

# A study on accessibility of healthcare services for black Africans living in Edinburgh and Lothian

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## **A study on accessibility of healthcare services for black Africans living in Edinburgh and Lothian**

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This study was made possible through joint partnership working with Lothian Sexual Health and HIV Strategic Programme Board, Waverley Care and Minority Ethnic Inclusion Service

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## 1. Introduction

Waverley Care is commissioned by NHS Lothian to deliver an African Health Project (AHP) covering both HIV prevention and support to black Africans and black African communities in the NHS Lothian area. Prevention activities include 1) raising awareness about HIV and delivering information about HIV transmission, prevention and testing and 2) identifying acceptable models on condom distribution including provision of information about sexual and reproductive health services and safer sex strategies.

The Minority Ethnic Health Inclusion Project (MEHIP) was set up in February 1999. The aims of the project are to improve the quality of and access to Primary Health Care services by the Black/Minority ethnic and refugee communities across Lothian; to promote the development of appropriate and accessible information resources for minority ethnic groups and provide advocacy to increase patient involvement and participation in their own health care. The project supports professionals to enable them to work more effectively with all minority ethnic individuals and groups. MEHIP is now run as a service (MEHIS).

The 2001 census estimated that 5,000 Africans lived in Scotland and the 2011 census is likely to show a significant rise in numbers. Africans living in Scotland come from various different backgrounds and have different objectives for living in Scotland ranging from education, to work, to joining family, to relocating for a better quality of life. In order to best deliver services to this group a short focussed survey was undertaken to obtain a better understanding of how much black African people living in Edinburgh and Lothian know about and use health services.

We recognise that Africans are not a homogenous group; the term describes diverse populations with a range of social and cultural beliefs and norms. For the purposes of the project and the survey we have used the term “African” to include all people who describe themselves as “black African”.

The following reports the findings from a survey that was conducted between April and June 2012. The survey was developed to collect information from Africans living in Lothian on: 1) How accessible they found GP surgeries 2) What their experiences were of visiting GP surgeries 3) What social services they most wanted to use 4) Whether they thought that HIV was an issue for Africans living in Scotland 5) What were their main concerns and health issues 6) How they preferred to access health information.

We also wanted to know more about the demographics of those answering the questions, particularly age, gender, employment and where they lived.

## **2. Background and rationale for the study**

The HIV/AIDS pandemic is a global concern that has left an indelible mark on the health and social fabric of almost every country in the world. A recent report estimates that 34 million individuals are living with HIV, with sub-Saharan South Africa the hardest hit of any region, accounting for 69% of people living with HIV worldwide (UNAIDS Report on the Global AIDS Epidemic 2012).

The number of black Africans living with a diagnosed HIV infection in the UK increased from 9,339 in 2002 to 25,331 in 2011; this is nearly a three-fold increase. Whilst about two-thirds of all people living with a diagnosed HIV infection in 2011 in the UK were male, about two-thirds of black Africans living with a diagnosed HIV infection were female. The vast majority of black Africans were infected through heterosexual sex; black African people are also at a higher risk of HIV, with 37 per 1,000 living with the infection; overall HIV prevalence in the UK is 1.5 per 1,000 people (Health Protection Agency HIV in the United Kingdom 2012)

High HIV awareness within African communities does not seem to translate into perceived individual risk. Studies have shown that those who did not use condoms, or used them inconsistently, did not perceive themselves to be at risk of HIV for several reasons: because they were married; because they had had the same sexual partner for several years; because they had young or sexually inexperienced partners; or because they trusted their partner(s) (Health Protection Agency Mayisha II Assessing the feasibility and acceptability of community based prevalence surveys of HIV among black Africans in England. 2005).

Africans continue to have the highest rates of late diagnosis of any group in the UK. In 2010, 66% of African men and 61% of African women were diagnosed after the point when antiretroviral treatment should have begun; late diagnosis results in poor survival rates, high health care costs and higher risk of transmitting HIV to others (African Health Policy Network World AIDS Day 2012 The impact of HIV on UK Africans).

NHS Health Scotland “Commissioning guide on HIV prevention on those from areas of high prevalence, especially African nations” and recommendations from NICE guidance on increasing HIV testing among Black Africans both suggest that engagement is often best delivered through the use of a generic (i.e. non HIV specific) approach to health and well being.

Within communities of high HIV prevalence, a preference is often expressed for more general health messages first and foremost, as opposed to HIV-specific campaigns. HIV

stigma continues to be one of the biggest barriers in promoting HIV awareness and testing amongst Africans in the UK.

Original research published in BHIVA HIV Medicine Journal (2009) on barriers to HIV testing for migrant black Africans in Western Europe identified cultural, social and structural barriers to testing, such as access to testing and care, fear of death and disease and fear of stigma and discrimination in the community. The article goes on to suggest that HIV testing strategies need to be grounded in outreach and community mobilisation, addressing fear of diagnosis, highlighting the success of treatment and tackling HIV-related stigma among black African communities. Stigma enhances secrecy and denial, which are also catalysts for HIV transmission.

In the AHPN newsletter issue 13 (2009), community mobilisation was a prominent feature. At the heart of such strategies were programmes that worked with local peer educators or “champions” to address fear of diagnosis, raise awareness of the success of treatment and tackle barriers stemming from HIV related stigma. Community preparedness and readiness were seen as paramount to the successful take up of HIV testing. In addition attaching HIV testing to wellness projects offering a range of health checks or other services such as advocacy and independent living skills were used to motivate uptake of HIV tests.

It is vital to understand the health and social concerns that are important to Africans living in Lothian in order to effectively engage with them, with a view to reducing HIV transmission, increasing HIV testing and reducing late diagnosis of HIV.

### **Health Inequalities**

Inequalities in health are multifactorial. They are influenced by issues such as environment, housing, educational achievement, material wealth, discrimination and lifestyle. Health inequalities are most often described in terms of socioeconomic status and linked to poverty and deprivation. However, health outcomes and health risks may also vary according to people’s age, disability, gender, race, religion or belief, sexual orientation and other individual factors. It is therefore important to look at health inequalities across the whole population in different ways wherever this is possible.

(“Equally Well” – report of the Scottish ministerial task force on health inequalities – 2008)

There is a plethora of evidence highlighting that people from minority ethnic groups experience poorer health than the overall UK population. Some examples include the observation of higher rates of diabetes, cardiovascular disease and mental illness among certain minority ethnic groups. Furthermore, the data suggests that patterns of poor health vary within ethnic groups. Large-scale surveys, such as the Fourth National Survey of

Minority Ethnic Groups and the Health Survey for England, show that minority ethnic groups as a whole are more likely to report ill health, and that ill health among minority ethnic groups starts at a younger age than among the white British population (Tackling health inequalities for minority ethnic groups; challenges and opportunities – Gurch Randhawa – A race equality briefing paper 2007).

### **3. Methodology**

The research used anonymous, self completion questionnaires to collect data. This methodology was agreed upon as it offered the potential of reaching a moderate number of participants and gave anonymity. The potential challenges included the lack of personal contact and support to encourage participation, perceived lack of confidentiality and potential difficulties in completion due to language barriers or understanding terminology.

The questionnaire was developed and tested with twelve participants (volunteers and service users with the African Health Project) for suitability with the target audience, after which it was revised.

Distribution was targeted after mapping local organisations and groups that worked with Africans in Edinburgh and Lothian, places where Africans gathered and providers of African related services. This exercise identified that there is not one single point of contact for Africans in Edinburgh, but there are various places and venues where Africans meet for social gatherings, entertainment, businesses, worshipping and through higher learning institutions. The research used these places and spaces to reach out to participants to fill out questionnaires.

Waverley Care also distributed questionnaires at a health event jointly organised with Health in Mind, which included presentations on sexual health including HIV epidemiology, prevention, testing and treatment, mental health and healthy eating and personal testimony from an African woman living with HIV.

Questionnaires were distributed around Edinburgh by the two staff and by six trained volunteers. Distribution was confined to Edinburgh as there were obvious places and events where Africans gathered that could be utilised and there are no such opportunities in any of the Lothian areas.

The research used informal methods; these involved distribution of questionnaires to barber shops, faith groups, African social gatherings, food shops, pubs and higher institutions of learning including Queen Margaret and Edinburgh Universities.

One hundred and ten questionnaires were distributed at various venues and events where Africans and Caribbean groups meet. Sixty four questionnaires were completed and returned and analysis of the questionnaires was done using SPSS and also verified manually.

### 3.1 Challenges encountered during research

Getting people to fill in questionnaires was not easy because people were concerned about the confidentiality of the information being given. Some participants had experience of HIV stigma linked to being African and felt that they were being targeted. Not all participants were fluent in English and needed the questions to be interpreted for them. Immigration issues for some meant that they were very reluctant to give any information and did not trust its anonymity.

In general, questionnaires that were left in venues to be completed were not returned. The best responses were when staff and volunteers were on hand to speak to people and to reassure them about confidentiality and to explain the reasons for asking the questions. However, volunteers were not available all the time; they had several other commitments and this impacted on the time spent collecting questionnaires.

## 4. Results

### 4.1 Gender and age

Sixty four completed questionnaires were returned.

**Table 1 Gender and age**

Gender	Age 16-30	Age 30-40	Age 50-60+	Total
Male	6	17	5	28
Female	12	18	6	36
Total	18	35	11	64

### 4.2 Employment

66% of respondents were in employment and 34% were not working. However, when asked later about their most desired service, access to employment was the most identified, which may translate as access to appropriate employment. Previous research by Waverley Care “Mapping Africans in Scotland” (2003) with eighty three respondents, found over half had a university degree or higher education qualifications and that only 1% had no educational qualifications. Educational qualifications however, do not translate into numbers of Africans in full-time employment or in employment commensurate with their qualifications, skills and experience.

Research undertaken in 2011 on the health and social experiences of African people living in Lothian (Ibrahim Hamani, University of Edinburgh) found that 47% of the interviewees acknowledged the lack of equal opportunity in employment having encountered difficulties around fairness, particularly in terms of looking for work and getting promotions. People highlighted a variety of discriminatory behaviours, including employers not believing they will do a good job until a report is delivered. Discrimination in the workplace and difficulty getting work/employment (to the level that matches experience and expertise) were significant issues for Africans living in Lothian.

As a whole, African people are among the most highly educated in the UK, yet African people in the UK are frequently employed in work that does not reflect their educational qualifications. This may be because African qualifications are not always considered to be equivalent to British qualifications. It can be difficult for migrants to attain English recognition of their professional or technical qualifications gained abroad. African men and women who have difficulty accessing decent employment can feel that they have lost their identity and their dignity (“The knowledge, the will and the power” NAHIP 2008).

### 4.3 Where people lived

The majority of participants were living in Midlothian representing 41%. 36% were living in Edinburgh, 9% were living in East Lothian, and 14% living in West Lothian. Although 64% of respondents lived outside Edinburgh, they were all recruited through Edinburgh based venues and events.

This is likely to reflect access to cheaper accommodation outside of Edinburgh city centre but a lack of African shops or venues away from the urban area, so that people will come in to Edinburgh to buy specific food stuffs, visit hair salons etc. Requiring cheaper accommodation chimes with the reporting that many Africans are likely to be in lower paid jobs.

### 4.4 Health issues

Participants were asked which health issues they were most concerned about against a list of options. Participants were free to tick as many or as few options as they wished. Table 2 records this information showing how many ticks each issue was awarded, regardless of how many the individual recorded.

**Table 2 – Health issues of concern**

Issue	Male (n=28)	Female (n=36)	Total (n=64)
Sexual Health	10 (15%)	18 (28%)	28 (43%)
Heart diseases	11 (17%)	8 (13)	19 (30%)

Alcohol and drug misuse	8 (13)	10 (15)	18 (28%)
Nutrition/Diet	8 (13)	10 (15)	18 (28%)
Cancer	5 (8)	11 (17)	16 (25%)
Diabetes	6 (9)	9 (14)	15 (23%)
Other	10 (15)	11 (17)	21 (32%)

Sexual health was the main issue identified, but far more so for women than for men. However, given that African women are disproportionately affected by HIV and that findings show that transmission in couples occurs more from men to women than vice versa, then there is a clear need for sexual health interventions with African men and discussion with men and women.

The other concerns were fairly evenly spread in terms of gender. Again, these reflect the findings from the 2011 Edinburgh University study which also highlighted a change in diet and environment as affecting health.

“Other” may well reflect some of the health issues in 4.5; for example 33 respondents were looking for support around exercise.

#### 4.5 Health areas of support

Participants were then asked about different health areas that they would like support on and again participants were able to select as many or as few issues as they wished. Table 3 shows the number of ticks each section received. The majority of participants ticked one or two areas; however several commented that no support was required.

**Table 3 – Health areas where support was identified**

Area of support	Number of responses
Exercise	33
Nutrition and diet	23
Sexual health	13
Mental health	6
Infertility	5
Giving up smoking	4
Alcohol intake	1
Non respondent/None	14

#### 4.6 Access to a GP

Participants were asked if they were registered with a GP practice. Fifty nine participants were registered with their local practice. Five were not registered (all men) and some of the reasons given for not being registered were:

- I don't feel sick
- I have just arrived so haven't registered yet
- I'm rarely sick so haven't decided to register yet

This is an encouraging level of registration and provides a real opportunity to increase the uptake of discussions with black African patients about HIV testing. We know from “It’s good to go for a test” (Prof. Viv Cree, Edinburgh University/Waverley Care 2008) research undertaken with Africans in Glasgow that GPs were the favoured option for HIV testing; not only did people prefer to go to their GPs but informants felt that GPs should take a more active role in inviting people to be tested.

Participants were asked if their work schedules prevented them from accessing health services and 22% indicated that this was the case. There may be a need for offering out of hours services including weekend and evening times to ensure that Africans have access to health services.

#### 4.7 Experiences at GP practices

Participants were asked about their experiences at a practice; it should be noted that although five participants were not registered with a GP, four of them made a comment on experience at a GP practice, suggesting they have previously had contact with a GP or had knowledge of other people’s experience.

Participants were asked to grade their feelings towards their experience at the GP surgery using a scale of 1 to 5, with 1 being very positive and 5 being very negative. 60% of participants indicated that their experiences were either very positive or positive; 25% gave a neutral response (grade 3) and 15% gave negative feelings. Only 1 participant felt their experiences were very negative. Most participants were happy with the experience they had at the GP surgery and earlier research with Africans in Lothian found the majority of respondents had a “very good” or “good” experience with their GP.

**Table 4 – Experiences at the GP practice**

Gender	V/positive	Positive	Neutral	Negative	V/negative	Total	
Male	10	5	9	3	0	27	
Female	15	8	7	5	i	36	
Total	25	13	16	8	1	63	

#### 4.8 Health services used

Participants were asked if they had visited and used any health services (other than a GP) while living in Scotland. Table 5 summarises services which had been used.

**Table 5 – Other health services used**

Service	Number of responses
Sexual health clinic	8
Heart diseases clinic	4
Mental health services	4
Diabetes clinic	3
Cancer clinic	3
Other	6
Non respondent/none	36

It is interesting to note that people have indicated a range of health issues they are concerned with as can be shown in Table 5 above (health issues of concern) whereas Table 6 shows lower numbers who have actually used health facilities linked to these issues. This suggests that people have got health concerns but are not seeking information and gives an indication to the challenges participants meet when accessing health services.

Interestingly, mental health was not listed as a concern, but four people have used mental health services.

People were also able to comment about their experience of services. Some of the comments about services used were:

- Unfriendly services as if you are a bother
- Training GP's about racism and race equality
- They should make sure they treat everybody the same way, give equal service
- Help to register with GP
- Provide translation services
- Not stereotyping all Africans same box. We are all different
- Waiting on reception could be quite depressing when you are ill

#### 4.9 Time preferences for accessing health services

When asked about the most suitable times of the day to access services such as the GP surgery or clinics, participants were offered a choice between weekdays and weekends with each day broken into three parts – morning, afternoon or evening. Participants were also given the option of selecting 'no preference'. The responses were very varied which suggests different people with different circumstances require a broad variety of options.

Tables 6 and 7 show the responses preferred times during the week or weekend. It should be noted that participants were asked to select only one option. However, most selected one for either the week or then the weekend. Several selected many different times so these could not be recorded in the tables below.

**Table 6 – During the week**

Time slot	Number of responses
Morning	13
Afternoon	11
Evening	10
No preference	15

**Table 7 – During the weekend**

Time slot	Number of responses
Morning	7
Afternoon	18
Evening	13
No preference	11

#### 4.10 Getting health information

Participants were asked where they would like to access their health information from and again participants were able to select as many or as few areas as they felt beneficial to them. Table 8 shows their preferences with a breakdown in terms of gender.

**Table 8 – How Africans want to get health information**

Area	Male (n=28)	Female (n=36)	Total (n=64)
GP surgery	21 (33%)	31 (48%)	52 (81%)
Hospital	19 (29%)	21 (32%)	40 (61%)
Post	15 (23%)	12 (18%)	27 (41%)
Local pharmacy	10 (15%)	12 (18%)	22 (33%)
Charity organisation	10 (15%)	9 (14%)	19 (29%)
Local library	6 (9%)	13 (20%)	19 (29%)
Family members/ friends	9 (14%)	9 (14%)	18 (28%)
Church /Mosque	9 (14%)	8 (12%)	17 (26%)

Sexual health clinics	5 (8%)	11 (17%)	16 (25%)
Email/ internet	6 (9%)	8 (12%)	14 (21%)
Community centres	3 (5%)	7 (10%)	10 (15%)
NHS 24	3 (5%)	6 (9%)	9 (14%)
Texts	5 (8%)	4 (6%)	9 (14%)
Other	3 (5%)	4 (6%)	7 (11%)

Table 8 illustrates that most people preferred GPs as the first option; working with GPs continues to be a good way to improve health services for Africans as well as trying to use different avenues suggested by the participants.

Waverley Care delivers a training session for GP practices “Increasing discussions with black African patients about HIV testing” and has had a reasonably good uptake from Edinburgh based practices. However, given that the response to 4.3 identified that 64% of respondents lived outside of Edinburgh, it will be important to market this training more actively to GP practices in the Lothians.

#### 4.11 HIV

Participants were then asked if they felt that HIV was an issue to African people living in Scotland.

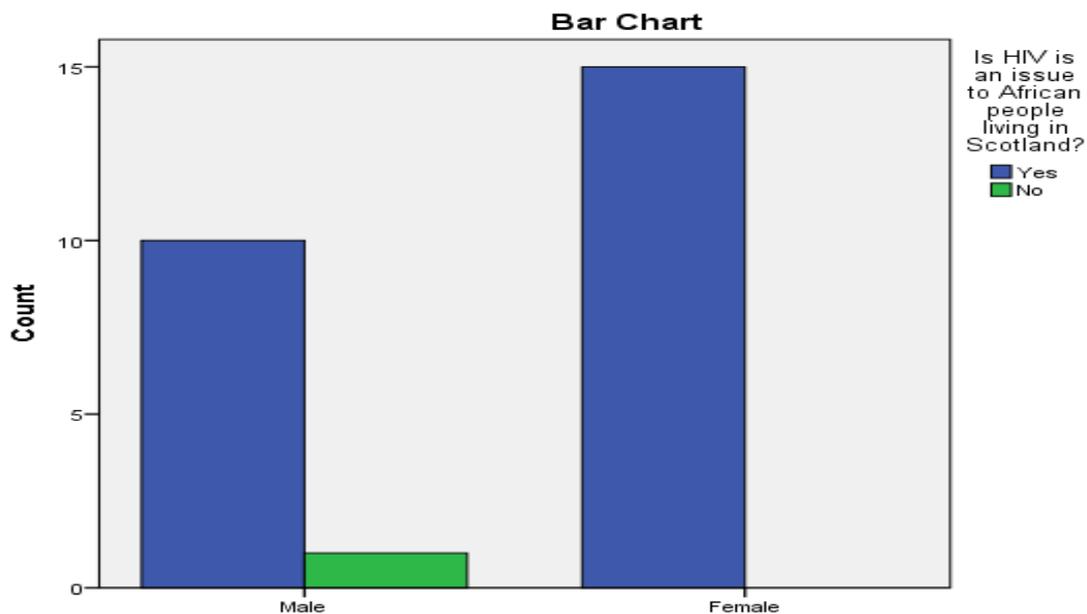
Over half of the participants declined to answer this question; this may well reflect the discomfort people continue to feel about HIV within this target group. However, research also shows that Africans in the UK do not believe that HIV is an issue in the UK because there is so little mention of HIV and there are no public campaigns about HIV. In addition a number of pieces of research, including “HIV becomes your name” identified that Africans did not believe themselves to be at risk of HIV because they were in a long term relationship or because they looked and felt well.

Findings from the London Voluntary Counselling and Testing Project (Sseruma W, Prost A) on barriers to testing identified:

- Low self perceived risk for HIV
- Lack of information about entitlement to care and unfamiliarity with NHS services
- Concerns linked to immigration – health is not a priority
- HIV related stigma – fear of consequence of positive diagnosis

Graph 1 shows the gender breakdown of the responses. This shows that again more women felt that HIV was an issue compared to the men. This backs up the previous finding above that women have a higher concern about their sexual health than their male counterparts but that getting African men to be more proactive about sexual health is vital.

**Graph 1 – Is HIV an issue for Africans living in Scotland?**



**4.12 Services in general**

Participants were asked to prioritise access to six different services in order of their importance to themselves. These included access to employment, access to benefits system, access to education, access to immigration support, access to housing and access to health services. Participants were asked to rank each area from 1 – 6 in order of importance with 1 being the most valuable and 6 being the least. Not all participants answered the question.

**Table 9 – Service priority**

Access to services	Number of people (n=54)	% of people (n=54)
Employment	21	39
Welfare benefits	2	3
Education	8	12
Immigration support	2	3
Housing	4	6
Health services	17	31

This chimes with the 2011 research which identified employment as the most common social issue for Africans in Lothian, followed by housing and immigration. The second most important issue was access to health services and we know from previous research that this can be because people don't know what health services are available, don't know if they are eligible to use them or don't understand what the service might offer.

"Some of the reasons given for services being seen as difficult to access included opening hours, e.g. not open out of 9-5, not knowing where they were and difficulties in travelling to them (this included not having enough money to travel), having to make and then wait for appointments.

Other comments included the lack of information about services or not really understanding what services offered and a concern that immigration issues either prevented people from using services or using services might cause immigration problems." (Community Consultation Lothian African HIV Strategy – Waverley Care 2008).

#### **4.13 How can NHS improve services for Africans?**

The final question asked for the participants opinions on how the NHS or any projects could improve health services for African people living in Edinburgh and Lothian. Several responses were given.

- More awareness of the health services that are there
- NHS to work more closely with churches/organisations
- Maintaining confidentiality not assuming that most Africans are illiterate
- Holding awareness campaigns
- Holding meetings with African churches and groups
- Having more ME staff
- Making information easily accessible
- Raising awareness
- Occasional partnership with African churches
- Work closely with community (ethnic) organisations
- Community NHS staff should be encouraged to attend workshops on ethnic minorities run by ME groups

#### **5. Summary and recommendations**

There is a paucity of research on the health and social needs of Africans in Scotland and what is available is very local. While we know more about HIV in relation to Africans in Scotland, priority issues, as can be seen in this study, are wider than just HIV or health. This study and the 2011 University of Edinburgh study were conducted with relatively small

numbers (64 and 36) and limited by time and resources. It is likely that there are groups and individuals not reached by the research, particularly those with no immigration status.

However, this study has revealed issues and concerns for Africans in accessing health services in Edinburgh and Lothian.

There is a strong need for local organisations and health care providers and others who work with Africans to increase education and training in understanding of this population.

Subsequent steps are recommended.

It is important to note that negative experience is a barrier for further engagement with the health service and also health promotion. Therefore, there is a need to explore further on the actual experiences in order to take appropriate action.

There is strong need for culturally sensitive training and awareness targeted at changing attitudes, perceptions and approaches of GP's and other health workers towards black Africans.

There is a need for further study to explore the kind of jobs African do in comparison to their qualifications.

There is a need to explore cultural barriers among men on health issues as well as finding out why African men tend not to seek help early enough when they have a health problem.

There is also a need to develop health promotion programs that can address specific identified needs in the study to improve health lifestyles.

Recommendations:

1. Improve knowledge of NHS services and access to Black African men, women and young people, with a focus on key health issues including health promotion
2. Promote awareness and knowledge of cultural issues relating to Black Africans to health care workers, including Primary Care
3. Continue to find culturally appropriately ways to promote the benefits of early HIV testing to Black Africans linking to acceptable services
4. Raise awareness of support services such as Waverley Care and MEHIS to include health promotion and employment opportunities to Black Africans.