potential service users.
- Immigration advice, care and support should become a key part of Positive Features' services.
- Positive Features should consider offering childcare and covering transportation costs of users to ensure that financial difficulties do not present a barrier to accessing services.
- More close work with Black and ethnic minority HIV organisations.

