

Community Engagement Project  
The NIHME Mental Health Programme

**Report of the community led research project focussing on:**

**The mental health needs of Black African people living with HIV**  
Carried out by UKC – UK Coalition of People living with HIV and AIDS  
London

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**The following people were involved in the development and delivery of this project:**

**Mercy Banda**

Mercy is a Careers Guidance Officer at UKC for clients living and working with HIV. In this capacity she conducts one-to-one interview sessions, offers support with form filling for courses, training, work placement or employment. Her role also includes the provision of appropriate information, signposting and referrals to various agencies – including Ensuring Positive Futures Programme (EPF) services. For Mercy, this Research Project has been an eye opener, as she learnt about the difficulties of accessing appropriate services in different boroughs across London.

**Daisy Byaruhanga**

Daisy Byaruhanga a single mother of a fourteen year old daughter and for the past 11 years has been the founder of Innovative Vision Organisation, an HIV/AIDS. In 2002 she won the Windrush Award for community work and in 2004 she won the London week of Peace award for diversity work.

Daisy got involved in HIV work back in Uganda in 1985 when she lost her best friend to AIDS. She subsequently lost over 30 of her family members and contemporaries both in the UK and Uganda.

She has also cared for family members and friends with mental health needs, as a result of their HIV diagnosis. Having lived in the United Kingdom for 17 years, when this project was advertised Daisy saw it as a great opportunity to contribute to this vital piece of work.

Daisy is glad she completed the academic requirements of this project successfully. She is now fundraising to conduct further research with clients accessing services of Innovative Vision Organisation, so that expertise and good practice can be shared nationally. Thank you to all our tutors, thank you to Haydn our Coordinator, thanks to all fellow researchers for sharing and thanks to all our respondents who have made this research a reality.

**Haydn Forde**

Haydn is 42 years old and worked as Project Co-ordinator on this piece of Research. He was diagnosed HIV positive in 1997; since then he has worked and volunteered with various HIV organisations, including The Aids Treatment Project, Positive Nation Magazine, The Landmark and THTDirect Helpline. Having recently obtained his MA Dramatherapy (Sesame) from the Central School of Speech and Drama, he has gained clinical experience as a Dramatherapist in many settings, including - Psychiatric (Jules Thorne Day Hospital, The Maudsley, The Drug and Alcohol Foundation) – Primary Schools (Children with emotional and behavioural issues) and for THT's Maisha Mema (Emotional Support for African people living with HIV).

**Patricia Kangogyere**

Patricia Kangogyere is a UK Coalition administration volunteer. She is a web-designer who decided to venture in a totally different subject of mental health. She has found it very inspiring and would like to take it further to the next level.

**David Kasule**

David is 45 years old and employed on the project as a community researcher. He decided to join the group because he had so much free time during the day. He has interviewed respondents, has learnt a lot about data analysis and ultimately how mental health issues are relevant to Black African people living with H.I.V.

**Lynne Kimaro**

Lynne Kimaro-Mother of 7years old.Hold BA in Education.Recently studying Early Years Professional Status (EYPS) at Metropolitan university north London. I had no previous experience in the field of Mental Health, but through this project I have learned a lot. I have always wanted to do something to the community, which is why I decided to be involved in this project, but who knows maybe one day I will pursue my career in this field.

**Phyllis Magombe**

53 years old. Currently volunteering in various capacities at UKC since January 2006 and has experience working with a number of HIV Community Based Organisations. As a result of this work, she was attracted to this Community Engagement Project particularly as she interacted with a number of HIV positive people who experienced mental health issues like depression as result of isolation, rejection and stigma. She wanted to explore the co-existence of HIV and Mental Health illnesses. Phyllis had previously been involved with similar research project at UKC on behalf of Salisbury Mental Health Project.

On this project she participated as a community researcher, advertising the project, developing the questionnaire, identifying relevant respondents and research methods, as well as conducting the interviews

**Rotzett Namisi-Keronegs**

I am 54 years of age. I am involved in volunteer work within the African communities and my local church. During this project, I have been able to learn and appreciate the importance of self motivation as a key ingredient to personal development and leadership skills through humility, observation and commitment to good work and ethics.

**Trizah Ndwaru**

Trizah Ndwaru: Formerly worked as a scientist in the water, sanitation, health and sustainable environmental management field. She retired after 20 years in the sector and changed course to the social sciences where she has found a new and exciting niche working and supporting communities, particularly within the HIV sector.

**Godwin Onwuchekwa**

Godwin Onwuchekwa (aka godwyns): I have a passion to help the human society, I found this research as the right launch pad to contribute the little I have but far above that, to also learn the ropes working with much experienced people. I was brought up on doing charity, from sweeping the church compound to visiting the aged, prisoners and teaching young people as well as adults. I presently study for my B.A. in Multimedia Technologies in a private college in London but hope to enter full time into the field of helping mankind. My main objective is to work in empowering the weak, helpless and less-privileged; simply inspired by the adage, "teach men how to catch fish, and don't give them fish to eat".

## ACKNOWLEDGEMENTS

**Special thanks** go to all the respondents who gave freely of their time to participate in the qualitative interview process and especially those who were so willing to come forward and speak frankly and in depth about their mental health needs.

The team is also deeply grateful for the enthusiasm and assistance of all the staff and volunteers at UKC who supported us in various ways throughout the project.

We extend heartfelt thanks to the Womens' support group at Positive East, Positively Women, Positive Nation Magazine and Innovative Vision Organisation.

A special 'thank you' goes to Imran Aziz-Mirza who acted as the support worker from UCLan throughout the main part of the development and data collection periods of this project. Thanks are also due to Manjit Bola and Pam Howard, also from UCLAN who delivered the training sessions in Mental Health and Research methods.

Deep gratitude goes to the members of our Steering Group who provided expert advice throughout -

Dr Jane Anderson,  
Brigid Hekster,  
Edith Kaggwa,  
Dr Damien Ridge,  
Dr Fola Rogers-Saliu,  
Dr Lorraine Sherr,  
Jack Summerside

## CONTENTS

<b>Section</b>	<b>Pages</b>
<b>Executive Summary</b>	<b>7- 9</b>
<b>Introduction</b>	<b>10-17</b>
<b>Literature Review</b>	<b>18-20</b>
<b>Delivering Race Equality</b>	<b>21</b>
<b>Method</b>	<b>22-27</b>
<b>Results</b>	<b>28-32</b>
<b>Discussion</b>	<b>34-37</b>
<b>Recommendations</b>	<b>38-39</b>
<b>Bibliography</b>	<b>40</b>
<b>Appendix</b>	<b>41- 58</b>

## **Executive Summary**

The aim of the study was to look at the mental health needs of Black African people living with HIV. The Research Team was recruited through internal correspondence and UKC's publication, 'Positive Nation' and by visiting support groups of partner organisations.

Training for this project was provided by the University of Central Lancashire and focused on developing an understanding of issues on mental health and research methods. There was also an opportunity for the Research Team to obtain a University Certificate in Community Based Research and Mental Health.

There was no direct involvement with NIHME in this project, however support for this work was provided by UCLAN's support worker, Imran Aziz Mirza and the Steering Group who offered invaluable advice and direction throughout this project.

After the initial training sessions in July, the Research Team met every Tuesday afternoon for two hours to design the interview script. After many in depth discussions, subsequent Ethics Approval and with the help of a focus group, the interview script was completed and ready for fieldwork at the end of October.

The research design could be described as a mix of both qualitative and quantitative methods. There was general feeling among the research team that 'real life' stories would be most poignant, therefore emphasis was placed on capturing the narrative flow of experiences, i.e. qualitative. The team also felt that this research method would be more appropriate to the respondents' cultural background

Materials used in the study included tape recorders, interview scripts, consent forms, pens and contact sheets giving details of agencies offering emotional support for interviewees, if needed. Respondents were also paid a stipend of £20. Travel expenses and child care costs were also covered.

## **What we found**

**Services** –In many cases, there was a stigmatised view of the term ‘Mental Health.’

**Relationships** – It is now recognised that the quality of relationships established with friends, immediate and extended family can determine mental well being. The fear of HIV, which can exist within various African communities, can rob people living with the virus of the emotional support which they might so badly need.

**Faith** – While most respondents continued to attend Faith groups for spiritual support and guidance, most felt unable to seek emotional support around their HIV status from their Faith group within their communities.

**Discrimination** – Respondents had a variety of negative experiences from health care service providers which impacted on their mental health and there was a desire to achieve increased satisfaction with services.

## What we recommend

- A **re-branding** of emotional support services for Black African communities living with HIV towards something that is culturally appropriate. As can be seen from our findings, most respondents had a stigmatised view of the term 'Mental Health.' The name is possibly the first point of contact a service user will have with any given service. Some HIV organisations have already taken the lead in re-naming their emotional support services, e.g. Maisha Mema at Terrence Higgins Trust, Rise Community Action, Cascaid and Innovative Vision Organisation. This trend needs to be more commonplace if mental health needs of this community are to be met.
- Our findings have shown that Black African people living with HIV can experience discrimination because of their HIV status from statutory services. There is a clear need to increase the amount and scope of training on basic HIV awareness in this sector. We would also like to recommend another dimension to this much needed training - a more **in depth journey into the emotional difficulties** that living with HIV can create, both for the infected and affected. This holistic approach is more in rhythm with the provision of a balanced range of effective therapies and is a development of the Ashanti proverb 'It takes a whole village to raise a child.'
- Following on from this, training on **transmission, safer sex and HIV stigma** also needs to be made available to various departments within the **NHS, GPs and dentists** to name a few. One of our respondents spoke about taking personal responsibility to educate her dental clinic by way of HIV leaflet provision in the waiting rooms, for instance. It might be possible for this work to be developed into **BME service users living with HIV to provide awareness training to various departments within the dental profession**, in an attempt to change attitudes of health practitioners towards African people living with HIV.
- Five respondents in our sample regarded their immigration status as a barrier to obtaining emotional support. Undoubtedly there may be many more individuals who feel this way. The African Emotional Support Group model within the HIV sector appears to be of benefit for most service users. Ideally emotional support is a basic human right. It therefore needs to be more widely communicated that **this support is available, regardless of immigration status**. In this way it may be possible to bring about increased satisfaction with services.
- More attention needs to be paid by HIV clinics on how side effects of HIV medication may be affect the mental well being of African clients living with the virus, who might not be able to communicate this emotional need. Again with this holistic approach it may be possible to bring about an **increased satisfaction with services**

## INTRODUCTION

### **The Centre for Ethnicity and Health's Model of community engagement**

#### **Background to the community engagement model**

We often hear the following words or phrases:

- Community consultation
- Community representation
- Community involvement/participation
- Community empowerment
- Community development
- Community engagement

Sometimes these terms are used inter-changeably; sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre's model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (UCLan) to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work.

In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include:

- Substance misuse
- Criminal justice system
- Policing
- Sexual health
- Mental health
- Regeneration
- Higher education
- Asylum seekers and refugees

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual and trans-gender people
- Women
- White deprived communities
- Rural communities

In addition to the DH, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard and Aimhigher.

## **The key ingredients of the model**

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community<sup>1</sup>, such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

The second key ingredient is the research task that the community undertakes. According to the Centre for Ethnicity and Health model, this must be something that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be the first time that these individuals have undertaken a research project.

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation.

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<sup>1</sup> The target community may be defined in a number of ways – in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

<sup>2</sup> This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

It is expected that the bulk of this money will be used to pay people from the target community as community researchers<sup>2</sup>. A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project<sup>3</sup>.

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals' career development as they progress through the project

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<sup>3</sup> Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

### The community engagement team

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

<b>National Programme Directors</b>			
<b>Northern Team</b>	<b>Midlands Team</b>	<b>Southern Team</b>	<b>Senior Programme Advisors</b>
<b>Senior Support Worker</b>		<b>Senior Support Worker</b>	
<b>Support Workers</b>	<b>Support Workers</b>	<b>Support Workers</b>	<b>Drug Interventions Programme</b>
			<b>Citizen Shaped Policing</b>
<b>Teaching And Learning Team</b>			
<b>Administration Team</b>			
<b>Communications Officer</b>			

## **Programme outcomes**

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

In 2005/6 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- The Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.
- The Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.
- Most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- All DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme reports would inform their plans for the development of appropriate services in the future.
- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

The views expressed in the report are those of the Research Team that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

Since 2000, over 200-community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Programmes.

## **The community in which the project was undertaken**

UKC was founded in 1993 to act as the voice of people living with HIV in the UK. It is the largest UK charity entirely governed by people living with HIV & AIDS, delivering a range of services, producing a number of publications and supporting those directly affected by HIV - partners, friends and family of HIV infected people.

In the fight against HIV-related stigma, the charity also seeks to influence government service-providing bodies such as the NHS and wider communities on a range of issues. UKC also focuses on issues of legality adversely affecting people with the virus, such as criminalisation of HIV transmission, treatment of people seeking asylum and access to HIV treatment and care.

The two main groups of people in which HIV infection is significantly prevalent in the UK are gay men and Black African people. Much attention has been paid to the fact that a growing proportion of new HIV diagnoses in recent years are in people for whom heterosexual sex was the route of infection. It is often obscured that the overwhelming majority of these diagnoses in heterosexual people are Black Africans, particularly people from Sub-Saharan Africa.

There are now estimated to be more than 7000 Black African people living with diagnosed HIV infection in the UK and it is estimated that half of this figure represent those who are infected, but unaware of their HIV status. The greater proportion of African people diagnosed with the virus are women. In 2001, the ratio was 2 women for every man, however it has been recognised that this is a consequence of UK ante-natal HIV testing policies.

Black African HIV-infected people have multiple indicators of deprivation. Many are refugees or seeking asylum, often with traumatic experiences of civil war, forced migration, sexual abuse and so on. Many do not have English as a first language, such as people from Rwanda or Somalia.

Levels of poverty are high amongst these Black African communities, not least because asylum regulations often do not permit people to earn money by working. Poor housing and living conditions are reported as a problem for more than half of the diagnosed HIV positive Black African population.

Around 85% affiliate to a Christian faith (around half of these being Catholic) and less than 10% Muslim (the majority of which are men). African people tend to be diagnosed at a late stage of HIV disease progression for many reasons, including - high levels of HIV-related stigma/discrimination in African communities and actual or perceived barriers to healthcare.

(Epidemiological data from Health Protection Agency sources, other data from Project Nasah, Sigma Research 2003)

## Literature Review

A cursory glance at the body of research conducted within the various communities living with HIV in the UK, will show that the data available from MSM communities certainly overshadows that of the African communities.

However the findings of research within the various African communities in the UK are significant and the following highlight some mental health needs of Black African People living with HIV –

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**I want to survive, I want to live, I want tomorrow** explored the circumstances of African men living with HIV in London, with particular focus on relationships between gender, masculinity and HIV that would inform health and social care issues in the UK. One of the findings of this study was that little attention has been paid to the mental health of African men who often suffer great loss of self esteem. (Doyal, Anderson, Apenteng (2004),

**My heart is loaded** - focusing on African women - looked at identifying the main factors that shaped their lives, including access to material, social and cultural resources, about the choices they faced and the constraints that limited their options. Particular attention was paid to survival strategies and their implementation in difficult circumstances so far from home. 'About a third of the women reported direct experience of HIV related stigmatisation, such as rejection by husbands or partners, eviction from their home and refusal to allow contact with children. When this was combined with the hostility many experienced as black migrants in the host community, the impact on mental health was often profound.'(Doyal & Anderson (2001)

**Shibah** looked at sexual health issues that affect African men and women who use HIV services in Lambeth, Southwark and Lewisham. The aim was to learn about their experience these services, in order to improve service delivery. One of the findings from this study outlined that respondents who were diagnosed HIV positive in hospital, felt too ill to benefit from HIV counselling, but expressed a desire to have this kind of support later on. (Chinouya, Ssanyu-Sseruma, Kwok (2003)

**Outsider Status** aimed to acknowledge and address the social inequalities that are the rationale for HIV-related stigma and discrimination. In a section of the report headed, 'The Diasporic Family', there was a discussion about the network of communication between various African communities in the UK and their families back home in respective African countries. The efficiency of this network means that disclosure of HIV status to communities in the UK can be easily communicated to family at home, thereby possibly severing sources of emotional support. 'For those who depended on ongoing emotional support from distant loved ones in order to survive the pressures of life in Britain, the risk of having these ties severed was too high. They recognised that they would not be able to successfully convince friends and relations in Africa that the news was not so dire because, in the African context, the reality of death from AIDS continues.'(Dodds, Keogh, Chime, Haruperi, Nabulya, Ssanyu Sseruma, Weatherburn (2004)

**Project Nasah** - (Sigma Research 2003) reported high levels of anxiety and depression, experienced by Black African people with HIV, as the second most common problem, closely behind 'having enough money to live on'. 71% of Black African people with HIV reported problems with anxiety and depression in the last year.

Major depression has been found to be more common in Africans with HIV than in White people with HIV, although they are three times less likely to be referred for specialist mental health care (Malanda, Meadows & Catalan 2001: Are we meeting the psychological support needs of Black African HIV-positive individuals in London? Controlled study of referrals to a psychological medicine unit)

In addition to this, as Black Africans tend to be diagnosed much later in 'HIV disease progression,' there is greater likelihood of organic brain disease as a result of HIV. Whilst an AIDS diagnosis might ordinarily increase the likelihood of routine referral, there is also the potential for staff to fail to recognise psychological morbidity in Black Africans, because of cultural differences or lack of familiarity with working with Black African clients.

Clearly, there is a high level of unmet mental health need amongst HIV- positive Africans. The London HIV Strategy includes a commitment to work on improving access to mental health services for people with HIV, as they are recognised as currently deficient. However there is little published data that explains the lived experience of those in need of support, from which to better understand the cultural and other barriers to service access and suitability.

For example, many Africans may be inhibited to seek external support, being more used to seeking advice from extended family. However, the African Diaspora may mean that such a network is unavailable to them in the UK. The nearest source of support - from members or officials in faith groups - may also be closed to them because of actual or feared stigma and discrimination.

Much psychological support available in the UK is rooted in European models of listening and supporting individuals to reach their own solutions – a model which can appear evasive and unhelpful to Africans, and indeed for many white people, who are more used to being advised more actively on what choices to make.

We would intend this research to reflect the experiences of community members, but also expect it to be a platform from which to make recommendations about the ways in which services could be made more readily acceptable and appropriate to the cultural traditions of African people. We believe that this research could help drive service improvement across London.

It is therefore important to note that the research conducted among the various African communities living with HIV in the UK is certainly not exhaustive. This community engagement project is the first of its kind which is looking specifically at Mental Health Needs of this community.

It is already a well documented fact that Mental Health is an issue for people living with HIV. The National Aids Manual's publication - 'HIV & Mental Health' - is a testimony to this fact. Among other issues, this informative booklet looks at dementia and mania which could be the result of advanced stage HIV infection. Also covered are depression, anxiety and emotional distress which many PLWHIV experience as a secondary health concern, even in the face of life saving treatments. UKC's Positive Nation magazine has also featured Mental Health (Nov 2003 issue 96) – Are we losing it? Mental health problems and HIV.

## **Delivering Race Equality**

Delivering Race Equality - colloquially known as 'the DRE' - is a twelve point action plan to improve mental health services for black and ethnic minority communities by 2010.

This study is a direct strand of the DRE and it aims to address the following points in the five year action plan.

- Less fear of mental health services among BME communities and service users
- Increased satisfaction with services
- A more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally appropriate and effective
- A more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services.
- A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

In relation to the above points, our findings will show that –

- A stigmatised view of the term 'Mental Health' was expressed by the respondents
- Discrimination experienced as a result of HIV status and an inability to perceive Mental Health needs, from dentists, HIV consultants and other NHS departments had an adverse effect on respondents' mental well being
- Most respondents expressed that emotional support services respected their cultural backgrounds, however all of them suggested ways in which these services could be improved.

## **Method**

As a **focus**, the study looked at the mental health needs of Black African people living with HIV. The Research Team was **recruited** through internal correspondence and UKC's publication, 'Positive Nation – The UK's HIV & sexual health magazine' and by visiting support groups of partner agencies.

**Training** for this project was provided by the University of Central Lancashire and focused on developing an understanding of –

- Models of Mental Illness (Psychiatric, Psychological and Lay/User View)
- Mental Health Diagnoses as labels and the view of seeing the person behind the label.
- Stigma associated with Mental Illness and possible ways to combat Stigma
- The modernisation of Mental Health Services, which included - Delivering Race Equality (DRE) in mental health service delivery; the function of the National Institute for Mental health (NIMHE) – Research, Good practice, Service User/Survivor involvement; the National Service Framework (NSF) – Health Promotion, Time frames, Primary care
- Social exclusion/disadvantage within the context of Mental Health, particularly within BME communities
- The Community Engagement Model, i.e. planning of a research project, advantages and disadvantages of various research methods, data analysis/explanation and report writing.

It was also impressed on the Research Team that there was an opportunity to obtain a University Certificate in Community Based Research and Mental Health as such, most of the research team also undertook the task of researching and completing written assignments.

There was no direct involvement with NIHME in this project, however **support** for this work was provided by UCLAN's support worker, Imran Aziz Mirza and the aforementioned Steering Group. The Steering Group offered invaluable advice and direction throughout this project in various capacities, including –

- Devising the interview script
- Identifying groups to be interviewed
- Data collection and analysis
- Years of professional insight into issues around Mental Health and HIV

The **research design** could be described as a mix of both qualitative and quantitative methods. There was general feeling among the research team that 'real life' stories would be most poignant, therefore emphasis was placed on capturing the narrative flow of experiences, i.e. qualitative. The team also felt that this research method would be more appropriate to the respondents' cultural background.

There were twenty eight **participants** in all, made up of six in the Focus Group and twenty two subsequent interviewees. The ages ranged from 25-52, with 15 women and 13 men.

**Materials** used in the study included tape recorders, interview scripts, consent forms, pens and contact sheets giving details of agencies offering emotional support for interviewees, if needed. Respondents were also paid a stipend of £20. Travel expenses and child care costs were also covered.

After the initial training sessions in July, the **procedure** was as follows – The Research Team met every Tuesday afternoon for two hours, with the aim of designing the interview script. After many in depth discussions, it was thought that the interview script should contain questions in the following categories –

- Core data, e.g. age, country of origin, sex, sexual orientation
- HIV medication and well being
- Living situation including accommodation
- Disclosure of HIV status to extended family members, faith groups and children
- Sexual relationships
- Leisure time
- Internalised and externalised stigma
- Perceptions of Mental Health, existing diagnoses, relevant medication and referrals to emotional support and symptoms experienced in the last twelve months.
- Current experiences of emotional support services

The final version of the Ethics Submission was sent on the 21<sup>st</sup> August 2006 and Ethics approval was received on the 23<sup>rd</sup> October 2006, so for the following two months the team continued to develop the interview script.

Contact was maintained with respondents who had expressed interest in the project. The Project Coordinator also advertised the project and recruited respondents by visiting 'women only' support groups, run by HIV service providers.

A comprehensive list of interviewees was continuously updated in the interim, as people were responding (by phone and by e-mail) to the advert for the Project, which appeared in Positive Nation Magazine, various HIV drop in centres and clinics.

The research team also promoted the Project by word of mouth within their communities and started to identify a potential Focus Group to support the final process of devising the interview script.

We held our Focus Group at UKC on 31<sup>st</sup> October. Facilitated by Daisy and Phyllis, the group consisted of 6 respondents, with a balanced male/female ratio.

African Nations represented included Nigeria, South Africa, Ethiopia, Kenya and Rwanda, with a variety of tribal groupings and languages, such as Tutsi, Kikuyu, Yoruba and South Sotho.

They all lived in various boroughs in South, North and East London and had migrated to the UK from between 1-10 years.

Two were asylum seekers, another two had limited leave to remain, while Indefinite Leave to remain and British citizenship numbered one each.

Five identified as being of the Christian faith, while one identified with being an atheist.

Five had experienced the side effects of HIV medication at the highest level (5) and one person was yet to start medication.

Everyone on the group was diagnosed HIV positive in the UK, had children abroad and had some extended family in the UK to whom they had not yet disclosed their HIV status.

They talked of knowing one or two voluntary organisations where they accessed emotional support but admitted there was great difficulty in obtaining practical support from statutory sectors, especially for travel and day to day living expenses.

None of the group was employed however some individuals were volunteers and relied on state benefits and grants from the voluntary sector.

Four admitted living with HIV made them feel different from other people and two were unaffected by this stigma. There was a general experience in the group of discrimination based on HIV status from service providers like the Home Office, General Practitioners and some GUM staff.

Two of people in the group experienced mental health difficulties before their HIV diagnosis and four after. Four admitted accessing medication as a result of mental health diagnoses, with two being hospitalised for a few days.

Four people continued to access support through various agencies, Positive Nation magazine and one to one support from counsellors. Their experience of General Practitioners was a lack of knowledge of referral pathways for people living with HIV and mental health issues.

The group concluded by saying the services they had accessed were not respectful of their beliefs and were not culturally appropriate to the African perspective. They further recommended following -

- The availability of more peer support groups
- The western psychological process of digging into past personal experiences was unnecessary and mentally torturous
- The development of Pastoral Work
- Increased family support, e.g. Aunties as since psychiatrists have failed to identify their needs.

The interviews then commenced on the 21<sup>st</sup> November and finished on the 6<sup>th</sup> of December. Interviews were held at two sites – Innovative Vision Organisation in North London and at UKCoalition in Kennington and where possible, two researchers were assigned to interview each respondent.

**Some difficulties experienced, included the design of the interview script.** This was a lengthy process, as it was important to include the views and concerns of the whole team. However the team meetings were always very well attended, as all of the researchers had a personal connection with the focus of the work. The Steering Group was extremely helpful in streamlining the quantity and quality of questions asked. The focus group was also beneficial, as it enabled us to arrange the questions according to the sections as outlined above.

Another difficulty we encountered was the **wait for approval** of the Ethics Submission. As a team we managed to keep in regular contact with people who came forward, however we did lose a few people. This also meant that we were unable to interview as many respondents as we would have hoped, i.e. 40.

**Matching respondents' availability** with that of researchers also appeared to be sometimes difficult. A few interviewees were also unable to **keep their appointments**, without giving prior notice. Some respondents also preferred not to be interviewed by **two researchers** or requested a **same-gender** interviewer. '**Research fatigue**' also began to take its toll, as the team also had various demands within their personal lives. However flexibility, excellent communication and dedication to the issue at hand existed among team members; in this way we were able to overcome these obstacles.

**Expectations** of some respondents also sometimes proved difficult, as some people expressed a need to see an almost immediate change in policies, asking difficult questions in the process. However the training provided by UCLAN enabled the research team to field these questions successfully.

It was also expected that **some interviews would be emotive** for the **members** of the **research team**. The African Emotional Support Service at the Terrence Higgins Trust was therefore contacted to offer standby therapeutic support for the team.

**The time-line of the project**, i.e. nine months sometimes appeared unachievable to the research team however the practicality of the Project Plan was useful to assuage concerns and build morale.

**Transcription and Analysis of Data** was undertaken by the team and for some this was the most difficult part of the process, as most people had never transcribed data before. There was also the difficulty of understanding the mechanics of SPSS, the software package used to analyse the data. However to make things easier, we started by transcribing as a group listening to recorded data, stopping frequently, comparing notes and referring to the UCLAN training handbook. We also had the benefit of reliable recording equipment. The Steering Group was again extremely helpful to point out any pitfalls in understanding and negotiating SPSS.

Finally one last problem and concern was the **lack of involvement from mental health commissioners**, despite repeated invitations extended through the London Development Agency to sit on the Steering Group.

## Results

<b>Number of respondents</b>	22
<b>Age Range</b>	25 - 52
<b>Women</b>	12
<b>Men</b>	10
<b>Ethnicity (Black African)</b>	
Ghana	2
Ivory Coast	1
Kenya	2
Nigeria	3
Uganda	11
Zambia	2
Zimbabwe	1
<b>UK Born</b>	1
<b>Immigration Status</b>	
Asylum Seeker	12
British Citizen	4
Discretionary Leave to Remain	1
Exceptional Leave to Remain	1
Indefinite Leave to Remain	3
Leave to Remain	1
<b>Spoken Languages</b>	
Ateso	1
Bemba	1
English	7
French	1
Luganda	5
?	2
Rukiga	1
Shona	1
Swahili	2
Yoruba	1
<b>Religion</b>	
Christian	16
Muslim	5
None	1
<b>Sexuality</b>	
Bisexual	1
Heterosexual	20
Refuse to answer	1
<b>Respondents who considered themselves disabled</b>	
No	5
Yes	16
Yes & No	1

### Boroughs

Bedfordshire	1
Brent	1
Croydon	1
Enfield	6
Hackney	1
Hammersmith and Fulham	1
Haringey	6
Southwark	3
Waltham Forest	1
Wandsworth	1

### Medication

<b>On medication</b>	<b>Not on medication</b>
19	3

Side effects of medication affecting wellbeing  
(On a scale from 0 to 5, with 0 being no effect at all and 5 the strongest effect) –

<b>Respondents</b>	<b>Scale</b>
1 (5.3 %)	0
1 (5.3%)	1
6 (31.6%)	2
2 (10.5%)	3
2 (10.5 %)	3.5
1 (5.3%)	4
6 (31.6%)	5

### Living arrangements

Respondents	
Who lived with someone	11
Who lived alone	9
Who sometimes lived alone and sometime with someone	2

### Faith Groups

Respondents	
Attended faith groups	8
Didn't attend faith groups	14

Respondents	
Did not seek support re: HIV status from faith group	17
Sought support re: HIV status from faith group	4

Extended family in the UK	
With family	15
No family	7

Children	
With	2
Without	20
Living in the UK	13
Living outside the UK	7

### Stigma

People who felt they had been treated negatively as a result of their HIV status	15
People who felt they experienced negative treatment within the health care system because of their HIV status	10

### Professional Help

Counsellor	7
Psychiatrist	1
Psychologist	1
Art Therapist	2
Group Therapy	1
Self Help Group	1
Hospital-based Care	1

### Symptoms in the last 12 months

Symptoms	Respondents
Anxiety	3
Feeling Low	1
Despair	1
Flashbacks	1
Nightmares	2
Memory Loss	2
Weeping	1
Sleeplessness	3
Loss of Appetite	2
Loneliness	5
Low libido	1

### Attending services providing emotional support

Number of services	Number of respondents
0	5
1	6
2	2
3	5
4	2
5	1
6	1

### Perceived barriers to emotional support

Immigration status	5
Women-only space	5
Men-only space	2
Service too far away	5
Service too near	1
Felt they would be treated differently	1
Language	1

All respondents suggested ways in which services could be improved, i.e. emotional support and generic HIV services and how they impinge on emotional well being.

## Discussion

To recap, our study aimed to address the following points as highlighted in Delivering Race Equality, while highlighting the mental health needs of Black Africans people living with HIV in London.

- Less fear of mental health services among BME communities and service users
- Increased satisfaction with services
- A more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally appropriate and effective
- A more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services.
- A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

We found that our findings could be themed into four main categories

**Services** –In many cases, there was a stigmatised view of the term ‘Mental Health.’

**Relationships** – It is now recognised that the quality of relationships established with friends, immediate and extended family can determine mental well being. The fear of HIV, which can exist within African communities, can rob people living with the virus of the emotional support which they might so badly need.

**Faith** – While most respondents continued to attend Faith groups for spiritual support and guidance, most felt unable to seek emotional support around their HIV status from their Faith group within their communities.

**Discrimination** – Respondents had a variety of experiences of service provision which impacted on their mental health and there was a desire to achieve increased satisfaction with services.

## **Services**

In order to discover our sample's perceptions of Mental Health Services, we asked respondents the following question – 'When you hear someone say mental health, what comes to your mind?' The following responses are relevant to the general perception of the term 'Mental Health.'

***'Loss of personal emotional control'***

***'Someone not normal, insane mentally confused.'***

***'Lack of co-ordination and lack of ideas and commitment because you can't plan for yourself...you have a mental problem.'***

***'I think of somebody mentally disturbed.'***

***'If someone has got mental health, head disease, something not right in the head, sickness of the head.'***

***'Yah different things; I wouldn't say, maybe that you are mad, but there are certain issues that can affect you mentally maybe like stress, maybe depression....Yah, you can be mad, but in this country mental health doesn't mean madness, but back in Africa if they say mental health, it means you are off; but here it can mean so many different things.'***

***'Before I was diagnosed with my depression, I would say for mental this person is not right, or someone very dangerous. But now, if you have a mental problem, because I have read and having been depressed, very badly depressed one time, I now know exactly what having a mental problem is. There are quite a few ways you can say someone is mental. I used to think someone who undresses and runs around and shouting. I got to the point one time actually not wanting to live really, seriously, just locking myself away from the outside world for weeks and weeks, I'd be just inside the house and I'd feel my head was exploding, until someone noticed when I went to the clinic (HIV), a clinical nurse noticed all my ways of behaving and he said I need to see someone. She made an appointment to see the psychiatric; they put me through all sorts of tests and we sat for an hour or two; he really saw that these are the things I was going through and I had been suffering from them for quite some time, not knowing these are the mental problem or depression.'***

From these statements, there could be a preconceived view of Mental Health Services held by our sample. This might mean that people would not feel that these services are relevant to their needs.

## **Relationships**

We thought that the quality of relationships people have with their friends, family and new situations involving strangers is a significant factor which will determine mental well being.' So when asked – 'How does having HIV influence your relationship with others?' respondents answered –

***'In think it breaks you down and you feel guilty; I can't go in club and pick up a girl, I feel guilty and I think you feel separated from people.'***

***'Fear of sharing things with others. The sink. At first I was afraid that even sharing the toilet, I would infect my children.'***

***'For me, I don't see any gap, I am that courageous. I don't feel when I am among them, I just feel like them because I don't know who how they are. I don't judge myself.'***

***'Yes it makes it difficult to make new friends and some of the friends - I told you before that some of my friends don't know my self status – so I keep it a secret to myself. Yes you are correct.'***

***'Like I said, when I first told my family members, they were very mean to me, very rude. My husband did not talk to me and I got evicted out of the house because of them. I do not want to go on the streets. It was terrible.'***

***'My auntie brought me. She lied to me. I was going to study. I was dumped in a house. I lived in a tiny room sharing with three kids. I washed clothes, cleaned house, took children to school, day in day out, no money, no food. When I fell very ill, I was taken to hospital. I was tested for HIV and was told I am positive. I attempted to commit suicide, my auntie was not supportive. One day I went to hospital and one guy took me to IVO. They have referred me to so many support groups.'***

***'I have some friend or cousins here (in the UK) - all I can do is lie, lie, lie I will never accept overnight sleep weekends, because of my medication, how my medication affects me at certain times, I rather be comfortable in my house or with a friend who is positive like me, then I would go freely and happy.'***

Here, the common thread is the difficulties that disclosure of HIV status can create. This might mean that emotional support services need to specialise developing various support mechanisms around disclosure for Black Africans Living with HIV.

## **Faith**

***'I mean, I have got this thing as an African person. I just believe in me and my father and his father - about five men in my life - and think of those people with all their powers and stand up and go – no church. No anybody. I don't really tell anybody my problems, apart from this organisation. I have been speaking to them now and then, on a personal level, but apart from that no.'***

***'Do you belong to any Faith Groups?'***

***'If you say belong? Yes.'* (Mosque)**

***Do you seek support about your HIV status from your faith group?***

***'No, that is the hardest part.'***

***Another respondent's reply to the same question –***

***'Not really because I have all the support outside, so really I am not in need for it.'***

***And another –***

***'Yes, they talk about awareness; they know (her HIV Status) and I seek support.'***

This shows the significant role of faith in sustaining the mental well being of Black African people living with HIV.

## **Discrimination**

***'If I can give an example, when I was diagnosed, I was going to hospital for chemotherapy. I was the first person to get there around 9 o'clock, (and) I was the last one to get out of the clinic and I was not in the usual rooms in which everybody is seen. I was taken to a very small room right, right down the corridor and I questioned them – why are you taking me down there.....unfair, discrimination, I feel very angry and I just need to control my anger toward the situation.'***

***'Dentists mostly; I told them about my HIV status, they have never called me back for anything since I told them. They have never called me, they started treating me differently. They changed completely; they haven't called me in 4 yrs, not even a check up nothing.'***

***'My dentist was away and I was due for an appointment and there was this one who was covering. When he looked in my file he saw that I was HIV; then he had to put on two different gloves and in between the gloves, maybe he put disinfectant....something that was leaking. Then I said, 'What is that leaking before you touch me!' He said 'No it's nothing.'***

***'And you are putting on two gloves, what is the problem?' I said 'No! I will wait until my dentist comes back, because the way you are putting on two gloves, it seems you have a problem with my HIV'...and I left.'***

***'The nurses (when I went for a blood test) the nurse asked me - How I got HIV, what was I doing? Maybe she thought I was a prostitute. I felt so bad. I feel they should be educated about HIV as well. I felt so discriminated and felt they need more awareness.'***

**And in a discussion about service providers...**

***'....Especially as an African, because our culture is different. It's important they understand the issues African women will be dealing with. In a western relationship base, the man and women are equal - the way they come to decisions, probably the women has an equal say... the African (woman) is doing what they man has told (her) to do. So it could be helpful if the support is being provided (with) an awareness of cultural issues.'***

From these accounts, it is clear that these respondents experienced discrimination from Health Care Services because of their HIV status. In addition to this, eight people in our sample were diagnosed with a mental health condition and five people were on medication to support their mental health needs.

## Recommendations

The overall aim of this research was to identify the Mental Health needs of Black African people living with HIV in the UK. Our sample was taken from the London area with one respondent from Bedfordshire. As a result of our findings, we would like to recommend the following –

- A **re-branding** of emotional support services for Black African communities living with HIV towards something that is culturally appropriate. As can be seen from our findings, most respondents had a stigmatised view of the term ‘Mental Health.’ The name is possibly the first point of contact a service user will have with any given service. Some HIV organisations have already taken the lead in re-naming their emotional support services, e.g. Maisha Mema at Terrence Higgins Trust, Rise Community Action, Cascaid and Innovative Vision Organisation. This trend needs to be more commonplace if mental health needs of this community are to be met.
- Our findings have shown that Black African people living with HIV can experience discrimination because of their HIV status from statutory services. There is a clear need to increase the amount and scope of training on basic HIV awareness in this sector. We would also like to recommend another dimension to this much needed training - a more **in depth journey into the emotional difficulties** that living with HIV can create, both for the infected and affected. This holistic approach is more in rhythm with the provision of a balanced range of effective therapies and is a development of the Ashanti proverb ‘It takes a whole village to raise a child.’
- Following on from this, training on **transmission, safer sex and HIV stigma** also needs to be made available to various departments within the **NHS, GPs and dentists** to name a few. One of our respondents spoke about taking personal responsibility to educate her dental clinic by way of HIV leaflet provision in the waiting rooms, for instance. It might be possible for this work to be developed into **BME service users living with HIV to provide awareness training to various departments within the dental profession**, in an attempt to change attitudes of health practitioners towards African people living with HIV.
- Five respondents in our sample regarded their immigration status as a barrier to obtaining emotional support. Undoubtedly there may be many more individuals who feel this way. The African Emotional Support Group model within the HIV sector appears to be of benefit for most service users. Ideally emotional support is a basic human right. It therefore needs to be more widely communicated that **this support is available, regardless of immigration status**. In this way it may be possible to bring about increased satisfaction with services.

More attention needs to be paid by HIV clinics on how the side effects of medication may be affecting the mental well being of African clients living with the virus, who might not be able to communicate this emotional need. Again with this holistic approach it may be possible to bring about an **increased satisfaction with services**

## Bibliography

Doyal, Anderson, Apenteng (2004), *I want to survive, I want to live, I want tomorrow*: London

Doyal & Anderson (2001) *My Heart is Loaded*: London

Chinouya, Ssanyu-Sseruma, Kwok (2003) *Summary of the Shibah Research Project*: London

Dodds, Keogh, Chime, Haruperi, Nabulya, Ssanyu Sseruma, Weatherburn (2004) *Outsider status: Stigma and discrimination experienced by Gay men and African people with HIV*: London

## Appendix

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# *UKC Community Engagement Research Project*

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This research interview is part of a Community Engagement Project conducted by UKC, funded and supported by the National Institute of Mental Health in England (NIMHE) and the University of Lancashire (Uclan).

The project is part of the Black & Minority Ethnic (BME) Community Engagement programme.

### UKC

UKC is a group of people living with HIV and AIDS, campaigning, researching and providing services by and for people like ourselves.

Our aim is to enable the diverse voices of people living with HIV and AIDS to be heard in order to influence change.

UKC is a membership organisation, a registered charity and a non profit making limited company.

Registered office - 250 Kennington Lane, London SE11 5RD.

### Aims of this Project & Interview

The purpose of this interview and project is to research the mental health needs of Black African people living with HIV and try to explore any links between Mental Health, the Stigma of living with HIV, undetermined immigration status and access to services/support. The research will take into consideration race, culture and religion when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive.

If you have any queries or complaints about the project, please call Haydn Forde (Project Co-ordinator) on 020 7564 2180 or e-mail – [hforde@ukcoalition.org](mailto:hforde@ukcoalition.org)

### **CONSENT FORM**

This study is being conducted by UKC and is about Mental Health Needs of Black African People living with HIV.

The aim of the study is to gain a better understanding of the needs of this community. A report on the findings will be used to inform policy and also to lobby for the services that YOU tell us you need.

**Please READ the declaration below and SIGN, or MARK in the space provided. Please ask the researcher to read the declaration and explain it to you if you wish.**

I have been requested to participate in this study and voluntarily accept.  
**I understand:**

The aims of the research and I have been free to ask any questions.

My participation is entirely voluntary and I can withdraw at any time.

I do NOT have to answer any questions if I wish not to, but I am encouraged to answer where I can.

Any comments that I make will not be attributed to me unless I give consent.

Names will not be recorded on the interview scripts. Completed interview scripts, recordings and transcripts from interviews, will be labelled with individual code numbers and will be stored in a locked filing cabinet at UKC. Only staff working on the project will have access to them.

All interview scripts, recordings and transcripts will be destroyed by shredding and other secure means once the final report has been written and accepted

All the information provided will be in **confidence** and it will only be shared amongst those working on the research, EXCEPT if I disclose information which reveals harm to others or child abuse – *(This will be dealt with in accordance to UKC disclosure procedure)*

**I confirm I have read and understood this information sheet.  
I agree to take part in the research project for Black African people living with HIV and Mental Health.**

**Date :** \_\_\_\_\_

## Core Questions:

1.1 Age last birthday:

16 -17

18 – 21

22 – 24

25 – 29

30 – 39

40 – 49

50 +

1.2 Gender:

Male

Female

Transgendered or transsexual

1.3 How would you describe your ethnicity :

**Black African**

Other (please explain)

.....

...

1.4 Country

1.5 Region

1.6 Tribal/cultural grouping (optional)

1.4 Were you born in the UK: **Yes**   
No

.....

If no, how long have you lived here:  Yrs/Months/Days

Less than 1 year   
1 – 5 years   
6 – 10 years   
**11 years or more**

.....

**1.5 How would you describe your immigration status:**

British Citizen   
Refugee   
Asylum Seeker   
Indefinite Leave to Remain   
**Other (please explain)**

.....

1.6 What is your first language?

Spoken:  
.....

.

Written:  
.....

.

1.7 Which languages are you fluent in?

Spoken:  
.....

.

Written:  
.....

**1.8 What is your religion:**

None	<input type="checkbox"/>
Christian	<input type="checkbox"/>
Buddhist	<input type="checkbox"/>
Hindu	<input type="checkbox"/>
Jewish	<input type="checkbox"/>
Muslim	<input type="checkbox"/>
Other (please explain)	<input type="checkbox"/>
.....	

**1.9 How would you describe your sexuality:**

Lesbian or gay woman	<input type="checkbox"/>
Homosexual or gay man	<input type="checkbox"/>
Heterosexual or straight	<input type="checkbox"/>
Bisexual	<input type="checkbox"/>
Do not wish to answer	<input type="checkbox"/>
Other (please explain)	<input type="checkbox"/>
.....	

**1.10 Do you consider yourself disabled:**

Yes (please explain)	<input type="checkbox"/>
.....	
No	<input type="checkbox"/>

**Interview script**

**(updated 07/11/06)**

**A study looking at the mental health needs of Black African people living  
with HIV**

1. In which borough do you live?

2. What year did you find out that you had HIV?

3. Are you accessing HIV medication?

- Yes
- No

3b. If yes, have the side effects of HIV medication affected your well being?

0 \_\_\_\_\_ 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5  
(None) (Strong)

4. In what type of accommodation do you live?

- Housing Association
- Private Landlord
- Council Tenant
- Home owner
- Squatting
- Homeless
- Other (Please describe)

5. Do you live alone?

- Yes
- No

5b. If no, then with whom do you live?

- Family members
- Partner
- Children
- Flat Sharers
- Friends
- Other

6. Do you belong to any Faith Groups, i.e. churches, mosques?

- Yes
- No

6b. Do you seek support about your HIV status from your faith group?

- Yes
- No

7. Are you in a sexual relationship at the moment?

If yes -

- One night stand
- Casual
- Long term (more than six months)
- Other

8. Do you have any extended family here in the UK?

- Yes
- No

9. Do you have any children? If no, go to question 16

- Yes
- No

10. Do they live in the UK with you?

- Yes
- No

11. How many children do you have?

12. Do they know about **your** HIV status?

13. Have your children been tested for HIV?

- Yes
- No

13b. If yes, do they know **their own** HIV status?

14. Do you know which HIV services they can access for support?

15. How do you feel about this?

16. How do you spend your free time?

17. Are you employed?

18. Do you get any specific support for a health issue?

- Freedom Pass
- Taxi card
- Disability Living Allowance
- Incapacity Benefit
- Income Support
- Support from a charity, e.g Crusaid
- Other

19. Who have you told about your HIV diagnosis?

20. Who **haven't** you told about your HIV Diagnosis?

21. Is there anyone else that you'd like to tell, but haven't?

22. Do you feel different from other people because of your HIV status?

23. How does having HIV influence your relationship with others?

24. Have you felt that people have treated you differently as a result of your HIV status?

25. If yes, have you experienced this within the health care system, e.g. dentists, etc?

26. How did you feel about this type of treatment?

27. When you hear someone say mental health, what comes to your mind?

28. Have you ever been diagnosed with a mental health condition? If no, go to question 35.

- If yes, was this before your HIV diagnosis?
- Was this after your HIV diagnosis?
- Did you receive a mental health diagnosis both before ***and*** after your HIV diagnosis?
- It would be useful to us to know how old you were when you received your mental health diagnosis.

29. If yes, which one?

- Schizophrenia (hearing voices, experiencing visual hallucinations)
- Bi-polar disorder (periods of extremely high moods -mania, contrasted with low moods –depression)
- Self harm
- Borderline personality
- Personality disorder
- Substance misuse (e.g. drug, alcohol, other)
- Addiction
- Sleep disorders
- Obsessive compulsive disorder
- Panic attacks
- Depression
- Sexual dysfunction
- Relationship issues
- Other

30. Are you on medication as a result of your mental health diagnosis?

- Have you ever been on medication as a result of your mental health diagnosis?
- How long have you been on medication?
- Who prescribed the medication?

31. Have you ever been admitted to a psychiatric ward?

32. If yes, for how long?

**33. Have you been admitted to *any* ward as the result of Dementia – (*an HIV related condition involving memory loss, difficulty in thinking or understanding, loss of concentration and confusion; changes in behaviour, including loss of interest, feelings of isolation and childishness; problems with movement and co-ordination, such as loss of balance or strength in the limbs* )**

34. Have you ever been referred to professionals because of your health problems?

- Counsellor
- Psychiatrist
- Psychologist
- Therapist
- Music Therapist
- Art Therapist
- Drama Therapist
- Group Therapy
- Community Groups
- Self help group
- Spiritual Advisor
- Hospital-based Care
- Other

35. Have you experienced the following symptoms in the last twelve months?

- Anxiety
- Stress
- Feeling low
- Anger
- Despair
- Depression
- Flashbacks
- Nightmares
- Memory Loss
- Weeping
- Suicidal feelings
- Sleeplessness
- Loss of appetite
- Loneliness
- Low libido (sex drive)
- Other

36. Where do you go for emotional support at present?

37. Did any of the factors below create problems to obtain emotional support?

- My immigration status
- The support was for women only
- The support was for men only
- The service was too far away from where I live
- The service was too near to where I live
- I thought I would be treated differently
- It was in language that was difficult to understand
- There was a long waiting list
- I didn't know what services were available
- Being Black African
- Other factors not mentioned above

38. Did the services respect your beliefs, faith or culture?

39. Did the services meet your expectations?

40. How might services be improved to match what you need?

41. Would you like to receive a report of our findings?

## **Debrief Sheet**

A final report will be created to present our findings. All contributors will be anonymous.

We hope to bring an improvement in BME (Black minority Ethnic) Services through this research, so your time will hopefully bring a difference.

**YOU are in your full rights to have your data removed at any point during the interview.**

**All data will be destroyed once accounted.**

If you have any questions or queries please contact one of the Researchers or the Project Co-ordinator

**Thank you for taking the time out to answer our interview Script.**