Waverley Care

HIV becomes your name

A report on the issues facing Africans living in Scotland who are HIV positive.

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1.1 Executive Summary

1. This is the second report from a three-year project funded through Voluntary Action Fund. Its purpose is to research the issues facing Africans living in Scotland who are HIV positive and to provide recommendations to service providers and policy makers on how needs can best be met.

2. The report is based on extensive one to one interviews with 25 Africans living with HIV, primarily from Edinburgh and Glasgow. Of the 25 people interviewed 10 were asylum seekers.

3. All of the dispersed asylum seekers had previously lived in London where they had access to a range of support services. None had chosen to live in Glasgow and most compared the services available to them there unfavourably to those they had received in London.

4. Most people had been tested for HIV in the UK because they had become ill with many receiving an AIDS diagnosis at the same time.

5. Reasons people gave for not seeking an HIV test earlier included denial, feeling and looking healthy, fear of stigma.

6. People's experience of HIV in Africa, as an illness without treatment and leading to a certain death compounded their reluctance to take an HIV test.

7. People's experience of accessing health care in Africa, only when physically ill, influenced their view of accessing health care in the UK.

8. All respondents were devastated by their diagnoses with shock, denial and suicidal feelings being experienced. This was partly influenced by their experience of HIV in Africa where it is usually a terminal illness and subject to stigma. Feelings of shame, humiliation and loneliness featured extensively.

9. Women tended to blame themselves but men tended to blame their partners or others.

10. Access to support and pre and post-test counselling varied but where they had been used they were found to be beneficial.

11. People valued support services where they were available, including the opportunity to meet other Africans living with HIV.

12. People had mixed responses following their decisions to share their diagnosis with others. Sometimes their feelings of rejection and isolation were compounded by stigma within the community. None of the respondents had felt able to share their diagnosis with families in Africa.

13. Some respondents felt that they had received poor treatment from medical staff at HIV clinics.

14. Asylum seekers in Glasgow described the HIV health services as generally helpful, but most described their GP's as ill informed and occasionally racist. All the Glasgow asylum seekers described difficulties in finding out about the services available on dispersal.

15. One common problem reported was in understanding the way health systems work in the UK. People struggled with the appointments system, the role of the receptionist and the sharing of confidential information.

16. A further common problem was the fear of being seen using HIV services. This has much to do with HIV related stigma within the African community.

17. Those respondents on treatment appreciated being on it and recognised the benefits but their knowledge base of HIV treatment was limited. People found the available information overly complicated.

18. There could be a gap between people's knowledge of English and their understanding of words and phrases in context e.g. understanding adherence in relation to HIV treatment.

19. Those respondents not on treatment were anxious about beginning them as they saw this as a marker in the progression of the disease and they were terrified about being unwell when they were on their own in a strange country.

20. All respondents with uncertain immigration status were anxious about being sent back to their home countries without access to HIV treatment, especially the regime they were already taking.

21. The most commonly identified health problem was depression.

22. The three main social issues reported were poor housing, lack of money and immigration problems. Many people expressed a wish to work and were frustrated at not being able to support themselves.

23. All respondents with uncertain immigration status reported that due to delays in the Home Office's decision making, their lives were put on hold and often this resulted in them feeling helpless and hopeless.

24. All of the asylum seekers in Glasgow reported housing problems including over-crowding, dampness and no heating. Where these had been reported to the local authority or housing association no discernible action had been taken.

25. All of the asylum seekers reported financial problems. Financial support provided through NASS was not seen as providing enough to live on and where NASS had been withdrawn people were dependent on friends and charities to support them.

26. People's experience of the immigration system was extremely negative with difficulties reported including access to and behaviour of lawyers and communications with the Home Office. Some asylum seekers were fearful that they could be subject to the very behaviours that had originally caused them to flee their home countries.

27. Nearly all respondents reported experiencing racial abuse and harassment from both individuals and institutions with whom they came into contact.

1.2 Introduction

According to 2004 data from UNAIDS, of the estimated 40 million people infected world-wide with HIV and AIDS, 25-28 million reside in sub-Saharan African countries. Sub-Saharan Africa, particularly Eastern, Central and Southern Africa, remains by far the region worst affected by the HIV and AIDS epidemic; it has just over 10% of the world's population but is home to more than 60% of all people living with HIV. In 2004 an estimated 3.1 million people in the region became newly infected, while 2.3 million died of AIDS. Among young people aged 15-24 years, young women and girls now constitute 75% of all those living with HIV/AIDS in that age group. Adult infection rates of almost 40% have been reported in some countries of Southern Africa. This is reflected in the pattern of the epidemic in the UK, which has strong historical links to this region.

In 2003, in the UK, there were 2624 new diagnoses of HIV infection in heterosexuals probably infected in sub-Saharan Africa. This accounts for 69% of all heterosexuals' diagnoses in 2003. Women outnumbered men among heterosexuals diagnosed with HIV in 2003, with 65% of new diagnoses being in women.

In Scotland, in 2004, there were 365 diagnoses of HIV reported to Health Protection Scotland (HPS); this total exceeds the previous highest number of diagnoses on record (348 in 1986) and more heterosexuals were diagnosed in 2004 than in any previous year.

As in the rest of the UK the increase in the number of heterosexual male and female diagnoses of HIV is mainly due to increasing numbers of persons originating from high HIV prevalence countries in sub-Saharan Africa. In cumulative HIV diagnoses reported to HPS, of the 529 people known to have acquired HIV in Africa up to the end of March 2005, over 50% are women.

HIV infected Africans tend to be diagnosed later than other population sub-groups (Burns et al 2001); they present with significantly more advanced disease than non-Africans and may have had their infection on average for a longer period of time.

In the Project NASAH study (An investigation into the HIV treatment information and other needs of African people with HIV resident in England 2003) more than a third of respondents were first diagnosed in an in-patient hospital setting and just under half were first diagnosed in an HIV/GUM out-patients setting.

The response in England to increasing numbers of Africans living with HIV has been the development of specific services; many created and delivered by African communities themselves. Whilst the overall number of Africans affected in Scotland is much smaller and organizational responses have been much slower, the community itself has seemed to stay very silent about HIV. This could be attributed to various reasons such as stigma and discrimination about HIV and race, fear of rejection by family and friends, concerns about immigration issues and a relatively small community.

HIV stigma can act as a powerful barrier to accessing services, to disclosure of HIV status in personal and social settings and to enjoying the same rights and freedoms as those who are not HIV infected. The challenges faced by African people with HIV need to be understood as existing within African settings in addition to mainstream settings. (Project NASAH)

Despite the increasing figures, there is little documented information about how the health needs of HIV positive Africans are met in Scotland. This lack of information ultimately limits the understanding of service providers on how to shape services so that they better meet the needs of Africans.

Waverley Care has responded by conducting this research which, as well as researching health care needs, is aimed at highlighting major issues regarding the stigma and double discrimination that Africans face. The research also aims to increase understanding of cultural issues within these communities and provide information to service providers and policy makers so that there can be a better informed approach to addressing their needs. One important strand of this is the connection the project has with the African HIV/AIDS Policy Network (AHPN) based in London. Our research in Scotland is able to bring a Scottish dimension that helps inform the work of the AHPN on a UK-wide basis and their work is equally able to help inform our research here in Scotland.

1.3 Background To The Research

Waverley Care was founded in 1989 to provide care and support to people infected and affected by HIV/AIDS. It does this through a range of projects including:

- Waverley Care Milestone - a residential respite care centre
- Waverley Care Day Care Service - supporting people through structured day care activities
- Waverley Care Solas - A community based information and support centre
- Waverley Care Buddy Service - offering a befriending service through trained volunteers.

The organisation works closely with many other agencies from the statutory and voluntary sectors and is represented in a number of national and local planning and policy fora.

Waverley Care Solas operates a number of projects including a national information centre, which had been the primary source of giving information to Africans living with HIV in Scotland. However, it became apparent that a much more targeted and pro-active approach was required if people from Africa were to be reached successfully.

Waverley Care proposed plans to recruit an African Outreach Worker to perform the following tasks:

- Undertake a mapping exercise of the African community in Scotland and their health care issues and needs, particularly in relation to HIV and other blood borne viruses.
- Establish a Scottish African HIV network.
- Liase with the African HIV Policy Network in London, attend relevant meetings and reflect the needs of Africans living in Scotland.
- Act as an information resource on HIV and other blood borne viruses to the African community in Scotland.
- Act as a link between major service providers and the African community.
- Act as resource to major service providers in making their services more culturally appropriate and therefore promoting greater access.

Through undertaking these key tasks we anticipated:

- A greater awareness amongst the African community of HIV issues and the benefits of testing for HIV.
- Services which were more culturally sensitive to the needs of the African community, therefore encouraging greater access.
- The development of policy that reflected the needs of the African community in Scotland.
- Increased ability to challenge discrimination relating to HIV and the African community.

It was planned that the project would work across Scotland but with an inevitable concentration in central Scotland where the majority of Africans reside. The majority of Africans attending treatment centres are within the Lothian and Greater Glasgow NHS areas.

The proposal emanated also from our contact with Africans living with HIV who told us that there was little recognition within the African community in Scotland of the relevance of HIV and no dedicated or targeted work with this community.

The research has been funded by the Scottish Executive and is administered by the Voluntary Action Fund (VAF).

The first year of the research was designed to gather information from Africans living in Scotland with regard to their health needs. Over 80 Africans participated in the research.

1.4 Summary Of The Main Findings From The First Year Of The Research

- Most Africans in the survey fell within the age range 30-34 years, an age when people are more likely to be mobile.

- The majority of people came to Scotland for educational purposes, followed by employment opportunities.

- Those Africans surveyed were relatively new migrants to Scotland and many came from countries with long standing links to the UK. Many countries mentioned as places of birth were those with high prevalence of HIV and were within the Sub-Saharan region of Africa.

- The majority of Africans in the survey had both higher educational and professional qualifications although these qualifications did not reflect their employment status and most of them indicated that they had immigration problems.

- Immigration problems resulted in increased levels of social isolation and exclusion due to separation from family units and lack of support networks. Twenty per cent of respondents with children did not have their children with them in Scotland.

- The friendliness of the Scottish people was cited as one of the most positive experiences about being in Scotland.

- However the majority of the respondents in the survey also mentioned that they had experienced racism.

- The largest number of people in the survey found out about health and other services through friends and family.

- Difficulties in accessing services were similar to those one would expect from the rest of the Scottish population.

- Respondents did not cite discrimination as a barrier to accessing services.

- The majority of the respondents displayed a good knowledge of HIV. However, some respondents mentioned that safer sex may not be practised over time due to complacency.

- Sixty nine per cent of respondents said that they had been tested for HIV. The majority of these fell within the age range 18-39 years.

1.5 Aims and Objectives Of The Second Year Of Research

This second stage of the research specifically addresses the HIV health needs of Africans living in Scotland and this report presents the information gathered during the interviews with Africans infected with HIV. In order to hear their voices and gain an understanding of the lived experience of Africans with HIV, 25 in-depth one to one interviews were conducted. Of the 25 people interviewed 10 were asylum seekers and 11 were in the process of applying for leave to remain on the grounds of health.

Sensitive interviewing was carried out, aware of stigma and anxiety attached to HIV/AIDS particularly within the African community. Careful consideration was given to the format of the interview with interviewees offered an opportunity to decide where and when the interview could best take place. Strict adherence to the principle of confidentiality was followed and interview times varied substantially from 2 to about 3 and sometimes 4 hours for each interview. The length of times depended on whether interviewees became emotional or not. Those interviewees who became emotional were given time to go through that process without interference and then the interview continued.

The aims and objectives underpinning the research were:

Aim:

- To increase access to HIV treatment and support for Africans living with HIV in Scotland.

Objectives:

- To target Africans living with HIV in Scotland to further identify their specific HIV related needs
- To address discrimination facing HIV positive Africans accessing services in Scotland.
- To identify barriers that prevent Africans living with HIV from testing early
- To identify factors that influence decisions about taking up treatment
- To find out what kind of information on testing and treatment is available and how services can be improved to meet the needs of Africans

1.6 Methodology

A mapping exercise was conducted to identify service providers where Africans living with HIV could be recruited for the research, focussing on those organisations providing HIV specific services. Agencies were given a leaflet to hand out and asked to encourage people to take part. The leaflet gave information about the research, contact details for the worker and options as to where people might wish to be interviewed and the gender of the interviewer.

Initially people were contacted through existing relationships with community based organisations and then through personal networks. The research was also advertised in relevant settings and people were requested to volunteer for interviewing.

The actual research consisted of in-depth one to one interviews which lasted between two to three and half hours, conducted in an environment where the interviewees felt comfortable and free to talk. Most of the interviews were conducted in respondents' own homes although some were conducted in HIV support centres such as Solas, Body Positive Strathclyde and Body Positive Tayside. We felt that it was important that people were interviewed in places were they felt safe and were not concerned about confidentiality and could, therefore, feel freer to talk openly. We were mindful that issues of confidentiality are of great importance to Africans living with HIV and also that people would be sharing very personal and sometimes distressing information.

We had initially intended to record on tape the interviews but most respondents expressed their concerns about what would happen to the information on the tapes afterwards; they feared that someone could get hold of the tapes and listen to them and consequently identify the interviewees. These concerns were raised despite the fact that respondents were reassured that tapes would be destroyed. People were happier for us to take anonymous notes.

We recognised that it was important that people felt able to trust and confide in the interviewer. This was done by giving respondents a chance to get to know the worker and asking questions about them and the research. This was to enable the respondents to feel comfortable in talking about their own experiences and it was also a way of showing them respect and appreciation. The interviews were very emotional and often brought up practical issues that the worker agreed to try and address or refer on. It felt that this was the first opportunity many people had been given to tell their story and to be heard by someone who was not judging them or expecting something from them. Most respondents broke down throughout the interview and many thanked the interviewer for listening to them.

The worker used her own supervision as a place to debrief and to receive support.

2 The Sample

The questions in this research were designed to determine the HIV specific needs of Africans living with the virus in Scotland and to identify issues and difficulties that Africans living with HIV are facing in Scotland. We aimed to do this through researching the "lived experience" of Africans with HIV disease.

2.1 Sex and Age

25 people living with HIV, from Sub-Saharan Africa were interviewed in this research. Of the 25 respondents, 7 were male (2 were asylum seekers) and 18 were female of whom 8 were asylum seekers. Of the others involved there was a mix of people who were visa-over-stayers and those who had permission to remain.

The majority of the respondents were aged between 30 and 43 years old. The oldest respondent was 56 years old and the youngest was 23 years old. As in year one's research, the majority of the respondents fell within the age range that is both mobile and sexually active.

2.2 Country of Birth

Respondents were asked *what country they were born in.* Of the 25 respondents, 23 said they were born in Africa while 1 was born in England. 1 did not mention the country of birth. Of those born in Africa, 8 were born in Zimbabwe, 4 in Zambia and Uganda respectively, 2 in Cameroon and Kenya respectively, 1 each in Malawi, Rwanda and South Africa.

The countries mentioned as places of birth are those countries with high prevalence and incidence of HIV and at the same time are Commonwealth countries that have links with Scotland.

2.3 Length Of Stay In Scotland

Similar to the findings of the last report, most Africans were new to Scotland and indeed to the UK as a whole. In this research only 1 respondent had been living in Scotland for over 20 years. 2 respondents had been living in Scotland for between 4 and 6 years. 9 respondents had been living in Scotland for between 2 and 4 years and 6 had only been living in Scotland for between 1 and 2 years. 6 respondents had been living here for less than a year at the time of the interview and one did not say how long s/he had been living in Scotland. The respondent who had been living here for over 20 years was aged 49 at the time of the interview.

11 of the respondents in this research lived in Edinburgh and the Lothians and 9 lived in Greater Glasgow. 3 respondents lived in Dundee and one in Perthshire. One respondent did not indicate where they lived. The majority of respondents living in Glasgow were not there by choice but were dispersed there through the National Asylum Seekers Support Service (NASS). Although we did not ask reasons for being in Scotland, we know from year one’s research that for people living in Edinburgh most came here as visitors and students.

2.4 Partners and Children

In this research 12 respondents had partners although they were not necessarily living with them. 11 said they did not have partners.

Of the 25 respondents, 23 said they had children and 2 said they did not have children. The ages of children ranged from 0-24 years. 5 respondents said their children were aged between 0 and 5 years, 10 between 6 and 15 years and 7 said their children were aged between 16 and 24 years. One respondent did not indicate the ages of their children. Despite the fact that the majority of the respondents had children, 10 of them did not live with their children; 10 said only one child was living with them; 2 said they lived with 3 of their children; 2 said they lived with one child and one respondent did not indicate how many children lived with her/him. Respondents whose children were not living with them said they lived back in their home countries.

Of these respondents 2 were from Kenya, 2 from Zambia, 3 from Zimbabwe and 1 each from Malawi, Rwanda and Uganda. 9 respondents who said their children were not living with them mentioned immigration problems as the reason for this. One respondent’s child was attending school in the respondent’s home country and this was the reason given for not living with them.

2.5 Religious Affiliation

Nearly all the respondents, 24, said they were Christian and one did not say which religious denomination, if any, they belonged to. This confirms that churches are places where prevention, education and awareness raising could be focussed. Waverley Care has already started focussing their work with faith groups

2.6 Educational Qualifications

The educational qualifications of respondents in this research varied from those who had '0' levels to those with university degrees or higher. However, as in the last report, most respondents in this research had attained higher education qualifications with 8 people having a university or higher educational qualification. 3 respondents possessed diplomas, 3 had 'A' levels or equivalents, 4 had '0' levels or GCSEs, 4 had primary education and 1 had third year secondary education.

However, these qualifications did not necessarily directly correlate with employment. Of the 25 respondents, including the 8 people with university qualifications or higher, only one respondent was in full time employment.

2.7 Income

There were 6 respondents receiving help from NASS, all of whom were unemployed, 2 were on social work emergency financial help and
2 on income support from the social security. Additionally 4 people were full time students while 1 person was signed off work. 3 respondents did not answer this question.

2.8 Immigration

We asked respondents whether they had immigration problems and 15 answered affirmatively. 10 respondents said they did not have immigration problems. The issues around immigration are explained further in this report.

3 Experiences of Africans Living with HIV in Scotland

The experiences of Africans living with HIV in Scotland vary from individual to individual; however there are significant similarities. Additionally, we found significant differences between those who came to the UK to seek asylum and those who are non-asylum seekers

Of the 25 people interviewed, 11 were non-asylum seekers but with an application with the Home Office for leave to remain in the UK, 1 had residency in the UK, 1 had a work permit, 2 had student visas and 10 were asylum seekers, 9 of whom had been dispersed to Glasgow and 1 who had moved to Edinburgh by choice.

The most significant differences were linked to enforced dispersal of asylum seekers. The national dispersal scheme was adopted as a policy in 1999, a major measure in response to the rise in asylum seeker applications and aimed at reducing the financial burden and relieving housing and social pressure in London and south-east England.

Under the scheme all new asylum seekers in the UK (predominantly London and south-east England) are transferred to a different region and not given a choice of where they will go.

However, asylum agencies say that there have been many significant problems with the system with asylum seekers arriving in locations with limited support services and no existing community to help to support them.

("What's going on?" – A study into destitution and poverty faced by asylum seekers and refugees in Scotland – The Refugee Survival Trust 2005) They argue that it would be better to keep an asylum seeker within a settled community from their own country or close to other relatives.

The majority of the dispersed asylum seekers in this report had previously lived in London where they had access to community, family and both statutory and community based HIV services experienced with working with Africans. None of the people in Glasgow had chosen to be there and in fact most of them compared Glasgow and the services available unfavourably with London (both in respect of HIV and asylum support).

"I feel small, why did they disperse us from London where we had established relationships with friends and organisations who checked on us?"

"In Scotland it has been a struggle because we had to start from the beginning like we had just arrived in the UK. The attitude of those we thought would help us is just unbearable and we feel really let down."

Significant differences in the findings between asylum and non-asylum seekers will be identified throughout the report.

3.1 Testing

In this research, 20 respondents were diagnosed between 2000 and 2004 in the UK. One respondent was diagnosed in 1989 and two in 1997 and all of these were diagnosed outside the UK. One person had had an HIV test in Africa and then had a second test in the UK.

Most people had had an HIV test because they were ill. Nine people were tested while in hospital and ten were referred to an HIV clinic by their GP. Three women were tested routinely through ante-natal tests, one person was tested following on from their partner testing HIV positive and one person chose to be tested because she had been raped and suspected she may have been infected.

"I ignored the issue until I started having this cough that is when I started thinking maybe I have AIDS and I will die. My GP worked hard to convince me to go to the hospital to be tested and he told me there is treatment. By then I was very sick. But even then I still did not ask for the test. I waited until the hospital staff asked me and that is when I said yes you can test me."

"Now looking back, even if I was looking healthy, I had been feeling unwell for some time but I did not want to accept it."

"I wasted a lot of time otherwise I would not have been in this mess; living like this, feeling ill most of the time and having problems with my legs."

When asked why they had not considered an HIV test previously, responses ranged from believing that they had always led a safe life; feeling and looking healthy; not seeing the point of knowing HIV status because there were no treatments available and it would open people up to discrimination, not least from health care staff; not wanting to know through fear and denial.

"Even if there was the opportunity (to be tested) *at home I would have preferred not to know because there is a lot of stigma and fear of dying due to no medicine. Why go to be told you have an illness which will kill you when there is nothing anyone is going to do about it."*

"You know it is one of those things you think you can never be the one because you have always looked after yourself, always leading a clean life."

"Although I had a lot of unprotected sex back home, it did not occur to me to have a test because in Zimbabwe there was no treatment at all and I did not want to put myself through the stress of worrying whether I was going to die soon. Also the attitude of people back home towards people who have AIDS is not the same as here."

"You know home is not like here where most of the time people mind their own business. There is a lot of stigma going on and a lot of finger pointing. Apart from that I was scared to know because I thought to myself what is the point of knowing when I know I will not be treated? It will just kill me quickly. So I pretended nothing happened and just went on like that."

"The clinic staff all look down on you as if you are the one bringing shame to other people. And also because there is no medication why put yourself through all that trouble of being called names when you know you are not going to get better."

"Anyway what is the point of testing when you know you will get nothing? No tablets, no other help like emotional support and also counselling. It is like you are told you are positive and then they you let to go and die on your own. No point is there?"

Additionally, the way health services are perceived back in home countries has implications on the decisions made on going for testing. In most African countries, health centres or clinics are accessed to treat an illness and not for prevention. Additionally, in African countries people don't go to clinics or for health check unless they are ill. This type of attitude towards health is reflected here and it seems that people don't feel the need to go for a test as a preventive measure or to benefit from early treatment. One respondent put it explicitly.

"it is very un-African like to walk in the clinic or health centre to be tested for anything when you are feeling fine. I never thought of going to the hospital at all even when at that time there was a lot going on and being talked about in terms of HIV. I was fine and fit so I did not see the point of going to the hospital to be tested. Even the hospital staff would have been surprised"

When asked how they thought they had acquired HIV, the majority suspected through unprotected sex, one person suspected a blood transfusion and seven of the asylum seekers identified being raped in Africa. The seven women who had been raped linked this to living in a country where there was conflict/war and/or being connected to an opposition political party. For these women the stigma of HIV was compounded by the stigma of rape.

"Being raped at home brings shame to anyone. It is like you are careless and very dirty."

"When I insisted on being tested at home (after being raped) *the doctor tried to discourage me at first saying I did not want the stress of being HIV positive and then when I insisted said I must have been very promiscuous."*

"I was scared of knowing the truth because the men who raped me were many and some of them may have been positive. Somehow deep down in myself I suspected that I was positive."

Even where people suspected they might already be HIV positive, all the respondents talked about feeling devastated by the diagnosis. They referred to wanting to die, feeling the world had come to an end, feelings of shock and denial. Several described severe emotional reactions requiring psychiatric help. People's responses were influenced by their knowledge, experience and understanding of HIV in Africa, where treatments are not seen as available, people are seen to be dying from AIDS and stigma and discrimination linked to lack of confidentiality are common.

"You know the stigma about HIV. When you tell some people HIV becomes your name. Before they call you by your name they will put HIV first. Some people are not to be trusted and they gossip a lot."

"It is a terrible illness and even if I was raped I still thought I had escaped the infection. Anyone would be surprised at being told you are sick and the disease you have will kill you."

"Even though I suspected I was still shocked. It is a very bad disease and anyone can be shocked. I was hoping that it did not happen to me and that by the grace of God I have been saved. You know you always hope that maybe you were lucky."

"It was like the end of the world and all I could think of was dying at this time when I was still young. It is the thought of saying I have joined that group of people who will die from AIDS that was scaring me."

"I was devastated, shocked and almost collapsed. The belief from home that when you are HIV positive and pregnant you will have a sick child irrespective of treatment nearly made me abort because I could not bear having a sick child who would be an orphan any way."

"It was hell. I collapsed and I thought I would not live another day. I just wanted to die and end it all especially when I thought that without being raped maybe I would have been fine."

To most respondents in this research an HIV diagnosis was been associated with death, being diseased and also a feeling of shame and of being dirty.

"HIV being HIV, it is like a death sentence. You still get shocked and scared. It is just natural. You feel bad; you cry and then move on. I will be surprised if someone did not get shocked and scared when told that you are positive."

Several people alluded to the loneliness of being in foreign land at the time of diagnosis, away from family and friends and familiar surroundings. Often the experiences that led to people seeking asylum compounded these feelings as did their experiences of being an asylum seeker.

People also worried about who would look after their children if they died here.

"I was more scared than I was back home because at least at home if I died they would easily find me and recognise me. But here what I feared was that if anything happened to me would rot in this flat without people knowing. What about my family, my children."

"I'm trying to make my life as normal as possible but it is not an easy thing to do when you are living away from your family and friends in a strange land."

"I kept on asking myself, why me in a foreign land, my husband is dead, I don't know where my son is, why Lord why?"

Access to support and pre and post-test counselling varied as did people's experiences of them. Where people had access to counselling they found it very encouraging and supportive, helping to keep them going. Several people identified support groups in London, Edinburgh and Glasgow as good sources of support but even with counselling and support people continued, at times, to feel helpless and hopeless.

"You never stop thinking that I will die of this thing. You can't help being scared."

For people who did not receive any counselling the experience compounded feelings of worthlessness.

"Someone just came and told me I was HIV positive. I felt that because I was an African therefore they did not care. Maybe they thought; let us tell her on her face, she is an African, who cares."

"I was just told that you are HIV positive and the staff was very unhelpful. I had a lot of questions to ask but I could not because I was scared that they might be angry with me."

Respondents expressed shame and humiliation at being HIV positive and women tended to blame themselves while the men blamed other people including their partners.

"I blamed my wife for everything; she was the one to me at the time closest and there was no one else to blame."

Once respondents had gone through the initial phase of anguish of testing positive, they then described a deep emotional reaction with a focus on how the results impacted on their lives and how they felt within themselves. Some respondents hated and blamed themselves for being HIV positive. Shame and blame are directly linked to an interpretation of a positive diagnosis as proof of promiscuity.

"…I hated myself and thought of myself as being a very bad person who has brought shame to the family."

Although another said *"Only I don't blame anyone for my mistakes. I was careless and now I'm paying for my carelessness."*

For some respondents the shock of being told the results was the hardest to deal with and also the thought that they may have infected their partners contributed to their fears and frustration.

"The shock nearly killed me. It was like being told you are going to die tomorrow. I felt bad once again and I don't know whether I infected my husband. Although we had been having protected sex, you still can't stop to think I was the first one to be diagnosed"

3.2 Telling people

HIV is still a very “silent” illness especially among African communities. Disclosure therefore is a very personal issue and people disclose for various reasons. In this research, the whole process of disclosure, who to tell, when to tell, the impact of telling, varied considerably from person to person.

While some respondents used telling as one way of moving on, others did not wish to discuss their status soon after being diagnosed. The process of telling took time for most respondents as people had to deal with the shock of being diagnosed first before disclosing their HIV status to anyone. We know from anecdotal evidence that people have to develop trust and confidence first before they can tell and those told are people who can be trusted to keep a secret.

In this research, all respondents interviewed had told at least one person about their status and who they told depended on how much they trusted the individual (s). Telling someone could also just mean briefly passing on information about HIV status and did not necessarily mean the issue was discussed.

A variety of reasons were given for telling others about HIV, from believing that they were people or agencies who would help, because they were close family or friends or because people felt obliged to tell. Generally people were very wary of telling anyone about their HIV, partly because they did not trust people to keep that information to themselves and also because of their experience of the way people react to HIV in Africa. People also had experience of their HIV status being disclosed by others against their wishes, either people they had told themselves or people making assumptions about them and spreading gossip.

“I had to tell some people at places where I go for help because I needed help and thought they could only help me properly if I told the truth.”

While sympathy from those told is a positive thing, sometimes the sympathy could feel suffocating and have a negative impact. Most respondents said that although this sympathy was appreciated, they did not always feel like talking about issues around HIV. For some this has resulted in less contact with close friends and family for fear of being asked questions about their HIV status and well being.

“They always want to know everything. I appreciate their compassion but sometimes it is too much.”

Another respondent said her family have been over supportive and said *“this makes me feel very bad because it makes me think I’m very ill.”*

The responses people received also varied; generally HIV services were seen as supportive as were other Africans living with HIV especially where peer support was available. Most respondents found that the people they told themselves didn't treat them any differently, however, some respondents did find that those they have told had distanced themselves from the respondents' lives and this has made the respondents feel isolated and rejected.

"They did not want to know me. They deserted me and even stopped visiting me while I was still in hospital. I felt very isolated and rejected as if I was a piece of rubbish…they treat me like dirt and some cannot even visit me in my house."

Because they felt rejected and abandoned by those told, most respondents internalised guilt and blamed themselves.

"At that time I felt suicidal, very frustrated and the only thing I could think of was dying as life did not seem worth living at all. I hated myself and thought of myself as being a very bad person who has brought shame to the whole family."

Two of the women described very angry reactions from their husbands, particularly one woman whose husband tested negative for HIV. He became very abusive and eventually they separated.

"He took it very badly and blamed me for everything."

"I felt very dirty, very unclean. It was so humiliating. This is the person I trusted who brought me here. In fact I was raped because of his political involvement."

Sometimes respondents felt that they had been treated badly and differently by their consultants and the nursing staff at the HIV clinics. One respondent said all the health staff at the hospital where she goes treated her well except one doctor who she said treated her very differently and she said

"it is like I'm from outer space and he would not come near me. He takes time to put on his gloves and sometime he wears 2 gloves even if he is just checking my tummy. I find that very strange behaviour especially from a doctor who is supposed to know better and give me encouragement."

Asylum seekers in Glasgow described the specialist HIV health services as generally helpful, but most people found their GPs ill informed, unhelpful and sometimes downright racist.

"The GPs attitude was to say – I don't care after all you are already HIV positive what difference am I going to make."

"The GP treated me as if I had a disease that would kill him straight away if he came in to close contact with me."

"When I told the GP I was not feeling well he told me – you just want to go to hospital because you are scared of being deported."

None of the respondents had chosen to tell their families back in Africa. This was partly due to the lack of information about HIV and treatments, the stigma about HIV and not wanting to distress family who would see a diagnosis as heralding imminent death. One respondent said:

"Imagine telling them when they are that far, it would destroy them because those guys have seen a lot of people dying from AIDS and how they suffer and if I tell them that I have HIV also they will think that I will be dying the same way. Also the stigma that goes on, my family will be insulted by other people."

3.3 Access to services

People described difficulties in accessing services for a number of reasons, both practical and emotional.

One common problem was in understanding the way the health system works in the UK. People struggled with the appointment system; not understanding why they would have to wait some days, if not weeks, for an appointment to see a GP when the need was now; not understanding when it was appropriate to go to the GP or the HIV clinic or Accident and Emergency.

"If you fall ill Brownlee tells you to go the GP and GP appointments are two weeks away and by the time you go to see him it is either better or you have got much worse."

"If I have pain they tell me to go to A&E but then they tell me it is not an emergency."

The attitude of some staff was also seen as a barrier to accessing services. The role of receptionists was not understood and people felt obliged to divulge information to receptionists about HIV in order to be seen by services. In fact, who needed to know about HIV or how this information might be shared amongst professionals was not understood.

"The appointment system makes access very difficult and the attitude of the receptionist is even worse because they ask for things that do not even concern them and as such people are forced to disclose in order to be attended to."

"They want to know everything and yet they are not doctors. It is terrible it is like you are being interrogated again."

On top of this many people found the attitudes of health staff to be discriminatory. This was particularly true for asylum seekers.

"I mean where is confidentiality and what about respecting us as human beings not just asylum seekers? It was as if we had no feelings whatsoever."

"When I told my GP about the pain he said – you are HIV positive what else do you expect? These people make you feel worse than HIV itself. I felt like dying really because what he was telling me was that I should just die."

"When I told my dentist that I was HIV positive he became very scared and put double gloves on each hand. He did not even treat me although I needed a filling or a tooth taken out. He just gave me pain killers. I felt very humiliated and rejected."

All the asylum seekers described difficulties in finding out about services on being dispersed to Glasgow. While they may have been assigned a GP or a health visitor they didn't know how to go about seeing them. They were also unsure how to get support and treatment around HIV and had unhelpful experiences in trying to get this through a GP. For example GPs wrote out prescriptions to continue people's HIV drugs which they were told to take to the pharmacy, which of course did not handle the treatments and one respondent narrated his experience of taking the prescription to the pharmacy as unbearable:

"The pharmacist said in a loud voice – we do not keep AIDS medicine here. Imagine how humiliated I felt in front of all those people in there. I went home and was reduced to tears. You know men don't cry openly in my country but that day I cried like a small child."

GPs also didn't refer people to the HIV clinic and this does not seem to have been arranged as part of the dispersal process.

The most common emotional response around access was the fear of being seen using the services, particularly HIV clinics and support services. This has much to do with HIV related stigma particularly from within the African community. Services are only accessed and used when it is very necessary for health reasons or at a time of crisis. This is mainly due to the cost share basis of most African medical services. Actually, respondents regarded being HIV positive as shameful and didn't want to be associated with services that offered HIV support.

However, when people did access HIV support services, particularly community-based services, they described them as very helpful and supportive in dealing with a range of social issues as well as with HIV.

3.4 Treatment

People who were on treatments knew what they were on, knew why they were on them and that the treatments would reduce the amount of virus in the body. They also understood the importance of adherence.

While the respondents appreciated the fact that they were on treatment, they did however feel that they were not given options and choices as to whether they wanted to be on treatment and on what type of treatment they wanted to be on. They said there was not formal discussion with their doctors about treatment options but instead they were told they had to be on treatment right away. When asked whether they understood why they were on a particular treatment, all respondents said all they knew was that Anti Retroviral treatments brought the viral load down and boosted the immune system. Some said treatment prolonged life. However all respondents said although there was enough information available on treatment, they did not really understand the information.

"Having enough information is not the same as understanding what certain words mean. For example it took me a long time to understand what adherence means…."

Although the information may be available respondents said it was too complicated to understand and sometimes medical staff did not give simple information. Some respondents have said they took the medication because they had no choice as one respondent put it *"sometimes the medical people themselves cannot even explain properly. I mean you are taking something you don't even understand properly and you not sure whether they have given you the right one for you. It is just like trial and error really and I just take them because that is where my hope of living another few years lies"*

They had limited information about side effects and although they may have been given written information, they found this information too complicated.

"I think the information is a bit complicated and I prefer someone to tell me in person then it becomes easier."

Most people didn't feel able to ask their consultants or others in the clinic for additional information and explanations.

"How can I ask them when every time I go there I see a different doctor some of whom have very little time any way because they are always looking at their watches. I don't want to delay them."

Most of the information came from other HIV positive people and much of this seemed to raise concerns about the side effects and the inconvenience of taking treatments while trying to hide this from others.

"People say the tablets can cause liver problems, they are very complicated to take and they are too many. Also people say it is very difficult to take in public because they are too many and you feel shy if there are a lot of people around you……"

Those who hadn't yet started on treatments were fearful of doing so. They were concerned about the side effects and about trying to manage the taking of the treatments. They knew that once they started the treatments, it would be for life and therefore were worried about the impact this would have on how they lived. They saw starting treatments as an indication of becoming ill and this started them thinking about being unwell when they were on their on amongst strangers and also fears about what would happen if they became ill while living alone.

"Oh my God! Who would sound the alarm if I am ill? It would probably take a long time before they discover I'm lying on the floor."

Most people were also concerned about being sent back to Africa where either there would be no treatment or the regimen they were on was not available.

Those on treatment had experienced a number of side effects, including weight loss, nausea, fatigue and anaemia. Some of these side effects had been discussed with consultants but some respondents have found it hard to discuss these issues with anyone and especially their doctors.

"….It makes me angry that I can't tell anyone about the treatment I get. I have no say whatsoever. Look at me I'm putting on weight on my stomach and I look like a pig but I can't tell my doctor because he will just brush me off. I don't know whether it is the medication causing this but I still want to know why I'm getting bigger on the stomach"

3.5 Other health issues

The most commonly identified health problem for both asylum and non-asylum seekers was depression. This was linked to issues about identity; what HIV made people feel about themselves.

"I hated myself and thought of myself as bad. I just wanted to be as I was before I came to the UK."

Feelings of worthlessness were compounded by the effects of the immigration system and other social problems such as financial difficulties and being on the receiving end of discrimination and racism.

Some people, particularly asylum seekers, said that they were seeing, or had seen, a psychiatrist or counsellor and four people had been hospitalised because of mental health problems.

Asylum seekers linked this to their experiences at home which had caused them to come to the UK to seek asylum and to the problems they had encountered as asylum seekers in the UK.

"It is now when all the shock and all the fears are coming. I'm so scared I can't sleep at night. I have nightmares and I fear that someone can come and do bad things to me. I did not have time to mourn my husband and I have not seen my son for a long time."

3.6 Social needs

People identified three main issues; poor housing; lack of money to live on; immigration problems.

We chose to ask specifically about immigration as we were aware that this was an issue for many people. We wanted to find out what experiences people had with regard to applications to remain in the UK and what the implication were for those who are still waiting for a decision from the Home Office. Again, there are differences between those seeking asylum and those who have entered the UK on a visa and have applied to remain because of their HIV status.

Ten people interviewed were asylum seekers and eleven of the others had applied to remain in the UK on grounds of health.

For this latter group the delay in decisions on immigration applications had had a profound impact on how people were able to live. While applications (and passports) are lodged with the Home Office people are not allowed to access public funds and are not allowed to work. This affected the way people lived and impacted on their health their HIV. Most respondents depended on financial help from charitable organisations such as CRUSAID for their up keep. This is still not enough to live on and pay bills.

"My financial problems have contributed to my depression, loss of appetite, feeling sick and helpless and sleepless nights worrying about what I would do just in case I run out of money."

Many people expressed the desire to work rather than depend on whatever little they were getting in terms of hardship funds. One of the things people found most frustrating was not being able to support themselves.

"I'm very frustrated because I can't work even though I want to, no access to help in terms of financial and housing and I have no help with my son. The home office thinks people like me are no humans because they live on thin air."

However, the majority of the non-asylum seekers had been helped to access reasonable Housing Association accommodation, although some were in poorer private rented or shared housing. A few were being financially supported through the Local Authority although this support was discretionary and limited.

All respondents mentioned that due to the delay by the Home Office in making decisions, it was difficult for them to make any plans about their future. People described feeling helpless and hopeless.

"I sometimes wish I was dead but I have to live because of my son, I don't want him to be an orphan, not if I can help it anyway."

Additionally most were scared that at anytime they could be deported back to their home countries. The feared that Home Office officials would appear at any time, day or night, to take them away. This caused increased stress and contributed to people's sense of insecurity, not belonging or being welcomed and also affected people's mental health. Respondents said that the Home Office determines how they lead their lives Scotland.

"It all comes back to one thing really, no plans you don't know whether the people from the home office will be knocking on your door the following day."

These findings are corroborated by the report "Outsider Status" (Research on stigma and discrimination experienced by Gay men and African people with HIV – 2004 –Sigma/NAT) that found that Africans living with HIV in England feel powerless due to immigration issues.

"Everything depends on immigration, health and happiness, no employment, everything depends on it. Because the law is changing every minute, you never know where you stand"

The majority of our respondents felt frustrated and angry and voiced resentment towards the Home Office and the way the system worked, causing them to feel constantly on the defensive.

Without passports people are not able to travel to see their families back in their home countries. Where there is death within the family respondents are not able to go for funerals, a very important ritual in any African culture; they have been separated from young children and are concerned about what might be happening to them and also that they might grow up forgetting their parent.

People have had to make very difficult and challenging decisions; whether to stay in the UK in order to get treatment or return to their home countries and face the prospects of dying early from AIDS related illnesses.

Poverty and destitution are major problems faced by people seeking asylum in Scotland. ("What's going on?" – 2005) and the effects of destitution are economic, political and social.

All the HIV positive African asylum seekers in Glasgow we interviewed had housing problems, including overcrowding, poor quality stock, damp and without heating. Where these had been reported to the local authority or housing association nothing had been done to remedy them.

In addition, everyone said that they had financial problems. The financial support through NASS was not enough to live on and where NASS had been withdrawn, because people's appeals had failed, they were dependent on friends and applications to trusts such as CRUSAID

Most immigration was being dealt with by lawyers in London and people had to travel there for appeal hearings with no idea of what was happening. Communication seemed to be very poor and people were left in the dark as to what was happening with their cases.

Some people had received letters from their London lawyer telling them that their applications or appeals had been refused and they were now trying to find a lawyer in Glasgow. The treatment people described at the hands of lawyers and the Home Office left them feeling even more vulnerable and helpless.

"He (the lawyer) *said you can pack your bags and go or if you don't go, have them packed, so when they come to pick you at least you have them ready. Alternatively you can just disappear underground and they will never trace you. But how can I disappear with a young child? Even without a child I'm ill, what happens if I am ill?"*

People clearly felt let down. They had thought that the UK was an open and fair society but their experiences were telling them otherwise. They felt that they were treated like criminals; that they could be visited at any time by people from the Home Office and taken away like they have been while living in London. They were scared that they could be raped or imprisoned; the very events that had forced them to flee from Africa in the first place.

"It is terrible, really bad what they do to us. We know we are beggars but we are people in trouble and we need help. Who would leave her family and her home to come here where we have nothing to live on?"

3.7 Racial abuse and discrimination

Nearly all the respondents interviewed in this research said they had experienced racial abuse and harassment from a number of sources including the community in which they lived. Some respondents said they felt that they were treated differently both by health workers and the public because of the colour of their skin. Some said the social services contributed to the racial harassment they faced by housing them in areas where there are a lot of people with anti-social behaviour.

"I was given a house in a very bad area and I faced a lot of racial abuse verbally. People used to bang on my door and calling me names. There are a lot of drug users in my block of flats and I was very unhappy and frustrated with everything. I was scared to get out of my flat."

Respondents with children said their children were called names at school and sometimes in the streets. This resulted in difficulties for the children in making friends and mixing freely with other children, resulting in isolation.

Those who had been able to find employment have also experienced racism and humiliation. One said, *"one day I went for work and we were having a meeting. People moved away from where I was sitting and they sat at the back and I was in the centre on my own. It was like they really wanted to a good look of me and I felt humiliated."*

Every asylum seeker in Glasgow had experience of being racially abused, on a daily basis going about their business and at the hands of officials.

People said that they didn't go out any more or as little as possible and didn't put their lights on at night for fear of being attacked. They experienced name calling, death threats and stones being thrown through their windows, being spat on and someone urinating through the letter box.

I'm scared even to go out and take my child out to play. I have been called names like black bastard, beggar that kind of thing."

"I heard them say (on the bus) *we have to sit on a bus with this black thing. You can imagine how I felt because the bus was full and everyone turned towards me. I really felt it is a sin to be black in this country."*

"People look at you like a piece of rubbish. People think you are a beggar, even GPs look at you like you are nothing. We feel small; really small. We keep asking ourselves is it because we are black? Is it because we are sick people and we are going to die that is why they don't care?"

All respondents were asked whether they had complained or told someone in a higher position about these issues. The response was that they did not think they had rights to complain about things and even when they wanted to complain, they did not know who to complain to as some of the racist remarks had been said by the very people at the very top.

"I have no one to complain to because the same people I thought I could complain to, are the same people who are doing this to me. It makes me very angry that I can't tell anybody about the treatment I get……I can't tell my doctor because he will just brush me off….."

Some felt they had no right to complain because they did not have the right of residence in this country.

"I did not think I had the rights because I did not have the papers…."

There was no confidence in challenging or reporting incidents.

"Report to whom? Even if I reported there is nothing that is going to be done about it. With racial abuse there is nothing that can be done because the same people that can do something are racist themselves."

3.8 Commentary

The testimony of HIV positive Africans who are asylum seekers and have been dispersed to Glasgow describes an experience that is profoundly degrading and dehumanising.

The reasons that led people to seek asylum in the first place are in themselves distressing. Many of the women had been raped, people had been on the receiving end of violence and intimidation, had had to flee their homes and countries, leaving behind a life, possessions, family, friends and sometimes spouses and young children.

They believed that seeking asylum in the UK would offer them a life free from persecution in a country where justice and freedom prevailed. They understood that there would be difficulties and challenges in adjusting to a new life in a strange land but were clearly shocked by the treatment they received.

A diagnosis of HIV was yet another burden to manage and a cause to fear further prejudice, on top of being discriminated against as a black African and an asylum seeker.

The fear of stigma is rendered even more destructive because of HIV discrimination amongst Africans, meaning that people were not even assured of support from fellow Africans.

Those Africans who have come to the UK to visit or study or work and who then test HIV positive face a stark and difficult choice; to return home with little possibility of surviving the virus or apply to remain in the UK in order to receive the HIV treatments to live and face the loss of independence, dignity and freedom.

People’s knowledge and experience of HIV in Africa had a profound impact on their response to their diagnosis. People found it difficult to separate their understanding of an HIV diagnosis as a death sentence, from an understanding of HIV as a treatable illness.

It is not surprising that most people suffered from depression or more serious mental illness, given the cumulative impact of fleeing in terror from one’s home, feeling abused in a place of apparent safety, being diagnosed with a heavily stigmatised and potentially fatal illness and having to make the choice between living and dying.

The support available to people, as dispersed asylum seekers, appears inadequate, to say the least. Neither NASS nor statutory or voluntary services in Glasgow appear to be adequately informing, let alone supporting, HIV positive Africans to access basic HIV services.

The financial support available to non-asylum seekers with pending immigration applications is entirely dependent on charity or, in a few cases, the discretion of the local authority.

African's visibility as physically different, will undoubtedly subject them to more overt racism, as is clearly the case for the people we interviewed. Managing to live as well as possible with HIV requires money to eat healthily, appropriate housing and the minimum of external stresses and insecurities, none of which is available to this group.

It makes nonsense of a Scottish commitment to support Africa and the issues of HIV in Africa when we subject Africans living with HIV in Scotland to inferior services, humiliating and discriminatory treatment and an uncertain future.

4 Key Issues and Recommendations

A. Africans generally test late for HIV and when they do test it is often because they have become ill with an AIDS related condition. There is a complex interplay between looking and feeling well; a tradition of not seeking medical attention until one is definitely showing signs of sickness and denial related to fears of being stigmatised.

- Recommendation 1

The development of an awareness raising campaign focussing on the benefits of early testing and targeting African communities in Scotland.

- Recommendation 2

To work with the Scottish Executive and the Sexual Health Advisory Committee to ensure that the proposed working group on tackling stigma and discrimination around sexual health takes into account the fears of Africans living in Scotland in relation to this issue.

B. Like most people facing a positive diagnosis for HIV, Africans experience a range of emotions that can affect their mental health and well being. Because they often receive an AIDS diagnosis at the same time the emotional reaction is particularly strong and is influenced by their experience of AIDS in Africa. Many feel isolated and in shock. Pre and post-test counselling was usually valued.

- Recommendation 3

Clinics and community based support services work closely together to establish systems that support Africans from diagnosis onwards. This is likely to include the need at least in the medium term of dedicated workers to work among African communities. In an era when clinicians are beginning to talk about reducing pre and post test counselling the impact of such decisions need to be more carefully considered.

C. Telling fellow members of the African community in Scotland sometimes led to major breaches of confidentiality compounding feelings of isolation and rejection.

- Recommendation 4

Mainstream organisations which have large African membership e.g. African churches are encouraged to address the issues of HIV and stigma and discrimination with their members.

D. People experienced a range of difficulties in accessing services. Some of these were practical such as not understanding the appointments system and the role of receptionists but others were attitudinal such as feeling that their individuality was denied. Dispersal of asylum seekers has had an extremely negative impact on the way services are accessed and, indeed, services in Glasgow have reduced since the research began. Glasgow GP's were not seen as knowledgeable or helpful much of the time.

- Recommendation 5

A leaflet explaining how the NHS and local authority services work in Scotland for all migrants would be beneficial.

- Recommendation 6

All staff in the NHS, including GPs, require further training on awareness of key issues for people from a black and minority ethnic background

- Recommendation 7

There is a need for advocacy, befriending and general support services to be developed and strengthened, particularly in Glasgow, for asylum seekers living with HIV.

E. Most Africans have a basic knowledge of HIV but do not have a strong knowledge base about treatments. They reported little discussion with medical staff about treatment and side effects and where information was available it was generally found to be too complex. Most people got their information from other Africans living with HIV; this information may or may not have been accurate.

- Recommendation 8

Clinic staff need to spend more time with African patients helping them to understand the information and ensuring that they know how to translate this understanding into action.

- Recommendation 9

The benefits of treatment should be more widely advertised as part of an awareness raising campaign.

F. While, like many other people living with HIV there is a negative impact on mental health, for Africans this is exacerbated by absence of familiar support mechanisms and other social issues.

- ♦ Recommendation 10

Support services need to consider how they can support the mental health needs of Africans living with HIV and, where appropriate, develop links with mental health specialists.

G. Many Africans are unable to access jobs that they are professionally qualified to undertake. This impacts on a range of other social factors including housing. Many are housed in highly deprived areas in peripheral housing estates where they are vulnerable to racial abuse including physical abuse.

- ♦ Recommendation 11

Local authorities should revisit their housing allocation policy and not place vulnerable people in places where their vulnerability exposes them to further harassment and abuse.

- ♦ Recommendation 12

Any review of immigration legislation should include the rights of people to work.

- ♦ Recommendation 13

Community development work in all of Scotland's communities should prioritise race awareness and equality work

H. Nearly all the Africans interviewed encountered difficulties with the immigration system. Effects were far reaching. People felt they could not plan for a future, were unable to work legally, ran into financial difficulties and were often separated from their families and loved ones for many years. This had profound effects on people's physical and mental health.

- ♦ Recommendation 14

The UK immigration and asylum systems need to be urgently reviewed. Evidence suggests that it would be better to keep asylum seekers within a settled community with immediate access to friends and families and not to disperse them.

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