

# HIV and Black African Communities in the UK

JUNE 2014: A POLICY REPORT



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**NAT is the UK's leading charity dedicated to transforming society's response to HIV.**

**We provide fresh thinking, expert advice and practical resources.**

**We campaign for change.**

## **Our vision**

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection

## **Our strategic goals**

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV
  - early diagnosis of HIV through ethical, accessible and appropriate testing
  - equitable access to treatment, care and support for people living with HIV
  - enhanced understanding of the facts about HIV and living with HIV in the UK
  - eradication of HIV related stigma and discrimination.
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**People from sub-Saharan African comprise one of the largest and most recently arrived BME communities in the UK, accounting for 1.8% of the UK resident population. Black African people are also disproportionately affected by HIV, in 2012 comprising 34% of all those diagnosed with HIV in the UK. Despite these statistics the HIV-related needs of black African communities receive neither the attention nor the resources they should from policy-makers, decision-makers and funders. This report from NAT reviews the wide range of policy issues relevant to HIV and black African communities and makes a number of detailed recommendations at the end of every section.**

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## Executive Summary



### HIV prevention

There is significant HIV transmission within black African communities in the UK but not enough resources for HIV prevention in terms of funding, continuity of support, population coverage or evaluation. HIV prevention should:

- move away from ethnicity-based communication
- increase knowledge, within African communities, of prevention options and treatment
- develop a shared knowledge-base as to what works e,g for engaging with faith groups, and
- think about the sexual health needs of black African young people born in the UK.



### HIV testing

Black African men and women are the group most likely to be diagnosed late, with serious implications for health and life expectancy. The failure of the NHS to implement UK guidance on HIV testing profoundly harms black African communities in the UK and must be addressed urgently. GP practices in areas with significant black African communities have an important role to play and are for the most part not yet doing enough.



### HIV treatment and care

Black African men and women with HIV are doing well on treatment in terms of the key agreed clinical indicators, but more should be done to ensure effective communication within the clinic about HIV treatment and the impact of treatment on infectiousness as well as other prevention options. We have more to learn about the outcomes which matter to black African patients themselves.



### Poverty, benefits and housing

The risk of HIV acquisition and black Africans' experience of living with HIV are pervasively influenced by the high levels of poverty, unemployment and poor housing faced by many people in these communities. Immigration-related restrictions are a significant cause of such deprivation, though not the only one. We cannot meet the HIV-related needs of black African communities in the UK without addressing wider inequalities.



### Immigration

The immigration system continues to harm the physical and mental health of black African men and women in the UK. The Government should provide for everyone living in the UK free access to all NHS services, not just to HIV treatment itself. The NHS and Home Office have to make sure high quality HIV testing, treatment and care are available and uninterrupted at every stage of the immigration system, including initial accommodation, dispersal and removal. This is not the case at the moment.



### Social care

Local authorities need to understand the specific social care needs of black African communities and take account of them in their training of social care staff, in their support for the local voluntary and community sector, and in their planning, commissioning and service delivery. Issues include ageing with HIV, the needs of those who have lived with HIV from birth, including both young people and those who are now adults, and the specific needs of women and of families.



## Mental health and TB

Black African people with HIV are also disproportionately affected by poor mental health and by TB. Voluntary and community sector support services and alcohol services have an important role to play in supporting better mental health. The national ‘Standards for the Psychological Support of Adults with HIV’ should be implemented. Improved immigration policy, for example around the right to work, would make a substantial and lasting improvement to mental health in these communities. There is still more to do in both TB and HIV clinics to improve testing for HIV and TB respectively.



## HIV stigma and discrimination

HIV stigma is a serious burden for many black African people living with HIV. A national strategy is needed to address HIV-related stigma, including within the NHS, and this should also be reflected in local initiatives, especially in areas of high HIV prevalence. We would expect effective anti-stigma approaches to include improved information on HIV treatment and prognosis, engagement with faith communities in anti-stigma work, and addressing wider racism, xenophobia and anti-migrant discourse.



## Black African women

Black African women living with HIV have specific needs which need to be addressed in policy and in health and social care support. They include (but are not limited to) improved experience at diagnosis, sexual and reproductive health rights, and addressing gender-based violence.



## Black African MSM

More research should be undertaken on the experiences of black African MSM (men who have sex with men) and greater awareness of black African MSM and their needs is required in both HIV clinics and the voluntary sector where they are too often invisible or ignored at the moment. More appropriate health promotion materials and ‘spaces’ (whether virtual or actual) for black African MSM to meet and find support should be developed.



## Black African young people living with HIV

There are a complex set of needs amongst young people living with HIV which social care departments must be sensitive to – the whole family approach now required from local authority social care departments may be fruitful in this regard. Attention must be paid to their sexual and reproductive health and to their experiences at school.



## African community leadership and capacity

The capacity of the African HIV voluntary sector has recently diminished significantly and black African communities, philanthropists and businesses will all be central to rebuilding an African (HIV) voluntary sector which is sustainable, impactful and community-led. Further funding and collaboration are needed to develop research around HIV and black African communities in the UK. Black African men and women living with HIV should be meaningfully involved in all policy development, planning and service delivery which affects them.



A

# HIV AND AFRICAN COMMUNITIES IN THE UK – CONTEXT

## Introduction

### HIV policy and African communities in the UK

HIV disproportionately affects black African men and women living in the UK. Whilst black Africans constitute 1.8% of the UK resident population, they accounted in 2012 for 34% of all people diagnosed with HIV. This is one of the starkest examples of health inequalities in this country and something which should be addressed urgently. We need to:

- reduce HIV incidence and late HIV diagnosis
- address and eliminate HIV stigma and discrimination
- maximise the benefits not just of HIV treatment and care but the wider care and support needed to live a long, productive and fulfilling life whilst managing this long-term condition.

Such outcomes require the right policies to be in place and then implemented both by national and local government and within all relevant agencies which have an influence on the lives of African communities in the UK. The purpose of this report is to provide a brief overview, based on a survey of the available literature together with discussions with experts and stakeholders (termed ‘respondents’ in this report), of what those policies

should look like. To put it in another way, what decisions do we want decision-makers to make which will improve our response to the HIV epidemic in African communities?

Of course there are many policy issues relevant to HIV in general and to all people living with HIV which as a result are also relevant to African men and women living with or affected by HIV. But this report will not focus on such issues. We aim to identify those HIV-related policies which will address issues either exclusively or disproportionately affecting African communities.

We use the term ‘black African’ to describe ethnicity – a term also used in the 2011 census. We accept of course that such terms are socially and culturally generated and that individuals have their own perceptions as to their ethnicity. Also, black African does not necessarily mean born in Africa. We would stress at the outset that black African communities are heterogeneous and diverse, and the use of this ethnicity category does not necessarily imply any inherent single community or identity.

The motivation for this report was a concern at NAT to ensure we are addressing in our policy work the needs of African communities in the UK. In 2012 NAT held a roundtable to explore HIV policy and African communities in the UK, and one of the



### Black African communities in the UK



Black Africans represent just **1.8%** of the UK population...



... but make up **34%** of all people diagnosed with HIV

recommendations to emerge was that NAT undertake this policy review. We see this report as a useful initial overview of matters, all of which merit far more detailed exploration. We hope this overview will support NAT's future policy work and also provide a broad agenda around which the African community and HIV sectors, and other interested stakeholders, can act.

We are very grateful to all the people and organisations we spoke to during the course of this project. They are listed at the end of this Introduction. We are also very grateful to AbbVie who provided funding for this project.

#### African communities in the UK

The 2011 census provides important and recent information on African communities in the UK. There are questions raised as to whether the census accurately captures the numbers living here from BME communities.<sup>1</sup> It is nevertheless the best data available on the UK population and is especially valuable for trends over time and for disaggregated and detailed data.

It is important to situate the HIV epidemic amongst African communities within the wider context of the overall UK population. The information is especially important because so many African men and women are relatively recently arrived in the UK – relying on the previous 2001 census figures had become immensely misleading. At the time of writing, not all of the census data to be published have as yet emerged, and there are also limitations as to what can be published on ethnicity if confidentiality is to be maintained. Nevertheless, there are already some interesting figures for us to consider.<sup>2</sup>

#### England and Wales

In England and Wales there were, according to the 2011 census, 989,628 people of black African ethnicity – 479,799 men and 509,829 women – which is 1.8% of the resident population of England and Wales. They are of predominantly younger ages – 443,395 being between 0 and 24 years

<sup>1</sup> For discussion on varying estimates, see: IOM. (2009) 'Ghana: Mapping Exercise London 2009'. Available at: [http://www.iomlondon.org/doc/mapping/IOM\\_GHANA.pdf](http://www.iomlondon.org/doc/mapping/IOM_GHANA.pdf)

<sup>2</sup> More detail can be found at [http://www.nomisweb.co.uk/census/2011/detailed\\_characteristics](http://www.nomisweb.co.uk/census/2011/detailed_characteristics)



old and 442,076 being between 25 and 49.<sup>3</sup> 666,352 of the resident black African population were born outside the UK (67%).

The census also gives for the English and Welsh population country of birth and year of arrival data for those born outside the UK. The figures differ from the ethnicity data since they are separate fields in the census questionnaire and there is not a necessary match between ethnicity and country of birth, particularly from an individual’s perspective. 1,312,617 people were born in Africa: 786,216 in South and Eastern Africa; 397,068 in Central and Western Africa; and 113,363 in North Africa. The main countries of birth were:

Nigeria:	<b>191,183</b>
South Africa:	<b>191,023</b>
Kenya:	<b>137,492</b>
Zimbabwe:	<b>118,348</b>
Somalia:	<b>101,370</b>
Ghana:	<b>93,846</b>

Thus 833,262 people were born in these six countries – or 69% of those in England and Wales who were born in sub-Saharan Africa (i.e. excluding North Africa). There are two points to make – one obvious one is that there is not a single African ‘community’ in the UK but a wide range of different communities and any interventions to meet their needs must take account of this fact. On the other hand, there are a few countries with large numbers in the UK which should help us focus attention on, for example, approaches which we know have worked and are working in the relevant countries of origin, or on travel flows between these countries and the UK.

More specific knowledge of regions or countries of origin can also inform needs assessment and the design of interventions. For example, the Mayisha II study found a significant difference in HIV testing



**93% of black African men and women say their day-to-day activity is not at all limited by their health, compared with 82% for the overall population.**

<sup>3</sup> The census also has important data on people of mixed white/black African ethnicity – for the sake of brevity we do not also analyse these statistics here but they may well be relevant to prevention interventions. There are 165,974 residents of mixed white/black African ethnicity of whom 113,146 were born in the UK.





rates depending on African region of origin, with 56.2% of people from Central Africa having ever tested for HIV, compared with 39.8% from Western Africa; and the proportion of respondents who had probably tested last in the UK and had tested in a GU setting varying from 64% amongst those from Central Africa to just 24% amongst those from Western Africa.<sup>4</sup>

Information is also available on year of arrival. Of the 397,068 from Central and Western Africa, 218,115 (55%) have arrived since 1 January 2001. Of the 786,216 people from Southern and Eastern Africa, 330,354 (42%) have arrived from 2001 onwards. In other words, there is a very high proportion of African men and women who have arrived relatively recently in the UK.

Where are black African men and women living in the UK? A significant majority live in London – 573,931 – accounting for 58% of the black African population of England and Wales, and 7% of the total population of London. Outside of London there is quite a broad distribution, though significant numbers live in the South East (8.8% of all black Africans in England and Wales and 1% of the overall regional population), the East (7.1% of the population of black Africans in England and Wales and 1.2% of the overall regional population), and the West Midlands (6.5% of the overall population of black Africans in England and Wales and 1.1% of the overall regional population). These four regions when taken together account for 80% of the black African population of England and Wales.

There are 11,887 black African people resident in Wales according to the 2011 census (1.2% of the overall population of black Africans in England and Wales and 0.4% of the overall Welsh population).

As might be expected of a more youthful population, black Africans are in better health overall. Just 33,274 Africans said their day-to-day activities were limited ‘a lot’ and a further 39,742 ‘a little’. In other words, 93% of black African men and women say their day-to-day activity is not at all limited by their health, compared with 82% for the overall population.

Poverty is closely related to economic inactivity – so the data on economic activity and ethnicity is important. Of the 691,393 black African residents over 16 years old, 482,909 (70%) are ‘economically active’, meaning they can work. This compares with 63% for the population overall – a function quite possibly of the younger demographic profile of African populations in the UK. However, amongst those who can work, unemployment is at 18% amongst African men and women compared with 7% overall. This is despite the fact that the black African population is far better qualified than the population as a whole, with 40% having a level 4 qualification or above, compared with just 27% for the population as a whole.

### Scotland

In the 2011 Scottish census 29,000 people (or 0.6% of the Scottish resident population) described themselves as ‘African, African Scottish or African British’.<sup>5</sup> As percentages of the local population, the highest proportions of black African ethnicity residents are in Glasgow, Aberdeen, Edinburgh and Dundee. Of those who reported being born outside the UK, two African countries were in the ‘top 15 countries of origin’ – South Africa (8th at 11,000) and Nigeria (9th at 9,000). Compared with the 2001 census there has been a particular increase in residents born in Nigeria (1,000 in 2001).

### Northern Ireland

In Northern Ireland 0.13% of the resident population in the 2011 census were black African which equates to 2,354 people.<sup>6</sup>

4 Rice B et al. (2013), ‘HIV testing in black Africans living in England’ *Epidemiol Infect*, 141, 1741-1748

5 <http://www.scotlandscensus.gov.uk/documents/censusresults/release2a/StatsBulletin2A.pdf>

6 The absolute number has not as yet been published.



# B

# HIV PREVENTION

To try to understand HIV incidence (the rate of transmission) in the UK amongst black African communities we need to look at those new diagnoses of HIV acquired whilst the person was living in the UK. Public Health England (PHE) recently developed a method to assign probable country of infection using information on CD4 decline rates. For 2011 they calculate that about half (52%) of all infections diagnosed amongst heterosexuals were probably acquired in the UK – a proportion which has increased from 27% in 2002. Overall, ‘Approximately half of heterosexuals born abroad (48%) acquired their infection in the UK. This highlights the need for further prevention efforts for those born abroad, particularly in sub-Saharan African countries’.<sup>7</sup> This modelling by PHE challenged the assumptions made by many clinicians when reporting to PHE on likely country where transmission took place. Thus this particular emphasis on primary prevention need amongst Africans in the UK is relatively new.

PHE estimates that over the past five years about 1,000 black African men and women acquired HIV in the UK each year.<sup>8</sup>

The significant majority of HIV transmissions occurring within the UK amongst black Africans are amongst those who have migrated here rather than those born here. In 2012 for the 1,279 black Africans for whom region of birth was reported, 74 had been born in the UK (5.8%), compared with 1,182 (92.4%) being born in Africa.

## Evidence of HIV prevention need

Two issues frequently cited in our discussions on HIV prevention and African communities were the need to improve HIV testing rates and the need to address HIV stigma. These two topics have their own dedicated sections in this report so here it is enough simply to reiterate that reducing the proportion of black Africans with HIV who are undiagnosed will reduce the proportion at risk of passing HIV on to their sexual partners; and that reducing stigma will, amongst many benefits, enable people to disclose, discuss safer sex and encourage testing.

<sup>7</sup> HPA. (2012), ‘HIV in the United Kingdom: 2012 Report’, p.12

<sup>8</sup> HPA. (2012), ‘HIV in the United Kingdom: 2012 Report’, p.4



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HPA ‘HIV in the United Kingdom: 2012 Report’ p.12

In discussion the issue of transactional sex was also raised, along with difficulty in such a poverty-driven context of negotiating condom use or, for those diagnosed with HIV, disclosing their status. Poverty was certainly seen as a ‘prevention issue’ – one respondent said he knew of a number of cases where people had to stay with a violent partner or have unsafe sex to stay in the home.

There have been a number of studies looking at HIV prevention needs amongst black African communities in the UK. As part of the NAHIP programme, Sigma Research have undertaken two surveys of the sexual HIV prevention needs of African people in England – the most recent, ‘Bass Line 2008-09’, provides important information. At the time of writing of this report, Sigma Research are in the process of again surveying black African people on prevention needs for HIV Prevention England.

Bass Line asked about sexual risk and precaution behaviours. Many of the agencies which promoted and disseminated the survey supported people with HIV so there may be a degree of oversampling of people with some knowledge of HIV, and 12.1% of respondents were diagnosed as HIV positive, significantly greater than the overall diagnosed prevalence rate in African communities.

There was evidence of sexual risk, with 10% reporting unprotected intercourse with someone definitely or probably of a different HIV status to themselves. More than half of respondents had a regular sexual partner and 25% of this group said they had sexual relationships outside their regular relationship. This was more common amongst men than women.<sup>9</sup>

One area of need identified was in attitudes to and use of condoms – where there was a high rate of reported condom failure (a third had experienced condom failure in the previous year<sup>10</sup> – this compares with 13% of men who have sex with men (MSM) in the Gay Men’s Sex Survey 2008<sup>11</sup>) and a stigma associated with the carrying of condoms.

There was a lack amongst many of safer sex negotiating skills – nearly a third said they were not sure they could talk easily about HIV and safer sex with new sexual partners. Moreover, amongst both HIV positive respondents and amongst those not diagnosed HIV positive, about a tenth did not feel they were in control in terms of exposure to HIV risk

9 Sigma Research. (2009) ‘Bass Line 2008-09’, section 4.6

10 Sigma Research. (2009) ‘Bass Line 2008-09’, section 4.6

11 Sigma Research. (2010) ‘Tactical Dangers: Findings from the United Kingdom Gay Men’s Sex Survey 2008’



with their sexual partner (slightly higher than the 7.2% of MSM who said their own sexual behaviour was less safe than they would like it to be in the Gay Men's Sex Survey 2006<sup>12</sup>).

There is important information also on black African knowledge and attitudes in Scotland where, for example, 24% said they were not confident to talk about safer sex to sexual partners, 33% said they did not feel in control around acquiring HIV and 24% said they did not feel in control around passing on HIV.<sup>13</sup>

It was also felt that the impact of drugs and alcohol use on sexual risk taking in African communities needs further research.

In the Bass Line survey knowledge of HIV was fairly good overall, though there may be some selection bias, as outlined above.

A further question is the degree of 'assortative sexual mixing' within African communities i.e. the extent to which African men and women in the UK have sex with other Africans. HIV risk is a product not just of a particular sexual behaviour (for example, having anal or vaginal intercourse without a condom) but also with whom the behaviour occurs. There is significantly higher HIV prevalence for example amongst both African and MSM communities in the UK so the chance, if your sexual partner is from one or both of those communities, of them having HIV is higher. If African men and women are continuing mainly to have sex with other people from African communities they will be at greater risk of HIV than if they are increasingly having sex with people from other communities. It seems at present that not much sexual mixing amongst first generation migrants is occurring.<sup>14</sup> This means a greater rate of HIV transmission within African communities.

In discussions, the Ffena Executive Committee emphasised the need for better information about HIV to go to African communities and were convinced this

would have an impact in improved prevention of transmission. There was a view that HIV awareness differed within and between African communities, for example there was better awareness in London than in Wales, and more denial in some particular faith or country-specific communities than in others.

Some questioned the effectiveness of mass media in HIV prevention for people from black African communities, stating that in systematic reviews they do not appear to be that effective. There needs to be greater resources and high quality evaluation dedicated to 'hands-on' behavioural and informational interventions.

There was uncertainty about whether intergenerational sexual relations were an issue in the UK, with many thinking probably not. The complex and diffuse nature of sexual relations was stressed by many respondents, with men having a number of regular partners at the same time though not living together.

There was also discussion of travel to and from countries of origin and sexual risk in that context. Evidence from the Mayisha II study showed that 43% of black African men and 46% of black African women had travelled to their home countries in the previous five years – 40% of the men and 22% of the women acquired a new sexual partner when travelling abroad. There was an association between having sex when travelling to country of origin and sexual risk, such as having been previously diagnosed with an STI and having a larger number of sexual partners.<sup>15</sup>

## Changing the paradigm

A recurring theme amongst those we spoke to during the preparation for this report, and in the relevant literature over the last ten years, has been the dislike of many black African men and women, and community organisations, for HIV prevention activity which singles black Africans out as the one ethnic group amongst heterosexuals who are at risk of HIV. We will also discuss this issue when we consider HIV stigma later in this report, but in this

12 Sigma Research. (2008) 'Multiple Chances: Findings from the United Kingdom Gay Men's Sex Survey 2006'

13 Waverley Care. (2010) 'African Health Project Baseline Survey'

14 For evidence from the Netherlands see: van Veen et al. (2009) 'Disassortative sexual mixing among migrant populations in the Netherlands: a potential for HIV/STI transmission?' *AIDS Care*, 21(6), 683-91

15 Fenton K et al. (2001) 'HIV transmission risk among sub-Saharan Africans in London travelling to their countries of origin', *AIDS Vol 15*(11), pp.1442-1445



“Poverty was certainly seen as a ‘prevention issue’ – one respondent said he knew of a number of cases where people had to stay with a violent partner or have unsafe sex to stay in the home.

section we will discuss how effective this is as an HIV prevention approach and what, if anything, needs to change.

A common point made was that HIV was considered a ‘black disease’ which increased stigma and prevented the media treating it with appropriate coverage and seriousness. There were contrasts made between the neglect of HIV in official government-sponsored health promotion, when compared with cancer for example.

One illustrative anecdote was of a mass media prevention campaign targeted at black African communities. The visuals the first time round only had black African faces on them. It received quite a lot of negative feedback from people in black African communities. It was later re-done but with white faces also included in the visuals – and it received a universally positive response.

A distinction was repeatedly made in discussions between targeted and tailored approaches in prevention. Targeting is ensuring those in need and for whom the interventions are designed encounter the interventions.<sup>16</sup> Tailoring is ensuring the interventions are relevant and useful when they are encountered. It makes sense to target resources at those people and communities who most need it. It therefore makes sense to target prevention resources at African communities because we know HIV prevalence is high (3.8%) and a significant number of black African men and women are acquiring HIV once in the UK. It would be ineffective and unethical to spread resources equally across the sexually active population, ignoring the facts of the epidemic and actual risk.

Targeting is an important element in the design of interventions – the recipient of the prevention activity, however, should not feel ‘targeted’, or ‘got at’, this can be off-putting. They should, however, feel the prevention message or activity is ‘tailored’, in other words suitable for them and designed with their needs in mind.

For black African communities already dealing with an immigration system, politics and UK media which appear consistently hostile to their arrival and

<sup>16</sup> Sigma Research (2009). ‘Bass Line 2008-09’ see Executive Summary



presence in the UK, and who wish simply to be accepted and respected by UK society, HIV prevention activity which publicly identifies black Africans as a group with HIV is threatening and distressing. As a result, information and support are avoided or ignored by many.

There is considerable resistance to what is seen as 'racial profiling' in prevention and a need instead to segment and define more carefully those at risk of HIV so people can identify with the information and messages communicated.

In any event, are we right to focus national prevention efforts so exclusively on African men and women amongst heterosexually active adults? The current national HIV prevention programme in England, HIV Prevention England, has as its remit only prevention amongst MSM and black Africans. However, it is estimated that about 25% of UK-acquired infections being diagnosed are neither amongst MSM nor black African communities. There is no national prevention programme for that 25%, nor have we heard of much by way of local activity. When the original arguments were made for targeting prevention resources at most affected communities, that was envisaged as complementing general population prevention work, not replacing it. In discussions we were told that many people in African communities cite such data to show that the apparent focus only on Africans is unjustified. They also claim, with reason, that our prevention is not keeping pace with demographic change. Whilst the majority of sexual relationships amongst black African men and women may well still be with other black Africans, there is an increasing number of mixed race relationships. What is our response?

Is it time to reconfigure how we do HIV prevention amongst heterosexuals in England? Black African men and women are significantly more at risk of HIV than others, so targeting prevention efforts and resources at this group must continue. But if that prevention is to be effective, and if our prevention is to reflect current epidemiology, we need in a far more nuanced way to integrate work in African communities with wider work amongst the sexually active heterosexual population. This will avoid the ethnicity-based focus which currently so alienates the intended audience and it will at



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the same time provide much needed prevention support for other heterosexuals at risk of HIV, who are currently neglected.

We would see a difference in visual imagery used in media campaigns, a greater visibility of HIV prevention in media aimed at the general public, especially in high prevalence areas of the UK such as London, and a discussion of risk which instead of focusing so much on ethnicity, focuses on behavioural risk, such as sex in a high prevalence country (thus including, of course, most African countries but also including others – and alerting travellers as well as migrants), unprotected sex with a new or casual partner, multiple concurrent partners, and so on.

### **UK-born people of black African ethnicity**

This change of paradigm is also necessary as we have a new generation of people (often termed ‘second generation’) of black African ethnicity but born in the UK. PHE data to 2013 (with 2013 data currently incomplete) shows that there have been a total of 886 new diagnoses of black Africans born in the UK between 2001 and 2013, out of a total new diagnoses amongst black Africans in that period of 34,781 (so those born in the UK constitute just 2.5% of total diagnoses).

It is inevitable that the sexual health needs of this group are going to be related to but also importantly different from those of their parents who migrated here. There will be similar risks for those second generation black Africans who only have sex with partners from within their black African community or travel to a high prevalence country from time to time and have sex there. But the nature of sexual mixing with other partners from other groups will be different, as will cultural and religious beliefs. The risk of HIV is still clearly there but far more related to poor sexual health in the wider local communities and within their generation, and to deprivation, coercive sex, and poor Sex and Relationships education in schools.

As the black African population becomes more diverse, with people in mixed race relationships, adolescents and adults born in the UK who are the children of black African migrants, children of mixed race relationships where one of the parents is black African, we need to keep pace with our prevention framework and activity.

### **Faith groups**

Whilst faith groups are sometimes characterised as barriers to effective prevention, a number of respondents pointed out that for many people their faith group (predominantly Christian or Muslim) or pastor/imam may be the one place where they could receive trusted support. Prevention and testing initiatives had to work out how to communicate through faith groups. It was important to use the potential of, for example, prayer meetings and of religious radio and television channels.

We were told, however, that many faith groups are independent, stand-alone organisations which makes it especially difficult to reach them all with health promotion and anti-stigma interventions.

A number of organisations such as the African Advocacy Foundation, AHPN, BHA, Naz Project London and George House Trust told us of work they are undertaking with faith communities. The positive opportunities of faith institutions to promote health and the prevention of HIV need to be harnessed given the trust placed in them by so many in African communities. It will be important for these initiatives to gather pace and scale, for innovative approaches to be trialled and effectively evaluated and for good practice to be shared and built on. Research is needed into the impact of testing, prevention and anti-stigma interventions on those who come across them in a faith setting, with data collected on changes in understanding, attitudes, behaviour and STI/HIV incidence.

It was suggested by some respondents that national and local government should approach faith leaders directly with an appeal for them to act to promote the health of their congregations – then ‘triangulating’ with voluntary sector capacity and expertise in the delivery of appropriate services. Currently it is too often left to the voluntary sector, even when in receipt of statutory funding, to be the sole body to approach faith groups to raise HIV as an issue.

### **Are we doing enough?**

Is there ‘enough’ HIV prevention for black African communities? We were warned by some not to fixate on volumes and amounts when often the issue was in the first instance one of the quality of the interventions. This is an important point. But of course they are not wholly separate matters. It may



be hard to develop good quality interventions if, for example, funding is inadequate to develop experience of what works well over time.

A problem most recently described in the needs assessment of the pan-London prevention programme is the inconsistent definitions used by commissioners in identifying HIV prevention expenditure and activity. This is an initial and significant hurdle to understanding quite what is being done to meet the HIV prevention needs of black African communities in the UK.

In discussions, a number of people said anecdotally that there were inadequate support and community workers for effective outreach work and inadequate coverage for health promotion interventions. Better mapping of particular African communities, and of churches, pubs and clubs attended was necessary, as was direct health promotion and peer educators entering such key settings to engage in direct health promotion. Sustained funding was needed to develop such services and skills. Some said that African HIV prevention was historically underfunded when compared with MSM work.

More condom distribution was also needed, we were told. Whilst dislike of condoms amongst African men is often cited, one respondent spoke of the eagerness with which free condoms were taken away when they were made available at African social gatherings.

One respondent said that African prevention was never done to scale either in terms of amount of money provided or timescales; there was little collected evidence and wisdom as to 'what works' and difficulty engaging community and faith leaders; there was too much 'stop-start'. It was also said that there was far less emphasis in African prevention work on new prevention technologies such as PEP (Post-Exposure Prophylaxis), PrEP (Pre-exposure Prophylaxis) and the use of HIV treatment as prevention (TasP). This latter point is evidenced by the findings of the recent Plus One study of African people in sero-discordant relationships from Sigma Research which found amongst the study participants that nearly a third were unaware of PEP and a further third were

unsure how it worked or how they might access it. There was a strong desire from numerous participants to find out more about PEP. About a quarter of participants had no knowledge of treatment as prevention and a half had some knowledge of the concept in theory but were unwilling to rely on it personally.<sup>17</sup>

### Evaluation

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An issue which NAT has been concerned about for some time is the need for robust and independent evaluation of prevention efforts. We are concerned that even though this matter was raised by, amongst others, the House of Lords Select Committee on HIV/AIDS, and was meant to be far more integral to the new HIV Prevention England programme, it still seems that evaluation outcomes are not in the public domain and are defined very late on in the lifecycle of the programme, and that the evaluation activity is accountable to the main contracted party and not to the commissioning organisation (currently the Department of Health but from April 2014, Public Health England). Our national HIV prevention programme should do more to model best practice in how to demonstrate appropriate and realistic outcomes. It is not surprising, if this is missing from a well-established national prevention programme, that we were told there was in many cases a similar problem at a local level.

This is of course not to say that prevention amongst African communities is ineffective. It is to say we too often do not know whether or not it is effective, nor in what ways it is effective.

### Recommendations

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- 1 To reduce HIV incidence amongst black African men and women in the UK, we need an effective response to late HIV diagnosis, to HIV stigma and to poverty in black African communities – the recommendations of this report relating to these topics should be implemented as part of a holistic HIV prevention strategy.
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<sup>17</sup> Sigma Research. (2011) 'Plus One: HIV sero-discordant relationships among black African people in England', see section 4 'Sex and risk'





- 2 Promotion of free and affordable condoms and lubricant, with advice on how to choose and use them, is essential to meet black African community HIV-related needs.

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- 3 Greater resourcing and staffing need to be provided for direct prevention interventions, health promotion and outreach work amongst black African men and women – local authorities with significant African communities should regularly survey local African residents to gauge the reach of prevention activities.

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- 4 Further research and planning are needed to meet the sexual health needs of black Africans born in the UK – this is an important opportunity to ensure HIV prevalence reduces significantly amongst second generation black Africans in the UK.

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- 5 HIV prevention for black African communities should explicitly address the risks associated with travel to and from countries of origin – using both healthcare providers and travel services/businesses to engage in relevant health promotion.

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- 6 HIV prevention services for black African communities at a local level are too often not resourced to the necessary scale and timelines to secure lasting capacity and success. Local authorities should work in a longer-term, engaged and sustained way with appropriate providers to ensure HIV prevention amongst African communities delivers impact over time.

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- 7 HIV prevention needs to be reconfigured so that it does not appear only to focus on black African ethnicity as defining HIV risk amongst heterosexual men and women. Resources must continue to target black African communities, as well as other groups with elevated HIV risk – that means a larger share of resources and coverage. But communication should identify risk more specifically, for example around multiple concurrent partners, unprotected sex with new and casual partners, and sex in countries of high prevalence, often linked to travel between the UK and such countries. National and local HIV prevention programmes must maintain and develop prevention interventions which meet the needs of black African people within this broader engagement with prevention need amongst heterosexuals.

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- 8 Important work is underway in different parts of the country engaging faith groups around HIV need in African communities – there should be structured and systematic opportunities supported to share best practice, use agreed evaluation tools to identify impact, disseminate results and promote the funding of effective interventions ‘to scale’.

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- 9 National and local government should approach faith leaders directly with a call for them to act in partnership with both state and voluntary sectors to reduce HIV risk and stigma and promote testing and access to healthcare.

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- 10 HIV prevention for African communities should do more to explain and make accessible prevention options to add to condom use such as PEP and treatment as prevention.

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- 11 We recommend agreement of consistent definitions for the reporting of HIV prevention activity – this will enable a far clearer national picture of what is being done to meet the needs of black African men and women at risk of HIV.

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- 12 There should be national work, ideally led by Public Health England and the Local Government Association, which recommends useful and proportionate evaluation criteria for HIV prevention interventions. This would help develop a nationally recognised and consistent evidence base around ‘what works’ in HIV prevention amongst black African communities.



C

# HIV TESTING

## HIV diagnoses amongst African communities

From the start of the HIV epidemic in the UK until 1997 a total of 1,853 African men and women were diagnosed with HIV in the UK. New diagnoses in 1998 and 1999 taken together -1,958 in total – exceeded all the diagnoses amongst Africans in the preceding years. This shows how closely HIV diagnoses have been linked to the significant migration to the UK from sub-Saharan Africa in the late 1990s and early 2000s.

At the time of writing, a total of 40,251 African men and women have been diagnosed in the UK.<sup>18</sup> Diagnoses reached a peak in 2003 with 4,063 black Africans being diagnosed and since then the number of new diagnoses has declined year on year. In 2012 the total was 1,522, the lowest total since 1999.

There is consensus that the main reason for this decline in diagnoses is a fall off in migration from sub-Saharan Africa, a result mainly of changes in UK immigration policy (for example, the application of strict visa requirements for people from

Zimbabwe). In other words, this overall decline does not necessarily reflect success in UK prevention efforts.

Therefore over time the proportion of new diagnoses of HIV acquired in Africa is declining and the proportion of HIV acquired in the UK is increasing. It should be noted that whilst the proportion of UK-acquired diagnoses is increasing amongst black African men and women, as an absolute number of new diagnoses it has remained fairly constant over the last few years, at about 1,000.<sup>19</sup>

## AIDS diagnoses and deaths

Both AIDS diagnoses and deaths amongst black African men and women have declined over time, which is encouraging news.<sup>20</sup> The highest number of AIDS diagnoses was in 2003 when there were 580 first AIDS diagnoses, equivalent to 14.2% of new HIV diagnoses amongst black African men and women in that year. In 2012 there were 115 first AIDS diagnoses, equivalent to 7.6% of new HIV diagnoses amongst black African men and women. We should note, however, that this compares with first AIDS diagnoses in 2012 for MSM being

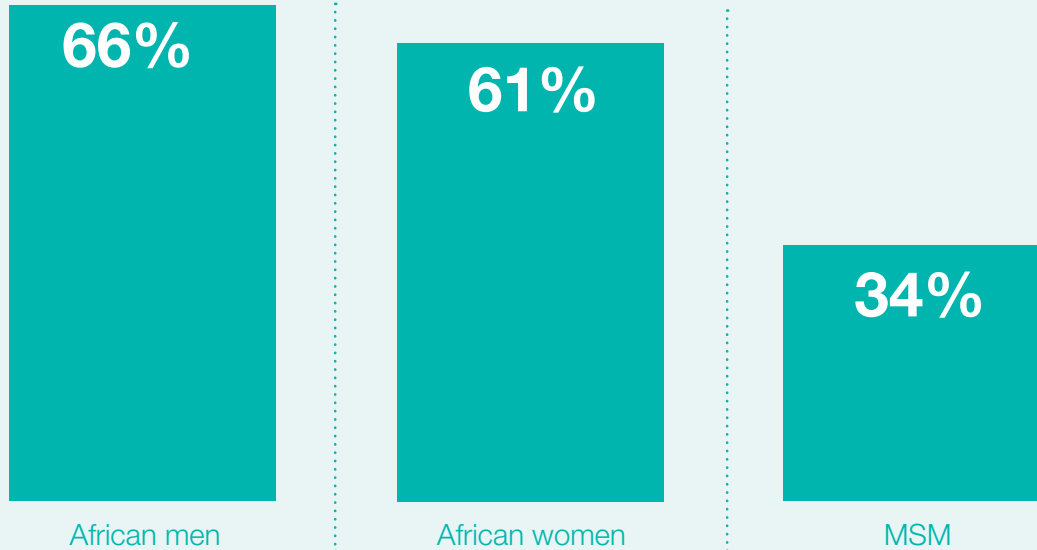
18 This number will be greater than the number currently diagnosed with HIV because of deaths, loss to follow up and departure from the UK.

19 PHE. (2013) 'HIV in the United Kingdom: 2013 Report' p.4

20 PHE HIV Data, 5. Prevention Groups HIV Data Tables, Men who have sex with men: Table 1, black African and black Caribbean: Table 1.



### Late diagnosis of HIV



equivalent to 4.7% of new HIV diagnoses for this group, so the levels are still elevated amongst black African men and women.

### HIV undiagnosed prevalence and late diagnosis

PHE estimate HIV prevalence for 2012 amongst African communities in England and Wales at 38 per 1,000, or 3.8%.<sup>21</sup> Prevalence varies by gender – 26 per 1,000 (2.6%) amongst African men and 51 per 1,000 (5.1%) amongst African women.<sup>22</sup> Prevalence amongst sub-Saharan African born pregnant women was 23 per 1,000 (2.3%).<sup>23</sup>

PHE estimates of the undiagnosed percentage amongst Africans aged between 15 and 59 are 27% undiagnosed amongst African men and 21% undiagnosed amongst African women. The population average is estimated at 22% and compares with, for example, 18% amongst MSM.<sup>24</sup>

Late diagnosis rates are higher amongst African communities than MSM. In 2012 (the last year for which there are data at time of writing) 66% of African men and 61% of African women were diagnosed late. That compares with 34% late diagnosis amongst MSM, and amongst heterosexual overall 65% of heterosexual men and 57% heterosexual women being diagnosed late.<sup>25</sup>

In brief, African communities are those most affected by late diagnosis. We know that late diagnosis can significantly reduce the benefits of HIV treatment. Someone diagnosed late is ten times more likely to die in the year following diagnosis compared with someone not diagnosed late.<sup>26</sup> Furthermore, someone diagnosed ‘very late’ (at or below a CD4 count of 200 mm<sup>3</sup>) loses ten years in life expectancy compared with someone diagnosed in time to start their treatment at a CD4 count of 350 mm<sup>3</sup>.

21 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.4

22 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.8

23 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.8

24 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, Appendix 1 – NB Mayisha II (2005), the most recent community-based study amongst black African men and women in the UK with unlinked anonymous testing, found then that two-thirds of those with HIV were undiagnosed

25 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.13

26 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.15



“**African communities are those most affected by late diagnosis. Someone diagnosed late is ten times more likely to die in the year following diagnosis compared with someone not diagnosed late. Furthermore, someone diagnosed ‘very late’ loses ten years in life expectancy compared with someone diagnosed in time.**”

### Rates of HIV testing

Data collected on HIV testing rates amongst African men and women suggest continuing low rates of testing, but with some improvement over time.<sup>27</sup> Mayisha II, a study undertaken in the latter half of 2004, found that 47% of respondents had had an HIV test at some point in the past, a result comparable to the NATSAL 2001 result of 40% having ever tested amongst black Africans. More recently Sigma Research have asked about HIV testing in their surveys of black African prevention needs – Bass Line 2007 survey and Bass Line 2008-09. Bass Line 2007 found an ‘ever tested rate’ of 52% and Bass Line 2008-09 found encouragingly a rate of 60.4%. We are awaiting the results, to be published shortly, of the (renamed) African Health and Sex Survey 2013 from Sigma Research, which it is hoped will continue to show improvements in HIV testing rates. There are of course limitations to these samples but a trend over time such as that found by Sigma Research must be welcome evidence that the emphasis and interventions around HIV testing in recent years have had some effect. It will be interesting to look for further confirmation for this when HIV testing rates are published for the recent NATSAL 2011 survey.

‘Ever tested’ is of course only one measure of testing effectiveness – with ongoing HIV incidence in an at-risk population, having ever tested is no indication of current testing need. You may have tested HIV negative before but if in the intervening months or years you have engaged in risk behaviour you need to test again. Data on frequency and recency of HIV testing is also very important. There is evidence of significant rates of ongoing HIV transmission amongst black African communities in the UK. In Mayisha II 45.2% of people with undiagnosed HIV had tested negative previously for HIV, and 30% of people with undiagnosed HIV had tested negative in the previous 24 months.<sup>28</sup> This shows that their HIV infection was recently acquired. Similarly another study from the same period found that amongst newly diagnosed black African men and women in

27 See for example Sigma Research. (2009) ‘Bass Line 2008-09’ p.16 – even in a sample recruited mainly through HIV support organisations 39.5% had never had an HIV test

28 Rice B et al. (2013) ‘HIV testing in black Africans living in England’, *Epidemiol Infect*, 141, 1741-1748



London between April 2004 and February 2006 37.1% (78/210) had a previous negative HIV test, 32.5% of these within the UK.<sup>29</sup>

This shows that testing once for HIV is insufficient for many black African men and women, that there is ongoing and current HIV transmission in this community, and that frequency of HIV testing needs to be improved. One difficulty has been the lack of clear consensus around a repeat testing recommendation for black African communities in the UK. Some organisations (including NAT in the past) have proposed an annual HIV test recommendation. The epidemiology would seem to justify such a recommendation as a way to address the very high rates of late diagnosis but we must also consider the acceptability of such an approach. Mindful perhaps of that question, Public Health England currently recommends that 'Black African men and women are advised to have an HIV test and a regular HIV and STI screen if having unprotected sex with new or casual partners'.<sup>30</sup> Further detail and consensus around this recommendation would be useful to support consistent health promotion in black African communities.

In Bass Line 2008-09, of the 48.3% who reported having tested HIV negative previously, half had tested negative in the previous year.<sup>31</sup> In looking forward we should be aiming not just to increase the percentage of black African men and women who have ever tested (almost by definition this percentage can only go up, though of course by how much is something we can affect), but also the percentage who tested recently.

## Barriers to testing

The most comprehensive and useful analysis of the evidence around HIV testing and African communities is published as part of NICE's public health guidance on 'Increasing the uptake of HIV testing among black Africans in England'. Readers are referred to the guidance itself and accompanying research documents for further information.<sup>32</sup>

We heard many examples of African people presenting often multiple times for treatment of an ailment, for example in primary care, and the chance for the offer of an HIV test being missed. One study, for example, found that amongst newly diagnosed black Africans in 15 London treatment centres (49.8% of whom had been diagnosed very late with a CD4 count of  $<200 \text{ mm}^3$ ), 76.4% (181/237) had seen their GP in the previous year, 38.3% (98/256) had attended outpatient services, and 15.2% (39/257) inpatient services, representing missed opportunities for earlier HIV diagnosis.<sup>33</sup> A key barrier to testing is the failure to offer the test by healthcare professionals – a matter we return to when discussing implementation of national HIV testing guidance.

This is particularly important in relation to GP services. In the study just quoted this is the healthcare setting where the significant majority of pre-diagnosis healthcare interventions take place. The authors also write, 'Medical attention was sought for wide-ranging reasons, often not obviously connected to underlying HIV status'. There is a reported unwillingness amongst many black African men and women to use GU services, which makes their GP practice an even more important opportunity for HIV testing. And in fact many more black Africans are diagnosed in primary care than gay men. Mayisha II found that a quarter of women who had previously tested in the UK and a third of men had tested in GP practices. So the evidence is both that this is a setting where black Africans are willing to test, and do so, but that there is still much more we could do to increase testing through engagement of primary care. It is depressing in this context that NAT has heard of two instances recently where local African HIV

29 Burns F et al. (2008) 'Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK', *AIDS*, 22(1):115-22

30 PHE. (2013) 'HIV in the United Kingdom: 2013 report', p.6

31 Sigma Research. (2009) 'Bass Line 2008-09', section 3.1

32 See <http://guidance.nice.org.uk/PH33>

33 Burns F et al. (2008) 'Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK', *AIDS*, 22(1):115-22



support organisations have approached local GP practices offering to discuss how best to support black African men and women around HIV testing and got no response.

We were told that when black African men and women do not feel seriously ill they will tend not to access health services. There is a concern, we are told, about not over-burdening the state's resources and a view that health services are to be accessed only in a crisis. This unwillingness to engage with health services when feeling well is compounded for many black African men and women with the pressure of other more pressing priorities: to secure residency status, to find enough to live on, to support dependents. In other words, poverty and social marginalisation are key barriers to testing.

There was a particular need to meet the needs of African men. The Ffena Executive Committee spoke of partner testing, and the need to create a culture where getting tested at the same time as one's pregnant wife was part of what it is to be a 'good husband'. There was some interest in linking the HIV test to other tests for men such as for prostate cancer. And for taking testing initiatives out into the community, for example clubs, workplaces and barber shops, or with employers. There were, it was claimed, people willing and able to do this work – the problem was the lack of resources to fund such initiatives.

There was debate amongst respondents as to the potential of both home sampling kits and HIV self-testing kits which will also soon be available. Their use and possible contribution to reducing late diagnosis in African communities should certainly be investigated. There has been encouraging initial work by THT on home sampling which has identified both the opportunities and challenges of promoting home sampling kits to black African men and women.<sup>34</sup>



**Amongst newly diagnosed black Africans in 15 London treatment centres, 49.8% of whom had been diagnosed very late - 76.4% had seen their GP in the previous year, 38.3% had attended outpatient services, and 15.2% had attended inpatient services, representing missed opportunities for earlier HIV diagnosis.**

Burns F et al (2008) 'Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK' *AIDS*, 22(1):115-22

<sup>34</sup> See Dr Mike Brady's (THT) presentation at Third Joint Conference of BHIVA and BASHH, April 2014. Available at: <http://www.bhiva.org/documents/Conferences/2014Liverpool/Presentations/140403/MichaelBrady.pdf>



A number of voluntary sector organisations have initiated community-based testing interventions for black African communities and many have reported success. There is not, however, as yet a detailed and evidence-based account for the UK HIV sector of what works around community testing for African communities and how best to integrate such projects into the wider local HIV testing 'economy'.<sup>35</sup>

One barrier to testing is ignorance or uncertainty as to where to get an HIV test. Bass Line 2008-09 asked those respondents who said they wanted to have an HIV test, or were unsure whether or not they wanted to, whether they knew where to get one, and a quarter (25.3%) said they did not.

The main reason people gave in the survey for never having tested was that they had no reason to think they had HIV, which included, for example, the rationale of assumed monogamy.<sup>36</sup> Low perceived risk of HIV was also found in Mayisha II and was not associated with HIV status (i.e those with undiagnosed HIV had as low a sense of risk as those without). Nor was perceived risk linked to number of sexual partners, having a history of STI or, strangely, uptake of HIV testing.<sup>37</sup>

Fear of an HIV diagnosis, including the social implications, was also a significant factor for many, indicating the role of stigma as a barrier to testing.<sup>38</sup>

### HIV testing guidance

There is important guidance on HIV testing amongst African communities produced by BHIVA, BASHH and BIS in the UK National Guidelines on HIV Testing. The Guidelines recommend that all people newly registering in General Practice and all general medical admissions should be offered an opt-out HIV test in high prevalence areas (where

diagnosed prevalence exceeds 2 per 1,000 in the local population). The majority of black African men and women will live in these local authorities.

In addition, the Guidelines recommend that HIV testing should be routinely offered and recommended to all men and women known to be from a country of high HIV prevalence (prevalence >1%) which includes every sub-Saharan African country. It is not entirely clear how this recommendation would work in practice but it might mean those African men and women already registered with a GP are offered a test – this group would not have their HIV testing needs met by the recommendation to test new registrants.

Interestingly, in the light of the discussion on repeat testing above, there is no recommendation for repeat testing for black Africans, though there is for MSM. Finally, there is an important list of 'clinical indicator conditions' where HIV testing should be routinely offered, for example TB.

More recently, NICE have issued public health guidance on 'Increasing the uptake of HIV testing among black Africans in England'. This sets out an excellent array of recommendations on community engagement, needs assessment, strategic planning, promotion of HIV testing and reducing barriers to testing as well as HIV referral pathways for both positive and negative results. In terms of the offer of the HIV test, the NICE public health guidance reiterates the recommendations of the UK National Guidelines, with additional recommendations to offer and recommend an HIV test to anyone who has a blood test in a high prevalence area (regardless of the reason), and for healthcare professionals to offer and recommend an HIV test irrespective of local prevalence rates 'to all those who may be at risk of exposure to the virus', for example having a new sexual partner or having tested negative during the window period.

35 For current evidence on community HIV testing more generally see: Thornton A et al. (2012) 'HIV testing in community settings in resource-rich countries: a systematic review of the evidence', *HIV Medicine*, 13, 416-426

36 Sigma Research. (2009) 'Bass Line: 2008-09', section 3.3

37 Rice B et al. (2013) 'HIV testing in black Africans living in England', *Epidemiol Infect*, 141, 1741-1748

38 Elam G et al. (2006) 'Barriers to voluntary confidential HIV testing among African men and women in England: results from the Mayisha II community-based survey of sexual attitudes and lifestyles among Africans in England', *HIV Medicine*, 7 (supplement 1), abstract 028



We have no intention in this paper of ‘reinventing the wheel’ and these two documents are at the centre of considerable advocacy and publication around HIV testing in recent years. NAT, for example, has produced ‘Commissioning HIV Testing’ a practical guide for commissioners. The problem is not in a lack of useful policy recommendations – it is in the failure to implement them. Public Health England in their annual report for 2013 on HIV in the UK report some improvement in testing rates and reductions in late diagnosis amongst MSM in recent years but ‘The uptake of HIV testing among black African men and women has remained low’. They cite a June 2012 audit of 40 sexual health commissioners in areas of high HIV prevalence which found ‘that 31% (11/35) had commissioned HIV testing for some new patient registrations in general practice, but only 14% (5/35) had commissioned routine HIV testing as part of general medical admissions to hospitals’.<sup>39</sup> A recent meta-analysis found that only 30% of eligible patients in high prevalence areas had been tested for HIV as recommended in national guidance, and only 22% of patients with clinical indicator conditions had been tested.<sup>40</sup>

The Public Health Outcomes Framework in England has as one of its indicators late HIV diagnosis. The expectation is that local authority performance on late diagnosis will be publicly available and subject to political and public scrutiny and pressure. Such pressure needs to be applied to get local authorities, NHS England and clinical commissioning groups to implement HIV testing guidance and reduce late HIV diagnosis, with attention paid to the varying late diagnosis rates of different communities.

Commissioners themselves should be alert to local failures to test in line with clinical recommendations. Commissioners should encourage ‘look-backs’ for those diagnosed very late to identify missed opportunities to test – as recommended in the BHIVA Standards of Care (Standard 1).

## Recommendations

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- 13 Actions should be implemented to reduce HIV stigma in African communities and increase knowledge of the effectiveness and benefits of HIV treatment (see relevant sections of this report) – this will address significant current fear-related barriers to HIV testing.

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- 14 The need to reconfigure HIV-related interventions aimed at black Africans away from ethnicity-based messages and imagery applies as much to HIV testing as it does to HIV prevention.

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- 15 Local authorities should, as part of their public health responsibilities, encourage black African and other relevant communities to access NHS services as a preventive and precautionary activity, even when one does not feel seriously unwell – this can only work if the current political hostility to migrant NHS access ends.

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- 16 The preference of many African men and women to use GP services needs to be explicitly recognised in the JSNAs (Joint Strategic Needs Assessments) of local authorities with significant African communities, and must affect local GP practice – for example, indicating clearly in GP waiting rooms through posters, leaflets and video screens that the practice is a safe, confidential, non-judgemental and supportive environment in which to talk about sexual health.

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39 PHE. (2013) ‘HIV in the United Kingdom: 2013 Report’, p.17

40 Elmahdi R et al. (2014) ‘Low levels of HIV test coverage in clinical settings in the UK: a systematic review of adherence to 2008 guidelines’, *Sex Transm Infect*, 90(2):119-24





- 17 Clinical commissioning groups in high prevalence areas need to engage with local HIV support organisations and African community groups to support improved HIV testing in GP practices.

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- 18 Local authorities need to improve knowledge amongst African communities of how and where to test for HIV as a key public health intervention.

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- 19 Further work is needed on how to promote effectively both self-testing kits and home sampling kits as additional testing options to black African men and women. Similarly, on the basis of successful individual projects, the UK HIV sector should develop a strongly evidenced consensus on what works in community HIV testing in African communities and how best to commission such interventions to reduce further local late diagnosis rates amongst black African men and women.

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- 20 Local commissioners should implement the UK National Guidelines for HIV Testing 2008 and ensure the routine opt-out offer of the HIV test in high prevalence areas for all people registering in a GP practice or presenting in general medical admissions in hospital, and for all people from countries with a generalised epidemic.

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- 21 Primary and secondary care should test for HIV routinely when patients present with clinical indicator conditions. To this end, NHS England and CCG commissioners, as well as local Directors of Public Health, should act on look-back reports in instances of very late HIV diagnosis, requiring HIV testing in relevant specialties.

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- 22 Public Health England should undertake a review of and engagement with clinical professional bodies of relevant specialties with the aim of securing clinical guidance on HIV testing consistent with that of the UK National Guidelines on HIV Testing and 'HIV Indicator Conditions: Guidance for Implementing HIV Testing in Adults in Health Care Settings'.

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- 23 Voluntary sector organisations supporting people with HIV should encourage and support, where appropriate, formal complaints in cases where a service user has been diagnosed very late, after repeated presentations with clinical indicator conditions to NHS services.

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- 24 Clear recommendations need to be agreed across Public Health England, clinical bodies and the HIV sector on repeat testing for black African men and women living in the UK.

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# D

# HIV TREATMENT AND CARE

## African men and women with HIV being seen for care

8,919 African men and 17,250 African women were being seen for HIV treatment and care in the UK in 2012 – 26,169 in total. There are, in other words, nearly twice as many African women as men living with diagnosed HIV. Policy interventions which address issues of gender and in particular the needs of women living with HIV will have a disproportionate impact on African people. African women make up 68% of women diagnosed with HIV, and are estimated to make up 65% of all women living with HIV, both diagnosed and undiagnosed.

PHE also publish data from 2001 for region of birth of those newly diagnosed, including for the 30,210 Africans diagnosed in this period. The distribution by region of Africa of diagnoses since 2001 is as follows (with percentages of the total African diagnoses):

North:	<b>225 (0.7%)</b>
East:	<b>18,939 (62.7%)</b>
Central:	<b>1,812 (6.0%)</b>
Southern:	<b>3,189 (10.6%)</b>
West:	<b>5,500 (18.2%)</b>

So whilst there are Africans living with HIV from all regions of Africa, a majority are from the Eastern region.<sup>41</sup>

In Scotland in 2012 there were 751 black African people receiving HIV treatment and care (2.58% of the population of black African people in Scotland). In Wales there were 297 black African people receiving HIV treatment and care (2.5% of the population of black African people in Wales). In Northern Ireland there were 91 black African people receiving HIV treatment and care (3.6% of the population of black African people in Northern Ireland).

<sup>41</sup> The Eastern region in this PHE analysis includes for example Uganda and Zimbabwe



### Quality of HIV care

A number of markers have been agreed for quality of HIV treatment and care, and in England have been formally made into a 'Quality Dashboard' against which individual clinic performance can be measured. What is striking is that there is no significant difference in these clinical outcomes for African men and women when compared with the wider population of people in HIV care, and that these outcomes are consistently good. For example, in the HIV Annual Report for 2013, PHE reports on 2012 data that 88% of people with HIV had a CD4 count (a marker of linkage into care) within one month of diagnosis and 97% within three months of diagnosis. Similarly the retention rate (those seen for care in 2011 also seen in 2012) was 95%. On treatment coverage 89% of patients with a CD4 count of  $<350$  cells/mm<sup>3</sup> were on anti-retroviral therapy (ART), and the majority of those not on ART had been only recently diagnosed – again there was no difference by ethnicity. Nor is there any ethnicity difference for the important indicator of an undetectable viral load within one year of ART initiation (in 2010 91% of African men and 87% of African women had an undetectable viral load, compared with 85% for the population as a whole).<sup>42</sup>

The extremely good clinical outcomes for people living with HIV need to be welcomed, as does the fact that there are within the patient population no significant inequalities, including by ethnicity. We will explore further in this report how such good outcomes might be supported and maintained, and whether these clinical outcomes give an adequate picture of the experience of HIV treatment and care.

The degree of health equality in key HIV treatment outcomes and the high levels of quality are to be celebrated and maintained. But it is important to supplement this clinical information with deeper and more nuanced information around patient experience. BHIVA is currently taking forward a project to identify Patient Reported Experience Measures (PREMS) which can capture aspects of health and care which may be missed were we to limit ourselves to discussion of CD4 count and viral load. Complementary work is also being undertaken

by AHPN. It will be interesting to see the outcomes of this project and any variation by community in what is deemed important to measure.

It should be noted that whilst African men and women do well in relation to the agreed outcomes in the Quality Dashboard, they do have a higher rate of AIDS-related deaths due to late diagnosis when results are adjusted for stage of diagnosis.

### Lost to follow up

At NAT's African HIV policy roundtable held in 2012 there was interest from participants in data on 'lost to follow up' amongst Africans living with HIV. We have seen above that African men and women do as well as others in the retention in care outcome indicator. There has additionally been a study by Public Health England and an audit by BHIVA on this issue. The BHIVA audit<sup>43</sup> found excellent retention in care between 2010 and 2011 with only 1.1% of patients seen for care in 2010, not attending for care in 2011 though continuing to live in the UK. For a further 1.5% the outcome was unknown and so some of this number may well also be lost to follow up. Whilst the number lost to follow up is relatively small, the audit did find that being black African meant a greater risk of disengaging from care. This is therefore a policy issue which merits consideration.

Furthermore, taken cumulatively, these lost to follow up percentages may still represent a significant number of people. Ethnicity and migration issues were also raised in a report on non-attendance at HIV specialist clinics in Scotland.<sup>44</sup>

BHIVA made two policy recommendations on the back of its audit findings: that HIV services should monitor attendance and seek to re-engage patients when necessary, and this should include liaising with GPs and checking the Personal Demographic Service; and that this process should be supported by public health agencies providing clinics with a list of patients reported one year but not the next.

42 HPA. (2011) 'HIV in the United Kingdom: 2011 Report', p.14

43 See <http://www.bhiva.org/documents/ClinicalAudit/AnnualReports/AuditRep2012-13.pdf>

44 NHS Health Scotland. (2011) 'A report on a study of non-attendance at specialist clinical HIV services in Scotland'



## Primary care

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We were told that black African communities value accessing health services through primary care. There were however many stories of mixed experiences of GP services. Whilst many did have good accounts of their GPs, others had some very poor and shocking experiences of discrimination, breaches of confidentiality and poor care. Stigma deterred some people from accessing primary care services. We have discussed in the sections of this report on HIV prevention and HIV testing the need for GP practices to do more to engage with and support their black African patients, and the value of collaborating with expert community/HIV organisations in that process.

## Treatment information

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The quality and effectiveness of treatment information for black African men and women, both those diagnosed with HIV and those undiagnosed, was raised many times in discussions and in the publications we read in preparation of this report. The AHPN/Ffena conference on 'African Women and HIV' called for 'patient-friendly, accessible information about treatment, clinical standards and other guidelines that recognise the specific needs of different groups'.

Treatment literacy was advocated by a significant number of respondents, often in the context of reducing stigma and encouraging testing and entry into care. A further point made was that such literacy was essential to informed consent for black African men and women to NHS services.

There was a difference of opinion amongst respondents on the self-confidence of African men and women in discussing their treatment and care with clinicians. Some said they are less confident than gay men on, for example, raising concerns about side-effects and seeking alternative drug regimens. Others said this was a stereotype and African men and women could be just as assertive as anyone else.



**What is striking is that there is no significant difference in these clinical outcomes for African men and women when compared with the wider population of people in HIV care, and that these outcomes are consistently good.**



A current problem is the uncertainty under the new commissioning arrangements brought in from April 2013 as to who is responsible for commissioning treatment information. This needs to be clarified urgently so as to ensure appropriate treatment information for African communities is developed and effectively disseminated.

We discuss here also evidence of poor understanding of both the therapeutic and preventive benefits of treatment. As has been stated earlier, the Plus One study<sup>45</sup> undertaken by Sigma Research amongst African men and women in sero-discordant relationships, found that a third of participants had never heard of PEP and whilst many had heard of treatment as prevention there was considerable discomfort or suspicion around the concept. Poor understanding of prognosis, as well as of the various harm reduction options available, meant unnecessary worry and distress. One quotation from a participant in the study is telling:

'You know when you go to the clinic nothing stays in your head. I can say my first eight years I didn't understand a thing... you know when the doctor tells you that's, some of the words they use are too English. So you don't understand what they mean so when you come to the [support] groups you get more explanation, I didn't know which one was CD4 count and which one is viral load, for a long, long time I just didn't understand.' [woman with diagnosed HIV quoted in the Plus One Study]

Treatment information is not, and not even mainly, about available online and hard copy written material. It is most importantly about effective patient-centred explanation from doctors, nurses and health advisers, as well as by HIV support organisations, including peer support. It appears there could be more and better explanation around HIV treatment for African men and women living with HIV – and to that end we need to develop more consistently used tools to assess patient understanding of treatment as well as improve training of NHS and voluntary sector staff to maximise effective communication.

### Recommendations

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- 25 The development of Patient Reported Experience Measures (PREMS) by BHIVA is an important opportunity to gather broader and more holistic measures of the quality and experience of HIV treatment and care amongst black African men and women. PREMS reporting disaggregated by key communities should be used to support targeted improvements in the quality of care.
  - 26 The BHIVA audit recommendations on attendance monitoring and re-engagement of those lost to follow up should be implemented.
  - 27 There needs to be clear responsibility and accountability for the commissioning and provision of treatment information for people with HIV (Public Health England and its partners should use the development of the national commissioning framework for Sexual Health, HIV and Reproductive Health to secure such clarity).
  - 28 Better assessment is needed of the quality and effectiveness of communication around HIV treatment within HIV clinics (and HIV support organisations), and in particular to black African service users, to support staff training and improvements in practice.
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45 Sigma Research. (2011) 'Plus One: HIV sero-discordant relationships among Black African people in England'



# E

# POVERTY, BENEFITS AND HOUSING

## Poverty

We have known for some time that African people living with HIV are seriously affected by poverty. The East London project, which surveyed a high proportion of black African patients in East London HIV clinics, found in 2004/05 that 40% of black African heterosexual men and women living with HIV 'did not have enough money to cover their basic needs' (compared with 9.6% amongst white homosexual men, for example).<sup>46</sup> Black African heterosexual women (35.3%) and black African heterosexual men (45.4%) were less likely to be employed than white (57.6%) or ethnic minority<sup>47</sup> (53.7%) homosexual men. Similarly the Sigma Research survey 'What do you need? 2007-2008' found that black African respondents were less likely to be in paid employment (35%) compared to Asian (50%) and White respondents (57%).<sup>48</sup>

Another important source for information on poverty, HIV and African communities is analysis of applications to the Hardship Fund, which provides emergency cash relief to people with HIV experiencing severe financial hardship – the Fund was managed first by Crusaid and more recently by THT.

One report has analysed Hardship Fund applications for the years 2006/2009 ('Poverty and HIV: 2006 – 2009' NAT/THT 2010). Between 2006 and 2009 7,934 people were awarded grants – their average weekly income excluding housing costs was £42 per week. 60% of applications were made by black African clients. More recently, THT have published their report 'HIV & Poverty' which looks at Hardship Fund applications in 2012. The majority of people – 81% – had a disposable income of less than £100 per week, 46% of applicants had less than £50 per week to live on and 35% had no disposable income at all. The largest group of applicants were black African women who accounted for 43% of applicants but who make up 23.3% of the population of people living with diagnosed HIV.<sup>49</sup>

46 Ibrahim F et al. (2008) 'Social and economic hardship among people living with HIV in London' HIV Medicine, 9(8):616-24

47 All ethnicities other than white

48 Sigma Research. (2009) 'What do you need? 2007-2008'

49 THT (2014) 'HIV & Poverty', pp.6 and 9



**“ Black African men and women in the UK have a significantly higher level of education than the national average – but for all that, they are more likely to be unemployed or in low paying work.**

We heard similar accounts from service providers such as Positive East where focus group participants ‘commonly cited challenges revolving around the lack or loss of money and the fear of losing benefits. Participants talked about not having sufficient money to meet their everyday needs, such as buying food. While many were receiving some or several forms of benefits, these were described as insufficient for providing a basic standard of living. The threat of benefit cuts and constant benefit reviews caused further worry for participants as this would make it more difficult to meet their and their family’s needs’.<sup>50</sup>

These reports demonstrate that amongst people living with HIV, African men and women are disproportionately affected by poverty. We discuss below the significant relationship between poverty and insecure immigration status. But there is clearly poverty also experienced by those with settled and secure residency status. Poverty is related to high unemployment rates amongst African men and women, as well as low pay, inadequate benefits and errors or delays in the benefits process.

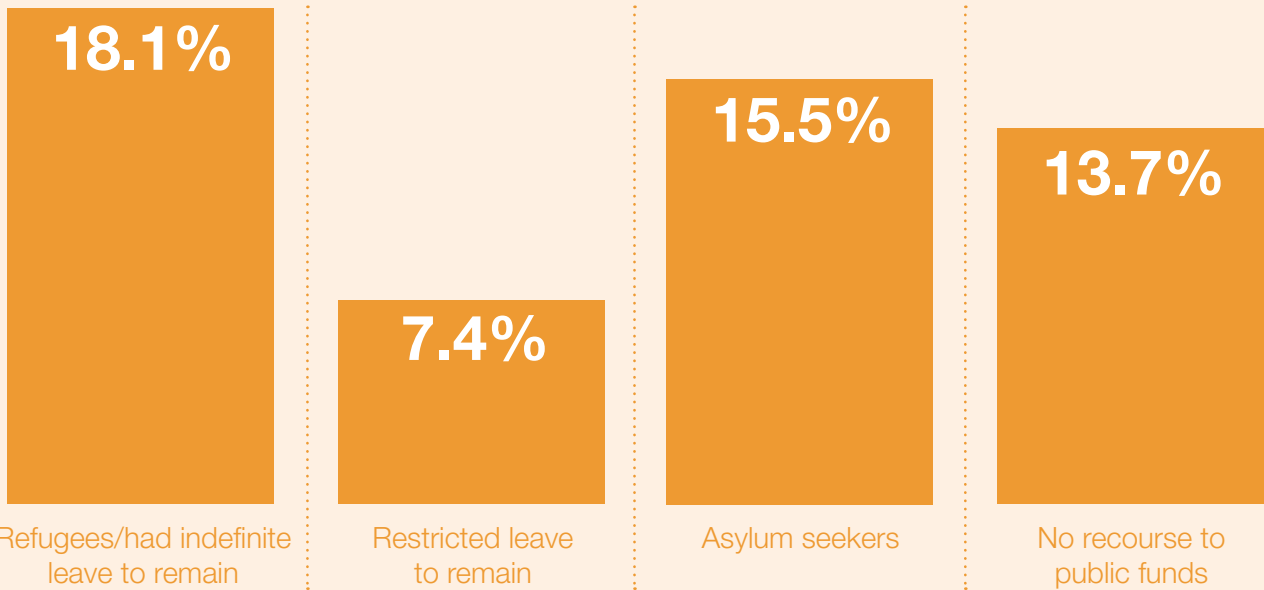
One issue in relation to employment was recognition of the qualifications received from educational and training institutions in Africa. Black African men and women in the UK have a significantly higher level of education than the national average – but for all that, they are more likely to be unemployed or in low paying work. Failure to recognise African degrees and qualifications erects a barrier for these communities to escape poverty. We were told of academic work on this issue and it was felt that it was a matter where HIV policy organisations should work alongside other policy organisations.

We cannot within the scope of this policy overview give a detailed account of poverty issues relating to employment and benefits. But it should be clear that policies aiming to reduce poverty and increase employment rates amongst people with HIV will disproportionately benefit African men and women because it is in this group that unemployment and poverty are particularly concentrated. We do not have good data on the numbers of African people living with HIV who have applied for benefits such as Employment Support Allowance (ESA) and

<sup>50</sup> Positive East. (2013) ‘Positive Voices’, p.9



Immigration status of Hardship Fund applicants - THT 2012 'HIV and Poverty'



Disability Living Allowance (DLA)/Personal Independence Payment (PIP). Nor do we know whether there is any difference in the outcome of application to, or experience of, the Work Programme. We should bear in mind that the majority of women living with HIV are African – so this gendered aspect of poverty must also be further explored, and the way poverty is experienced by women must be different in some ways from the way it is experienced by men.

One impact of poverty was that it made people and especially men, culturally positioned and pressured as the family breadwinner, to focus predominantly or exclusively on working and gaining income to escape poverty rather than taking care of their health, and thinking about their possible HIV risk.

A number of respondents claimed that they had seen a significant increase in poverty recently, with food poverty being a real problem. This of course affected both mental and physical health.

The contribution of immigration restrictions to poverty

There is a significant relationship between poverty and immigration status. Between 2006 and 2009 ordinary living expenses grants from the Hardship Fund went disproportionately to asylum seekers and, when taken together, asylum seekers (26.6%) and those with no papers to be in the UK (8.7%) constituted the largest group of Hardship Fund applicants (35.3% in total). 18.9% said they had the right to stay in the UK. Application letters were analysed for major drivers of the poverty experienced and in 29% of cases it was immigration.

Similarly in THT's 2012 report 18.1% of applicants were refugees/had indefinite leave to remain, 7.4% restricted leave to remain, 15.5% were asylum seekers and 13.7% had no recourse to public funds.<sup>51</sup>

At the root of the poverty experienced by many people within the immigration system is the denial of the right to work for those who are still seeking asylum (this process can take years). Instead they have to rely on a benefit significantly below the benefits available to UK residents on income support. Currently single people receive £36.63 per week, rising to £72.52 for a married or civilly

51 THT. (2012) 'HIV & Poverty, p.8





partnered couple. Children are given £52.96 a week and single parents £43.94 a week. These are small amounts and cannot protect the recipients from poverty and significant need. A recent (9 April 2014) judicial review has determined that the Home Secretary acted 'irrationally' in setting the amounts so low – the Home Office has accepted the judgment. This does not necessarily mean the amounts will be increased, simply that the decision will need to be re-taken.

For those 'without papers', whose immigration claims have been exhausted and unsuccessful, there are neither benefits nor right to work. These people – often described as those with 'no recourse to public funds' – are most often destitute and very reliant on the sort of support the Hardship Fund provides.<sup>52</sup> Schedule 3 of the Nationality, Immigration and Asylum Act 2002 prohibits local authorities from providing support to a large proportion of the people with no recourse to public funds.

There is a particular problem for those who have had their immigration or asylum application refused but who the Government accepts are currently unable to return to their country of origin. This group can access some statutory support for shelter and subsistence, known as section 4 support. However, the subsistence support is in the form of vouchers rather than cash and can only be used at certain approved retail outlets. Putting aside the indignity and stigma attached to this process, the vouchers deny people the chance to shop around for cheaper goods, offer in any event minimal support, and provide no cash for phone calls, bus fares and other often vital items of expenditure.<sup>53</sup>

It is striking that a significant percentage of people forced to seek help from the Hardship Fund are those who have gone through the immigration system and do now have refugee status or leave to remain and the right to work. One can only assume that for many people the transition from asylum seeker to refugee status/leave to remain is not an easy one. Asylum-related benefits and housing are withdrawn but living costs remain and the struggle to find work in what is currently a difficult job

market. The 2006/2009 report identified this as a particular issue for Government attention – both Home Office and DWP – with a recommendation that those who are eligible for benefits 'are guided and assisted through the application process, so that the delay in receiving benefits is minimised'.

### Housing

Although from a few years ago, some of the most complete data on housing amongst HIV positive black Africans comes from the East London project, which found that black African heterosexual men and women were less likely to own their own homes (8.7% and 7.3%) than ethnic minority or white homosexual men (18.9% and 38.5% respectively). Homelessness was uncommon but a significant proportion were living with family or friends (9.2% of black African men and 9.4% of black African women). More than 20% of black African women and nearly 15% of black African men had moved home at least three times in the preceding three years compared with 6.8% of white homosexual men and 9.0% of ethnic minority homosexual men.<sup>54</sup> Living with family or friends can involve real difficulties around privacy and disclosure, where even your own home is not a 'safe place'. The frequent moving between dwellings for many suggests real instability and vulnerability in many Africans' housing circumstances. Respondents told us that today many black African people find themselves in similar circumstances, 'sofa surfing' between short-term accommodation from friends and relatives, unhappily dependent on others for shelter with implications, for example, for their ability to negotiate safer sex or handle disclosure of status.

Poor housing has been reported by African people living with HIV, including damp, overcrowding, being forced to share accommodation with strangers, and a lack of basic facilities.<sup>55</sup> There is a particular issue with the quality of accommodation provided by the Home Office to asylum seekers and those on sections 4 and 95 support.

52 For more detail see:  
NAT. (2014) 'People living with HIV who have no recourse to public funds (NRPF)'

53 Still Human Still Here Evidence to parliamentary enquiry on the destitution of asylum seeking families Jan 2013

54 Ibrahim F et al (2008) 'Social and economic hardship among people living with HIV in London' HIV Medicine, 9(8):616-24

55 Positive East. (2013) 'Positive Voices', p.10



Respondents spoke of a significant increase in housing problems recently, prompted in part by changes to benefits and legal aid access. It was claimed such poverty stressors were having an impact on adherence, with either loss of adherence completely or people oscillating between waves of adherence and of non-adherence. NAT has recently published a briefing based on a snapshot survey of 18 HIV service providers across the country.<sup>56</sup> The interrelationship between problems with benefits and accessing stable good quality housing was abundantly clear in survey responses. The significant majority of organisations said that HIV and related health issues were a primary concern from those who approached them about housing needs and the majority of their concerned service users also felt that their poor housing was having an impact on their health and HIV treatment.

Rules and practice are changing on how local authorities prioritise people's needs for the provision of housing support. HIV is still referred to by the Department of Communities and Local Government as an example of an indicator which should mean someone can access 'reasonable preference' in housing allocation<sup>57</sup> – in other words, it is a vulnerability which should be taken into specific account when considering need. However, new criteria are being adopted by many local authorities, and a common one is a requirement of a certain number of years of residency in the local area. This may well cause problems for migrants who have been in the UK a relatively short time and been in Home Office supported accommodation. If they are granted leave to remain and lose this Home Office accommodation, they will be unemployed initially and in need of immediate housing. Local residency requirements may well deprive them of the shelter they need. Flexibility is needed from local authorities for this group.

### Recommendations

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- 29 Research is needed into the proportion of black African men and women with HIV currently living in poverty, in poor housing and who are not in paid employment.

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- 30 Research is needed on whether African men and women living with HIV and with relevant needs are accessing and benefiting from disability-related benefits such as Employment Support Allowance and Disability Living Allowance/Personal Independence Payment. Any barriers to accessing these benefits and the assessment process for black African claimants should then be addressed.

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- 31 More information should be researched and gathered on how poverty and poor housing are affecting mental health, coping, ability to care for dependents and autonomy/choice in sexual relations for people living with HIV.

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- 32 People who currently have no recourse to public funds should be entitled to support to meet the basic necessities of life. The Schedule 3 restrictions should be revoked which currently prevent local authorities supporting people with no recourse to public funds.

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- 33 Asylum seekers should have the right to work in the UK if their case has not been resolved in six months, or if they cannot be removed from the UK through no fault of their own.

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- 34 The Government should support a national and official process of recognising and validating African academic and professional qualifications to support African migrants attempting to enter employment.

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56 NAT. (2013) 'Housing and HIV: A survey into the housing advice and support needs of people living with HIV'

57 Communities and Local Government. (2013) 'Allocation of accommodation: guidance for local housing authorities in England', Annex 1



“ **Between 2006 and 2009, ‘The Hardship Fund’ awarded 7,934 people grants - their average weekly income excluding housing costs was £42 per week. Sixty percent of applicants were made by black African clients.** ”

35 Asylum support should be raised to the level of Income Support

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36 The use of vouchers for people on section 4 support should end, being replaced by cash support. Section 4 support should be raised to the level of Income Support.

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37 The Government must improve the quality of the housing stock for asylum seekers and those on section 4 support, and address issues of safety and privacy for those living with HIV.

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38 The Home Office and DWP should work together to ensure asylum seekers granted leave to remain and eligible for benefits are guided and assisted through the application process and that delays in receiving benefits are minimised. The same must apply to those in need of housing when they have to leave Home Office asylum support accommodation. There also needs to be targeted support for these individuals to enter the workplace.

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39 There has to be flexibility from local authorities in relation to local residency requirements for those granted leave to remain and who then apply for housing support.

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40 Local authorities must ensure their housing assessment processes acknowledge, as recommended in official guidance, that HIV is a ‘protected characteristic’ and housing decisions reflect the vulnerability of people with such a fluctuating condition to poor and unstable housing.

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# F IMMIGRATION

What proportion of Africans living with HIV are currently within the immigration system? Given the significant HIV-related policy issues linked to immigration it would be very useful to have precise information on this score. Evidence at the moment is patchy. Immigration statistics from the Home Office do have data on countries of origin but do not of course provide information on HIV status or other health conditions. And almost by definition there are no authoritative estimates on the numbers of people living here without lawful residency or permission, nor of their demographic breakdown. It is hoped, subject to the success of a planned pilot and future funding, that there will be an annual survey undertaken by PHE via clinics capturing a representative sample of patients – this will ask about ethnicity, country of origin and residency status, and thus give us a better sense of the answer to this question.

There is data from the 2004 East London project, based on a robust clinic sample in that area, which found amongst HIV positive patients that about half of black African heterosexual men and women had insecure residency status.<sup>58</sup> That was, however, a decade ago. And certainly talking to people for this project there was a definite sense of the residency

status of many people being resolved in the interim. At the same time, immigration restrictions have meant it has been much more difficult for people from sub-Saharan Africa to enter the UK. With more applications being resolved and fewer new applications being made we must assume that the percentage of African people with HIV whose application is under active consideration by the Home Office has reduced.

Whilst the majority may be granted residency status, one result of accelerated resolution of cases could also be a greater number having no further lawful residency or access to asylum-related benefits as their application is finally refused. In the 2004 East London study just 3.2% of black African respondents said they had ‘no papers to be in the UK’. We have seen, however, that the group of people with no recourse to public funds is disproportionately represented amongst people with HIV living in poverty and as much in 2012 as in 2006. There could therefore be something of a two-way split in the experience of recent African migrants, with the position of many becoming much better as they secure residency status but that of others becoming even more desperate and precarious.

58 Ibrahim F et al (2008) ‘Social and economic hardship among people living with HIV in London’, *HIV Medicine*, 9(8):616-24



**The restrictions on migrant access to the NHS and the accompanying discourse of so-called ‘health tourism’ was in the view of some a definite disincentive to access healthcare amongst all Africans.**

Certainly service providers also spoke of significant numbers of service users in poverty and destitution, with no recourse to public funds. We may not know what proportion they constitute overall of black African people living with HIV, but in absolute numbers there is clearly still significant need.

It was also noted that migration patterns from sub-Saharan Africa have changed over the last fifteen years – migration from Zimbabwe may well have slowed down significantly, but in more recent years there have been more people entering the UK from Nigeria, for example. We heard of the significant levels of HIV stigma and discrimination feared and experienced by people from Nigeria and other West African countries.

It would, however, be a mistake to assume that once you are granted refugee status or leave to remain that immigration policy no longer affects you. Many people told us that the aggressive, some termed it ‘toxic’, atmosphere around immigration policy had a profound impact on newly arrived communities irrespective of an individual’s precise residency status. In some instances it results in confusion as to their rights even when they do have leave to remain and in fact enjoy rights very comparable to UK citizens. The restrictions on migrant access to the NHS and the accompanying discourse of so-called ‘health tourism’ was in the view of some a definite disincentive to access healthcare amongst all Africans, and especially to consider whether one might be at risk of a stigmatised condition when all one is trying to do is ‘keep one’s head down and fit in’. Another told us that many clients at his organisation were so scared by police stopping people at underground stations and doing immigration checks that they did not go out to appointments at their HIV clinics or solicitors, and this was irrespective of whether they had papers demonstrating they had a legal right to be in the country.

There is a particular emphasis in evidence on the difficulty coping with uncertainty and the length of time it takes the Home Office to make immigration decisions. A number of Positive East focus group participants spoke of the toll on both physical and mental health, with episodes of depression and hopelessness, and in a few instances psychosis.



We have discussed in the section on Poverty, Benefits and Housing the impact of immigration rules and restrictions on poverty amongst black African men, women and children. In addition to the difficulty in subsisting felt by many in the immigration system, there are specific challenges around NHS access, initial accommodation centres, dispersal and detention of asylum seekers and other migrants.

### Access to NHS services

Most migrants can access NHS services, but asylum seekers do in practice have difficulty in many instances registering with a GP. In theory an asylum seeker has a right to be registered with a GP as long as there is room on the practice list. In reality it can take pressure and advocacy for this to happen.

The situation is far worse for those commonly referred to as 'undocumented migrants' – this group includes people whose asylum claim has been finally refused, those who have overstayed a visa and those who have entered the country unlawfully. For a number of years they have had to pay for most secondary care services. Exceptions to charges have included emergency care in an A&E department, treatment for infectious diseases and treatment in a sexual health clinic – HIV was not, however, exempt until advocacy and campaigning, led by NAT, persuaded the Government to end charging for HIV treatment in England from October 2012. This was a welcome move to encourage migrants to test and attend HIV services. Scotland has provided in law for free HIV treatment for all since 1 May 2014 (in practice charges have never been applied in Scotland for HIV treatment). In Wales and Northern Ireland there is, in theory at least, still the possibility of charging certain migrants for HIV treatment but we trust that in the near future these two nations will also exempt HIV treatment from NHS charges on public health grounds.

However, the Government has recently proposed extensions of the charging system in England which will seriously compromise the health of people with HIV, amongst others. In particular, proposals to introduce charges for any treatment provided in primary care will be a de facto deterrent to many undocumented migrants accessing GP services. This will make a bad situation even worse – since GPs with open lists do not currently have an obligation to accept requests to register from undocumented migrants, they already find it often

to be very difficult to register with a GP practice. This coincides with HIV clinics ending the sort of 'one stop shop' healthcare provision they used to provide. The patient will be told that they need to go to their GP for their primary care needs rather than the HIV clinic. For those not registered with a GP, or who may have to pay for primary care, we are going to begin to see serious health inequalities emerging.

There will of course also be a deterrent to access primary care for those migrants with undiagnosed HIV, removing important testing opportunities and fuelling late diagnosis with the attendant harms to health, risk to life and elevated costs to the NHS.

As harmful will be the proposal to charge for emergency care in A&E departments. People will only attend when their health is severely compromised, where the NHS will have to pay significant additional costs for their care which will never be recouped. Migrants who incur NHS debts above £1,000 which they are unable to repay are reported by the NHS to the Home Office and any further immigration application is refused until the debt is paid – an impossible undertaking for the majority. This compounds the deterrent to accessing healthcare.

### Initial Accommodation Centres

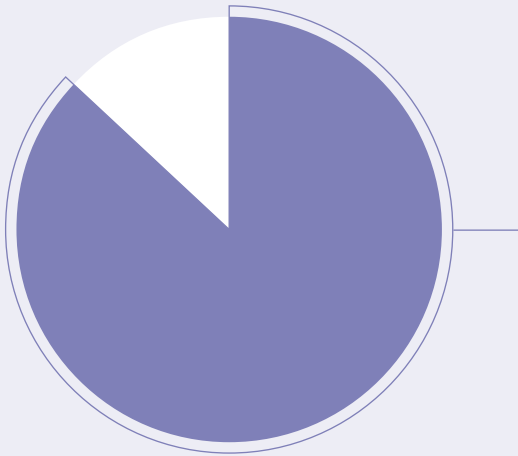
Those who apply for asylum on arrival and need housing are sent to Initial Accommodation Centres (IACs) from where they are within a short time dispersed further. There has not been much attention recently to the quality of healthcare being provided in IACs but one issue to have emerged is whether or not we should use the opportunity provided by IACs to offer HIV tests to those from high prevalence countries. A recent study looked at results of offering an HIV test to all those passing through one such Initial Accommodation Centre between October 2011 and October 2012 – there was an 87% acceptance rate of the test, and amongst those tested a positivity rate of 7%, approximately twice the prevalence rate estimated by Public Health England for black African communities in the UK.<sup>59</sup> We understand there is resistance to the proposal of universal HIV screening across the IAC estate, with arguments

59 Sidebottom M and Street E. (2014) 'HIV Testing in an Initial Accommodation Centre', *HIV Medicine*, 15(3):252

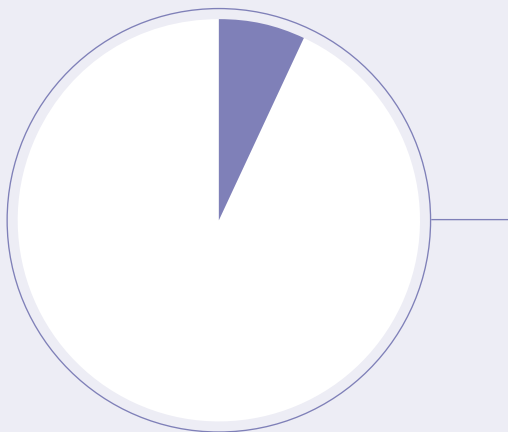


### IAC HIV tests

Acceptance rate of the test was 87%



Amongst those accepted, 7% tested positive



such as the need for pre-test counselling, shortages of time and money, and concerns around point of care testing. The results of the pilot, however, speak for themselves.

### Dispersal

An asylum applicant who needs support with accommodation can apply to the Home Office where housing is allocated on a no choice basis, often a significant distance from the applicant's port of entry or current UK place of residence. Applications can be made either on arrival in the UK or (more frequently) 'in-country' some time after arrival. In these latter instances especially, where for someone living with HIV a relationship of treatment and care has been established with an HIV clinic and very often a local support organisation, dispersal can risk rupturing important support networks and even interrupting treatment.

NAT and BHIVA produced guidance on how to ensure clinical continuity of care in this instance and NAT advocated for dispersal policies which reflected the particular vulnerabilities of people with a long-term condition such as HIV. Current dispersal policy, as a result of this advocacy, is to aim to disperse someone within travelling distance of their current HIV clinic, as long as accommodation is available. This is welcome – however, there is no Home Office accommodation available in London so those who apply from London will have to move some distance away. In London, therefore, flexibility on timing of dispersal and possibly support in some temporary accommodation whilst care transfer is organised would be important but do not seem to be happening. We have also heard from some organisations that the Home Office takes a very extended view of what it means to be 'near' your HIV clinic. Furthermore, many Home Office officials seem in practice to ignore the guidance and have to be reminded of it by asylum seekers themselves or by support organisations.



## Immigration Removal Centres

NAT has undertaken two surveys of HIV treatment and care in Immigration Removal Centres (IRCs), the more recent in 2013.<sup>60</sup> NAT also published with BHIVA in 2009 guidance on how to provide high quality and continuous HIV care to people in immigration detention.<sup>61</sup> In the more recent survey we asked about care provided for the year 2011/12 – during which time we found 62 of the 95 cases of people with HIV in the detention estate were African. There is, however, ‘double-counting’ since a proportion will have been in more than one of the reporting centres. The likely figure of HIV positive Africans in that year going through IRCs is more likely to be of the order of 50. The sense of our report is that about half of detainees are removed and about half are either transferred to another centre in-year or go back into the community.

Key issues to have emerged in our 2013 report include:

- Interruptions in treatment on arrival and during stay
- Inconsistent practice in provision of the recommended three months supply of ARVs on removal from the UK
- Shackling both on the way to clinic appointments and during consultations in some instances, and cancelled appointments due to staff/transport needed for some other priority
- Poor record keeping at some IRCs
- Poor notification to the HIV clinic of removal, transfer or release.



**Evidence demonstrates the difficulty in coping with the uncertainty and the length of time it takes the Home Office to make immigration decisions has led to issues with both physical and mental health, with episodes of depression and hopelessness, and in a few instances psychosis.**

60 NAT. (2013) ‘HIV Care in Immigration Removal Centres’

61 NAT/BHIVA. (2009) ‘Detention, Removal and People living with HIV’





One significant difficulty has until recently been the fact that healthcare in IRCs was commissioned by different commissioners, depending on location, with a high turnover in providers. From April 2013 NHS England will begin taking over commissioning responsibility for the entire immigration detention estate and NAT has had very productive discussions with the NHS England team on the need to take account of our survey findings and develop a national service specification which addresses these problems.

It is one thing to work to ensure HIV treatment and care in IRCs is of comparable quality to that available to those in the community. But that does not address the policy question of whether or not it is right to remove people to countries where access to ARVs is inadequate or compromised. At one meeting with a local African support group NAT attended there was a strong message that NAT should campaign against such removals. African men and women with HIV clearly feel particularly concerned at the prospect of removal given their dependence on life-saving treatment. AHPN's 'Destination Unknown' campaign has highlighted some of the issues.

In summary, only a very small number of African men and women with HIV are going through Immigration Removal Centres. This is not though to dismiss the seriousness of the issues for those who are in IRCs and the need to address them urgently. Moreover, the wider impact of poor treatment in IRCs on the sense of security amongst Africans in the UK and trust for authorities must be taken into account.

### Recommendations

41 Research is needed into the numbers of African people living with HIV who have an immigration application being considered by the Home Office, and the numbers who have no recourse to public funds.

42 NHS treatment and care should be free of charge for all people actually living in the UK, irrespective of residency status. In particular, and most urgently:

- Wales and Northern Ireland should as a priority exempt HIV treatment and care from NHS charges (as is the case in England and Scotland)
- The denial of immigration applications to those with NHS debt should end
- There should be no extension of NHS charges to primary care or emergency care
- GPs should not have discretion to refuse registration of those with undocumented residency status when they have room on their lists.

43 Guidance needs to be implemented which keeps dispersed asylum seekers within their current clinic area if asylum support accommodation is available in that area. There should be a reasonable interpretation of proximity to one's clinic. Where no asylum support accommodation is available (as we understand is the case in London) short-term emergency accommodation should be provided for situations where immediate dispersal would mean dangerous interruptions to treatment but the alternative prospect is homelessness. Home Office officials need to be reminded of and adhere to guidance.

44 NHS England should agree a service specification which secures consistent high quality HIV treatment and care across the detention estate. This should include timely and confidential access to clinical consultations, no interruptions to treatment, efficient handovers of clinical information when people enter or leave a detention centre, and provision of at least three months' supply of ARVs for those removed from the UK.

45 There should be the universal offer on an opt-in basis of HIV tests in Initial Accommodation Centres and the routine offer of HIV tests in line with BHIVA and NICE guidelines in Immigration Removal Centres – with prompt referral for those diagnosed HIV positive into high quality HIV treatment and care.



# G

# SOCIAL CARE

## Ageing and HIV

Though Africans living with HIV are currently more likely to be younger than the overall age profile for all people with HIV in the UK (17% are over 50, compared with 25% overall), the issue of black African men and women ageing with HIV was raised in discussions. Many were very isolated and lacked appropriate support. It was very hard to get through a social care assessment (the Fair Access to Care assessment known as FACS) and be deemed eligible for local authority assistance. With increasing mental and physical health issues and some having to deal with matters such as mobility impairment or dislike of large crowds, there was a real danger of isolation leading to serious deterioration in well-being.

## Adults living with HIV from birth

Thanks to the successes in reducing mother-to-child HIV transmission, it is believed that the cohort of children and young people living with HIV from birth will reduce significantly in the coming years. But what has to be acknowledged is that adults who have been living with HIV from birth will continue to have distinct HIV-related needs to those who have acquired HIV in their maturity. There are 1,603 people living with HIV in the UK who acquired their HIV from mother-to-child transmission<sup>62</sup>. The vast majority of this group are black African men and women. Some of the distinctives are therapeutic and clinical – for example, significant numbers having to move on to second or third line therapies. Others are psychological, having had to live with a stigmatised condition from birth, having had to become sexually active in that context and with criminalisation of HIV transmission as a threat, having had to navigate issues of secrecy and disclosure within family, with sexual partners and at school and with friends. We were told many have grown up without stable family support networks – they may, for example, have been brought up by an ‘auntie’ because they lost their birth family at a young age – that auntie

<sup>62</sup> PHE HIV Data, 1. National HIV Data Surveillance Data Tables, People living with HIV and accessing care: Table 15.



moves away and a young adult is left to cope alone. For many there are issues of basic living skills. Some have chaotic lifestyles and there are issues around clinic attendance and adherence. It is likely that many will have ongoing social care needs. Social care departments will need to draw on experience and best practice developed by HIV clinics and voluntary sector organisations such as Body and Soul.

### Intergenerational challenges for African communities

Many respondents told us that there is an issue of tensions between the parental generation in African communities who had migrated to the UK and their children born here – they have had, of course, very different experiences. Issues of HIV in the family and the tensions around disclosure and speaking about the condition simply add further pressure on what is often a complex and difficult situation anyway.

### Appropriate social care support

There was comment on the decreasing number of specialist HIV social workers. There is still, however, significant HIV-related social care need where trained and expert social workers need to understand the particular challenges and issues around living with HIV. One respondent suggested that voluntary sector providers might usefully employ trained HIV social workers who can be drawn upon by generic social care departments from a number of local authorities to meet such needs – this would ensure such expertise was flexibly available without requiring one local authority to employ an HIV specialist social worker full time.

We were told there was poor knowledge of their rights amongst black African men and women living in destitution, for example the rights of children. There was also a generalised fear of presenting to the authorities linked both to HIV and migration status. In NAT's report on 'The impact of social care support for people living with HIV', whilst ethnicity was not analysed as a distinct issue, it was clear that fear of breaches of confidentiality around HIV status was a significant deterrent for many patients to be referred to their local social care department,<sup>63</sup> and that many of the patients expressing such fears are black African.

### The importance of voluntary sector support

We were told that a voluntary sector organisation may well be the only place outside the HIV clinic where an individual is able to talk about their HIV and receive support around self-esteem and seeing the potential of their future lives. A stable organisation becomes an alternative community for those who avoid what would otherwise be their usual support systems because of fear of stigma. It was important for there to be integrated care pathways between HIV clinics, social care and voluntary sector support, but they were not always in place. NAT is currently developing a briefing which will collate some of the evidence around the value of open access social care, predominantly delivered by voluntary sector organisations, and around how they meet social care need effectively.

It is of course striking, given the levels of social need described in this report, that outcomes for African men and women for some key clinical indicators (e.g. proportion on treatment with an undetectable viral load) are very good, and as good for African men and women as everyone else. This is an indication of how effective the support services historically in place are in preventing people in such circumstances from failing in adherence and clinic attendance. The continuing good HIV-related outcomes for African people in great need is the best argument possible for the impact and value of these support services. Key services include peer support, counselling, support around family/children needs, and advice on benefits, housing and immigration.

<sup>63</sup> NAT. (2011) 'The impact of social care support for people living with HIV', p.7



A particular problem at the moment is the lack of clarity as to who should commission these services in the new commissioning landscape post-April 2013. Whilst some funding has always come from local authority social care budgets (both from the AIDS Support Grant when that ring-fenced budget existed and more recently from the overall local authority grant which has as one of its elements a calculation for 'HIV/AIDS Support'), much of the funding came from NHS Primary Care Trusts (PCTs) until their abolition in March 2013. It is not clear who will pick up the commissioning of these services going forward – some are being commissioned from local authority public health budgets, a few Clinical Commissioning Groups have got involved, there is debate as to whether NHS England has a role. If everyone has a role, the risk is that in practice no one does. A number of support services are under threat despite the evident need. Work is currently underway to develop a national commissioning framework for sexual health, HIV and reproductive health, to address precisely these sorts of issues of fragmentation, responsibility and accountability. We hope this process might help address the problem.



**A stable voluntary sector organisation becomes an alternative community for those who avoid what would otherwise be their usual support systems because of fear of stigma. It is important for there to be integrated care pathways between HIV clinics, social care and voluntary sector support but they are not always in place.**



## Recommendations

46 The welcome recent attention given to ageing and HIV at the level of both policy and services should identify the specific needs of older black African men and women living with HIV and how to meet those needs.

47 Social care departments should understand the distinct pressures, experiences and needs of adults who have lived with HIV from birth and seek expert professional support, for example from HIV clinics and the voluntary sector, in meeting those needs.

48 In considering social care needs of African men and women living with HIV, the challenges of family life need to be understood in the context of inter-generational tensions which may occur between first and second generation migrant communities.

49 HIV expertise is needed in the delivery of social care – if there are fewer HIV specialist social workers employed, local authorities need to demonstrate how generic services can meet the multi-faceted, specific and complex needs identified in this report. Generic social care departments should receive training in basic HIV information and sensitivity, including around stigma and confidentiality. Voluntary sector organisations are one valuable resource which local authorities could and should draw on.

50 More should be done by HIV clinics and the voluntary sector to inform African men and women with HIV of their rights to support. They should be encouraged to take full advantage of their legal right to get from

their local authority social care department an assessment and comprehensive signposting to options for support. There are limits to the support that local authorities are able to provide to people who are currently subject to immigration control (people with No Recourse to Public Funds).

51 Open access support services for people with HIV, historically often funded by the AIDS Support Grant until its abolition or by PCTs until their abolition, have been an integral element in the support of people with HIV, including black African men and women, especially those in poverty. These services must continue and to that end:

- the national commissioning framework for sexual health, HIV and reproductive health services should identify clear commissioning responsibilities for such services
- the evidence-base for the need for and effectiveness of such interventions should be disseminated and further developed
- there needs to be better integration between clinical, social care and voluntary sector services for people with HIV, including black African communities.



# H

# MENTAL HEALTH AND TB

## Mental health

Poor mental health was described by many African men and women living with HIV. This was attributed in significant measure to the isolation that HIV stigma brings and the stresses of the immigration system and not having enough to live on. Mental health services are accessed sometimes within the HIV clinic, sometimes from voluntary sector organisations and sometimes from NHS mental health services.

From December 2009 to January 2010 NAT held three focus groups, in partnership with Positively UK (then Positively Women), George House Trust and GMFA, as part of our project looking at psychological support services for people living with HIV.<sup>64</sup> Participants at the George House Trust focus group were exclusively black African and there were also black African women participants in the Positively UK focus group.

Anxiety and depression were reported from all three focus groups as well as the challenges of new diagnosis and disclosure of status. Stigma contributed to poor mental health and low self-

esteem and for black African participants the immigration system added to such self-esteem issues, especially the inability to work legally and earn one's own income, and this was felt to be an area where more support is needed. There was discussion of thoughts of suicide and reference in the black African focus group to the use of alcohol as an 'escape'. Alcohol was turned to by some out of unhappiness at not being able to fulfil community expectations – for example the man as the breadwinner. Fear of removal from the UK profoundly affected some individuals' mental health. Others have pointed out to us that it is not only stigma which fosters poor mental health but also the loneliness which for many is part of the migration experience.

Participants in all of the groups talked about needing some form of support with managing relationships with partners, family, friends and community, whether it be support with disclosure, help at times of crisis such as relationship breakdown, or support with forming relationships. There was reference to the difficulty in negotiating safer sex, especially where one was economically dependent on one's partner.

64 NAT. (2010) 'Psychological support services for people living with HIV', see in particular Appendix – for a more recent study see Positively UK. (2013) 'States of Mind: Improving mental wellbeing in the HIV community'



“ **The distinct and real needs of black African men should also be addressed, which often link in to mental health issues and culturally-produced views on masculinity which are profoundly affected by an HIV diagnosis.** ”

Black African participants in this study also spoke of frustration at long waiting times and bureaucratic referral procedures for mental health services; some spoke of an apparent requirement that the mental health issue be demonstrably related to HIV before a referral could be made, and for one participant inability to afford transport to the counsellor who was at some distance. It should be added, however, that many spoke positively of counselling once received and how helpful it had been.

Such ‘formal’ psychological support, whether provided by the voluntary sector or clinical services, was especially valued by black African participants, many of whom had concerns about trusting informal support structures such as friends and family because of HIV stigma and fears around breaches of confidence. Peer support groups were greatly valued, where advice could be got from others with greater knowledge and experience of HIV, as were virtual forums where people could be met in similar situations. There were mixed feelings about the church as a source of support. Some could be very helpful, others could be judgemental and reinforce stigma.

There was a sense in our focus groups and in the expert seminar we also held on this subject that some HIV clinicians could do more to check how the patient was doing in terms of their mental and emotional well-being.

More recently, some good experiences of mental health services were reported by participants at Positive East focus groups as part of their ‘Positive Lives’ project, but also some poor and chaotic services with long waiting times and multiple assessments, especially attributed to cuts in mental health services. There was also a concern that services were there only to address crises, with little or nothing available to meet lower level needs and act preventively and holistically.<sup>65</sup>

It is clear that all people with HIV have elevated mental health needs<sup>66</sup> but there are specifics to that need amongst black African men and women, which include the impact of the immigration system, the use of alcohol, issues of disclosure and

65 Positive East. (2013) ‘Positive Voices’

66 See ‘Special Issue: Mental Health Considerations in HIV and AIDS’ eds. Sherr, Harding and Catalan. (2011) *Psychology, Health and Medicine*, 16(5)



relationships in the family context, and the distinctive aspects of stigma within African communities. In addition, black African men and black African women will have specific and different needs relating to their genders.

We have a separate section in this report on black African women but the distinct and real needs of black African men should also be addressed, which often link in to mental health issues and culturally-produced views on masculinity which are profoundly affected by an HIV diagnosis.<sup>67</sup> One London study found that black African men were those amongst people living with HIV with the highest rates of suicidal ideation.<sup>68,69</sup>

It was agreed by many that more research is needed into the mental health needs of black African communities in the UK. There was discussion of attitudes to mental health within African communities. On the one hand, we were told that experiences of depression, anxiety and difficulty coping are simply put down to 'life', to be endured, and that mental health issues were always thought of in terms of serious psychotic illness. On the other hand, some thought a change of culture was beginning to occur within African communities and services available from voluntary sector services (such as Positive East, who employ a clinical psychologist) and from NHS services are valued.

AHPN have recently published an important study of 'The Mental and Emotional Wellbeing of Africans in the UK'.<sup>70</sup> The report includes findings from a survey of 100 African men and women in the UK (this was not a survey of black African men and women living with HIV – it does not appear respondents were asked about their HIV status). They found that financial concerns and worries were a principal trigger for individuals' mental health and wellbeing problems. Other significant triggers were immigration issues, health problems and relationships and family. Over 50% of respondents said they would look outside of their family for support.

There has been recent progress at a policy level in identifying the mental health needs of people living with HIV. Following on from NAT's report on 'Psychological support services for people living with HIV', there was the development by BHIVA, the British Psychological Society (BPS) and MEDFASH of 'Standards for psychological support for adults living with HIV'. These are referenced both in the service specification agreed by NHS England for HIV specialised services and in Standard 6 'Psychological care' of the BHIVA Standards of Care for People Living with HIV'. This is of course an essential foundation for service development and improvement – but they need to be implemented. They were published just as financial austerity started affecting planning and budgets and it is not clear how consistently they have been implemented. We need to make the case for these services even in these financially straitened times.

67 Doyal L et al. (2009) "'You are not yourself": Exploring masculinities among heterosexual African men living with HIV in London' *Social Science and Medicine* 68:1901-1907

68 Sherr L et al. (2008) 'Suicidal Ideation in UK HIV clinic attenders' *AIDS*: 22(13):1651-1658

69 Doyal L et al. (2009) "'You are not yourself": Exploring masculinities among heterosexual African men living with HIV in London' *Social Science and Medicine* 68:1901-1907

70 AHPN. (2013) 'The Mental and Emotional Wellbeing of Africans in the UK'.





### Tuberculosis

Eighteen percent of the 8,963 TB cases reported in 2011 in the UK were amongst black African men and women.<sup>71</sup> TB is particularly associated with migrants from Africa and from the sub-continent. It is mainly concentrated in large urban areas, and in London especially which for 2011 had the highest percentage of new cases (39%) and the highest burden of disease (44.9 per 100,000).<sup>72</sup> Rates of TB in London are higher than in any other capital city in Western Europe.

TB is one of the most common AIDS-defining illnesses in the UK. African people with HIV are disproportionately affected by HIV/TB co-infection. The incidence of TB among people living with HIV in 2010 was 10.9 per 1,000 among black African heterosexuals compared with 3.1 per 1,000 amongst white heterosexuals with HIV (and 0.14 per 1,000 among the general population).<sup>73</sup>

Tuberculosis is therefore an HIV policy issue for black African communities in the UK.

There are significant rates of HIV/TB co-infection. Information on co-infection is hard to gather because the additional confidentiality around HIV makes matching of data difficult. A recent study in the journal *AIDS* suggests that almost 1 in 10 (9.4%) of heterosexual adults living with diagnosed HIV in England and Wales between 2002 and 2010 were also diagnosed with active TB. 84% of the people identified in the study were black African.<sup>74</sup> TB incidence amongst people with HIV is decreasing over time. This decline in incidence is welcome though it should be noted that this is not a decline in absolute numbers of people being diagnosed with TB and HIV, but a decline in the percentage rate because of the increase in the overall number of people living with HIV. A significant number of co-infections continue to occur.

TB is an infectious bacterial disease and an airborne infection. The majority of people who breathe in TB bacteria do not become unwell. They either clear TB completely or hold it in a dormant state, known as latent TB infection (LTBI). Latent TB cannot be passed on to others but it can become active and be passed on if the immune system becomes compromised.

HIV greatly increases the likelihood of developing active TB. People co-infected with HIV and TB are 21 to 34 times more likely to develop active TB disease than those without HIV. TB also progresses faster in people living with HIV and is more likely to be fatal if left undiagnosed or untreated (TB is curable with antibiotics). Taking treatment also prevents people with active TB passing it on to others. Late HIV diagnosis is a significant issue because a low CD4 count increases the risk of severe extrapulmonary TB such as lymphatic or meningeal TB.

Effective ART also prevents latent TB progressing to active TB – a further reason to see prompt HIV testing and diagnosis as a key anti-TB intervention.

The main policy issue is the prompt diagnosis of both TB and HIV since late diagnosis poses such risk in terms of morbidity and death. One problem is that different clinical bodies have slightly different recommendations in relation to HIV and TB testing for relevant patients. For example, the NICE clinical guideline on the diagnosis and management of TB states that all patients with TB should have risk assessments for HIV testing. By contrast the BHIVA/BASHH UK National Guidelines for HIV Testing recommend, following the WHO - universal HIV testing for patients diagnosed with TB. Evidence suggests there has been improvement in HIV testing in TB clinics but a BHIVA 2011 survey of PCTs found that still only 77% of TB clinics were implementing routine offer of the HIV test (rising to 85% amongst clinics in high HIV prevalence areas). Where the test is offered studies find very high take-up. But it is clear there are still missed opportunities for HIV testing amongst TB patients.

71 HPA. (2012) 'TB in the UK: 2012 Report'

72 NAT. (2013) 'HIV/TB co-infection in the UK'

73 HPA. (2013) 'HIV in the United Kingdom: 2011 Report', p.19

74 Rice B et al. (2013) 'Decreasing incidence of tuberculosis among heterosexuals living with diagnosed HIV in England and Wales', *AIDS* 27(7):1151-7



For patients diagnosed with HIV, BHIVA recommend a screening process to determine the need for testing for latent TB. Whilst current guidelines recommend testing for latent TB in patients coming from high endemic countries, a recent study found little evidence that this was in fact taking place. That study found a substantial number of heterosexual adults in England and Wales being diagnosed with TB more than six months after their HIV diagnosis and conclude that 'active TB could have been prevented in some cases had testing and treatment for latent TB been a routine part of initial assessment at the time of diagnosis'.<sup>75</sup>

Public Health England are rolling out a Latent TB Infection (LTBI) screening programme. There are challenges in terms of linking those at risk to primary care and to ensure community engagement to avoid TB-related stigma. In London there has also since 2005 been a 'find and treat' programme which involves a specialist outreach team as well as peer supporters and which has a mobile X-ray unit working in every London borough. This programme screens about 10,000 people a year and it would be useful for them to screen for HIV at the same time, given the number of people with undiagnosed HIV they most probably come into contact with.

### Recommendations: Mental health

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- 52 Further research is needed on the mental health needs of black African men and women living with HIV in the UK, and on the services and interventions which prove effective in supporting their mental and emotional health and well-being.

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- 53 Local authority commissioners should commission voluntary sector and/or community/peer support services, which provide essential and accessible level 1 psychological support for many black African men and women living with HIV.

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- 54 Alcohol services need to be sensitised to possible need amongst black African communities, including those living with HIV.

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- 55 Local authorities need to work with the NHS to implement the BHIVA/BPS/MEDFASH national standards for the psychological support of adults living with HIV and Standard 6 of the BHIVA Standards of Care for People Living with HIV.

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- 56 Audit is needed of the current implementation of the BHIVA/BPS/MEDFASH national standards for psychological support of adults living with HIV.

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- 57 Immigration policy and processes, and related barriers to employment and benefits, need to be reformed [see Immigration section of this report] to end the destructive and stigmatising impact on people's well-being and mental health, for example provision of the right to work after six months stay in the UK.

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<sup>75</sup> Rice B et al. (2013) 'Decreasing incidence of tuberculosis among heterosexuals living with diagnosed HIV in England and Wales', *AIDS*, 27(7):1151-7



### Incidence of TB in the UK, 2010

Among black African heterosexuals with HIV

10.9 per 1,000

Among white heterosexuals with HIV

3.1 per 1,000

Among the general population

0.14 per 1,000

### Recommendations: Tuberculosis<sup>76</sup>

- 58 Consistent recommendations need to be agreed amongst BHIVA, the British Thoracic Society and NICE on testing for TB and HIV.
- 59 Further work is needed to secure universal HIV testing in TB clinics.
- 60 Current recommendations to test all HIV patients for LTBI from highTB-endemic countries should be consistently implemented, and explicit consideration be given by BHIVA to the proposal that LTBI testing be routinely undertaken for those newly diagnosed.
- 61 Blood Borne Virus (BBV) testing, including HIV testing, should be introduced into the London Find and Treat service.

<sup>76</sup> For a full set of recommendations see: NAT (2014) 'HIV/TB co-infection in the UK'



# STIGMA AND DISCRIMINATION

An issue repeatedly brought up in discussion was the high level of stigma and discrimination experienced by African people living with HIV, both internalised stigma and stigma within African communities, as well as wider social prejudice. Discrimination involves being treated worse as a result of a particular characteristic. Stigma is less about treatment and more about attitudes – it is a socially constructed shaming of particular characteristics or identities.

In 2004/05, the East London project looked at experience of HIV-related discrimination<sup>77</sup> and found that once number of years since diagnosis and body showing signs of living with HIV were taken into account, there was no difference between gay men and black African heterosexual men and women in experience of discrimination. Nearly a third of people living with HIV said they had been discriminated against because of their HIV status. Of this number almost a half said it had been from healthcare workers (especially GPs, dentists and hospital staff outside the HIV clinic). For black African women and for gay men HIV-related discrimination was associated with having suicidal thoughts and depression.

More recently the People Living with HIV Stigma Index gathered information from 867 people living with HIV across the UK.<sup>78</sup> They did not collect information on ethnicity but did on migration status – 276 respondents were migrants – 195 women and 81 men, living mainly in London, Manchester and Leeds. Apart from seven of the men, all were heterosexual. It can be assumed, given the demographic profile of the HIV epidemic in the UK, that the vast majority of migrant respondents were of black African ethnicity.

51% of the men and 54% of the women had disclosed to their current partner (the respective percentages were 60% and 42% where the partners were co-habiting or married). People with HIV have a right to privacy and autonomy in relation to the disclosure of their status, although in law if there is a risk of transmission to one's sexual partner, prior disclosure of status is a key defence should transmission occur and a complaint be made. Experiences of breaches of confidentiality when HIV status was disclosed to family members or partners is a key deterrent to disclosure, even to a loved one. But non-disclosure may render the person with HIV at risk of prosecution and, more fundamentally, deprives that person of their key

77 Elford J et al. (2008) 'HIV-Related Discrimination Reported by People Living with HIV in London, UK' *AIDS and Behavior*, 12(2):255-64

78 See 'Give Stigma the Index Finger!' – Initial findings from The People Living with HIV Stigma Index in the UK 2009



source of emotional and psychological support in relation to an issue which may well at times be very hard to manage alone.

Felt stigma was common:

- 59% of men and 48% of women said they felt guilty about having HIV
- 68% of men and 66% of women reported low self-esteem
- 75% of men and 72% of women said they could be the subject of gossip
- 63% of men and 46% of women feared abuse.

People employed strategies to avoid stigma including self-isolating from friends, avoiding social gatherings and deciding not to have sex. For women especially there was also the decision against (more) children. Just over a fifth of both men and women reported being denied healthcare as a result of their HIV status in the preceding 12 months, including from dentists. There was evidence that significant proportions of migrant respondents were unaware of their rights under UK law and policy.

The Sigma Research study 'Plus One' undertook qualitative research amongst 60 black African men and women in sero-discordant relationships (44 were HIV positive and 16 were HIV negative). The paragraph in the Executive Summary on 'External Influences on the Relationship' bears quoting in full:

'Community-level stigma related to HIV was a major concern for most of those taking part. It negatively influenced the social support that people with HIV and their partners were willing and able to access from traditional sources, such as family or friends. Many had not disclosed their own or their partner's HIV status to children they cared for, which meant keeping a difficult secret in the family home and adding unseen pressure on the relationship. Those who had experienced rejection tended to lose self-confidence, and as a result were often profoundly isolated. While in a few instances, friends, family or faith leaders were supportive, it was common to be reliant on professional support services to help cope with everyday life. Support groups at local HIV charities in particular offered an opportunity to be open and

honest about the nature of HIV in their relationships and to share experiences and gain advice from people in similar circumstances.'<sup>79</sup>

A number of studies and reports testify to this continuing challenge. Positive East's report 'Positive Voices' states that participants in their focus groups 'noted that because of stigma they often felt as if they had to hide their HIV status, hide or shy away from social situations or were unable to develop friendships, relationships and social networks. This caused and compounded feelings of isolation ... Participants also noted being shunned or disowned by friends, family and community as a result of disclosing or having their HIV status disclosed'.<sup>80</sup>

One issue linked to stigma and discrimination was trust in the confidentiality of health services. Such fear of disclosure and its consequences impedes access to services and especially HIV testing. This was raised, for example, at our meeting with the Ffena Executive Committee.

An important qualitative study of the experience of HIV stigma among both black African and gay communities in the UK was 'Outsider Status', undertaken by Sigma Research in 2004. It is especially valuable for the insights provided into multiple stigma and discrimination. Black African men and women living with HIV experience stigma and discrimination not just related to their HIV positive status, but also to their status as migrants and as black African. HIV prejudice, racism and xenophobia combine and interact to exert significant burdens and pressures.

In the Outsider Status study 'African respondents described racism and racial segregation in Britain as a matter of routine'.<sup>81</sup> This was especially felt in smaller towns and rural areas, and in the British media, which fuelled gross and hostile oversimplifications about 'asylum seekers'. There was significant experience of barriers to services and hostile attitudes and assumptions. Overall many respondents spoke of a feeling of powerlessness.

<sup>79</sup> Sigma Research. (2001) 'Plus One Study'

<sup>80</sup> Positive East. (2013) 'Positive Voices', p.7

<sup>81</sup> NAT/Sigma Research. (2004) 'Outsider Status', section 2.1.1



In relation to HIV status, a large majority of 'Outsider Status' respondents 'felt that the majority of the British population believed that all African people have HIV or AIDS'.<sup>82</sup> They believed this exacerbated racism and anti-African feeling among the British.

The study took place at around the time of the first criminal prosecution for reckless HIV transmission. 'Many African men and women felt that the criminal justice system was being used to target and vilify African men with HIV. They argued that by allowing the complex matter of HIV transmission to be focussed upon by the courts in this way, with prosecutions aimed at African male asylum seekers, all African men with HIV would be regarded as guilty by association'.<sup>83</sup>

There was a strong sense amongst participants in the 'Outsider Status' study that public education campaigns about HIV would decrease HIV stigma. This opinion continues to be reflected in reports on African communities' views and in the discussions NAT has had. In surveys of public opinion undertaken for NAT by Ipsos MORI there is a clear association between being better informed about HIV and having more supportive attitudes and fewer negative judgements towards people with HIV. However, it is not clear whether there is a causal relationship between these two facts. More research would be useful here. But it makes sense at least to say that some manifestations of stigma, for example assumptions around infectiousness or imminent death, would reduce if there were better knowledge of the facts in the wider population.

A common complaint was the experience of both racism and HIV stigma and discrimination within the NHS. This is the most common setting for the experience of discrimination, where of course people may well be or feel especially vulnerable. Midwifery was one context where culture clashes seem to occur around non-disclosure of HIV status to sexual partners. Some midwives out of a misplaced sense of public health obligation criticise such non-disclosure, putting immense pressure on the mother to disclose, and even involving authorities such as social services or the police.



**Black African men and women living with HIV experience stigma and discrimination not just related to their HIV positive status, but also to their status as migrants and as black African. HIV prejudice, racism and xenophobia combine and interact to exert significant burdens and pressures.**

<sup>82</sup> *ibid.* section 2.2.1

<sup>83</sup> *ibid.* section 2.2.2



Stigma, we were told, has to be challenged in the NHS, and bodies such as Health Watch involved and energised in such a process.

Many respondents said that education about HIV was central to any anti-stigma efforts. Others said more work was needed to develop a more nuanced and detailed understanding of stigma in African communities. And there was a need for greater resources to go towards health advisors and psychologists to meet these stigma-related needs.

It was pointed out that one of the main impacts of stigma was the social isolation it brings – and that the Government was beginning to realise the toll such isolation took on society as a whole. In the 2013/14 Adult Social Care Outcomes Framework is a new indicator of the ‘Proportion of people who use services and their carers, who reported that they had as much social contact as they would like’. The Framework document explains, ‘There is a clear link between loneliness and poor mental and physical health. A key element of the Government’s vision for social care, set out in the Care and Support White Paper is to tackle loneliness and social isolation, supporting people to remain connected to their communities and to develop and maintain connections to their friends and family’. Whilst for the moment the indicator is limited to the social isolation of those who use social care services, the Government acknowledges the wider harm isolation can bring and aims to develop a population-based measure of loneliness. It is therefore important that local authorities recognise the need to address stigma if they are to meet the new social care outcome indicator in the Adult Social Care Framework.<sup>84</sup>

More broadly, many respondents felt that more should be done by national and local government to address HIV stigma, and current inaction was contrasted with efforts around mental health such as the ‘Time to Change’ campaign on mental health stigma. The lack of action on HIV stigma in England is a direct result of a failure to develop a cross-cutting national strategy for HIV, despite this being a UK Government commitment in the UN.

It is good by contrast to see a focus in Scotland’s Sexual Health and Blood-Borne Virus Framework 2011-2015 on the elevated stigma experienced by many people living with HIV in African communities. One of the five outcomes in the Framework is ‘A society whereby the attitudes of individuals, the public, professionals and the media in Scotland are positive, non-stigmatising and supportive’.<sup>85</sup> This has catalysed and resourced important work in Scotland to address HIV stigma.

A number of themes recur in discussion of stigma experienced by black African men and women living with HIV:

- The role certain churches/mosques, and in particular faith leaders, can play in exacerbating stigma (and conversely addressing stigma should they wish to)
- The relationship between stigma and poor understanding of both the effectiveness of HIV treatment and the extremely good prognosis of people living with HIV who adhere to such treatment
- The impact of stigma on social isolation and mental health, and on the possibility and safety of disclosure of HIV status to sexual partners
- The importance of HIV support organisations and services to address the needs of black African men and women in the context of such isolation and community stigma, supplying often the only safe place where people can be themselves and discuss relevant concerns and issues
- The lack of structured and effective anti-stigma interventions amongst black African communities, and the need for a strategic approach to address this issue.

84 Department of Health ‘The Adult Social Care Outcomes Framework 2013/14’

85 The Scottish Government. (2011) ‘The Sexual Health and Blood-Borne Virus Framework 2011-2015’



### Recommendations

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- 62 Further research should be funded into current experience of HIV-related discrimination and stigma (including multiple stigma and discrimination) amongst black African men and women.
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- 63 Research should be funded into attitudes to HIV amongst black African men and women not diagnosed with HIV.
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- 64 A national strategy is needed for HIV which has as one of its key goals the elimination of HIV-related stigma and discrimination.
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- 65 Consensual recommendations, with leadership from Public Health England and with cross-government support, need to be agreed as to what may constitute effective anti-HIV stigma strategies and interventions at national and local levels.
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- 66 There is a particular problem around the experience of both HIV stigma and racism/xenophobia in the NHS. This should be explicitly and urgently addressed by HealthWatch and NHS England, with training, awareness raising and complaints and disciplinary procedures put in place to change this culture.
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- 67 Greater efforts should be made to disseminate information about HIV, HIV transmission and the effectiveness of treatment. This information should be disseminated at a population level in areas of high prevalence (for example, across the whole of London), and also amongst groups most affected by HIV, such as black African and MSM communities.
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**A common cause of complaint was the experience of both racism and HIV stigma and discrimination within the NHS. This is the most common setting for the experience of discrimination, where of course people may well be or feel especially vulnerable.**





- 68 The felt experience of HIV stigma in black African communities is inextricably linked to and compounded by experience of racism, xenophobia and anti-migrant discourse. The experience and fear of HIV stigma amongst black African men and women living with HIV will only reduce as they also experience a decline in prejudice relating to their ethnicity and migration status. Local authorities with significant black African populations must take a lead in 'changing the narrative', in council publications, activities and services, welcoming, celebrating, exploring and encouraging the contribution of African men and women to their community.
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- 69 The Royal College of Midwives should address experiences of HIV stigma and discrimination experienced by women living with HIV.
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- 70 Faith groups and faith leaders have an important role in challenging and reducing HIV stigma, and in modelling appropriate respect and support for people living with HIV. High-level political approaches to some of the most attended churches from both national and local government leaders should foster such engagement.
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- 71 Local authority commissioners should commission support services to address the social isolation resulting from HIV stigma within African communities, and thus meet one of the key Adult Social Care Framework Outcome Indicators.
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J

# BLACK AFRICAN WOMEN

It has been known for some time that the HIV epidemic in Africa is 'gendered' in terms of transmission, with women particularly at risk. This has to date been reflected in UK new diagnoses amongst black African communities as so many of those diagnosed acquired their HIV before migration to the UK. Whether this continues once most HIV diagnoses are of UK-acquired infection remains to be seen.

Of the 40,251 total HIV diagnoses in the UK amongst black Africans, 14,588 were men (36%) and 25,660 were women (64%). In any consideration of the policy response to the HIV epidemic amongst Africans in the UK this gender dimension should be noted and addressed. The balance between male and female diagnoses has shifted over time. In 2003 34% of new African diagnoses were men, and 66% women; in 2012 this had changed to 41% men and 59% women.

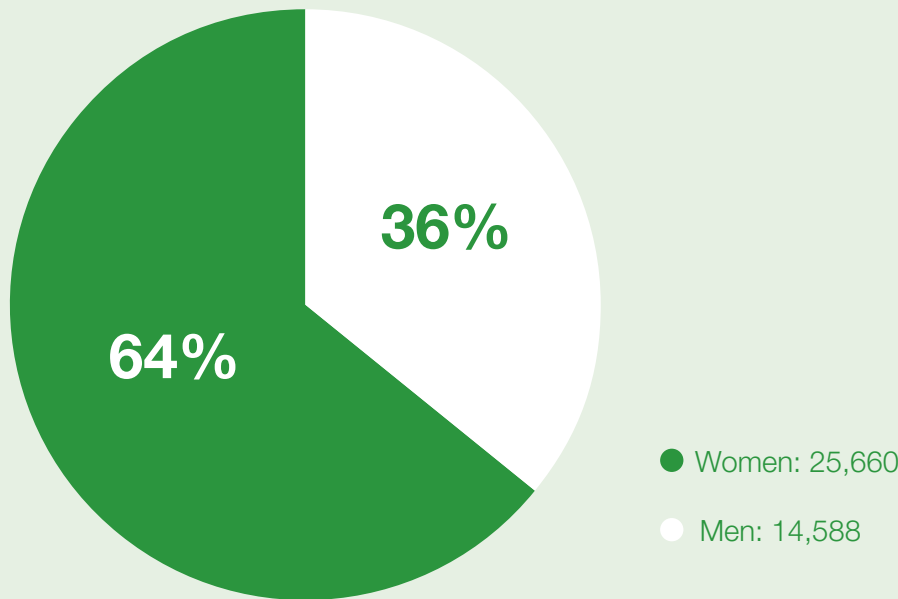
This gendered dimension to the HIV epidemic means that any policies which particularly address the needs of black African communities inevitably also particularly affect black African women. But we cannot assume an automatic benefit. The gendered aspects of need and how policy relates to such need must consistently be taken into account and mainstreamed into policy advocacy.

An important qualitative study of African women living with HIV in London – 'My Heart Is Loaded' – looked in 2001 at the experiences of 62 women from 11 different countries.<sup>86</sup> The majority have experienced at least one traumatic event in their lives such as rape, the murder of a family member or partner, direct experience of HIV-related death and ill health of close relatives and friends. About a third of them were asylum seekers at the time of the study. Motherhood was a significant issue, with a desire to conceive but also concerns about the health of children and sexual partners. There were difficulties raising children often in poverty and as single parents without adequate childcare support and there was the anguish for some of not living with their children, some of whom were still in Africa. They faced the challenge of being a migrant and the poverty and poor housing (often with children) which we know to be the common experience of migrants to the UK going through the immigration system. There was depression and anxiety and periods of feeling unwell linked to their HIV status.

86 Doyal L et al. 'My Heart is Loaded: African women with HIV surviving in London' The Health Foundation, Positively Women, QMUL, THT. See also 'Anderson J et al (2004) 'Women from Africa living with HIV in London: a descriptive study', AIDS Care, 16(1):95-105



### Total HIV diagnoses among black Africans in the UK



The HIV clinical services were greatly valued as were voluntary sector organisations (though there were some women too tired or too afraid of gossip to attend such groups). Faith was especially important though this was in the context of considerable fear of how their HIV status might be received in their congregations.

Of course many of these issues resonate with other sections of this report – poverty, fears around disclosure, asylum issues and poor housing, the importance of faith, stigma and discrimination – these are issues common to both black African men and women living with HIV. They are all, however, experienced by black African women as black African women – with, for example, specific beliefs about and expectations for women around religious example, family roles, relationships, responsibility for children, the obligation to be resilient. Support services have to be literate in the gender-related dimensions of these many needs, offering spaces for women to help each other, providing support around family life and disclosure (or non-disclosure) in intimate relationships.<sup>87</sup> Commissioners also need to address the specific needs of African women with HIV in their Joint Strategic Needs Assessments (JSNAs).<sup>88</sup>

Have things moved on since ‘My Heart is Loaded’ in 2001? More recently in 2011, ten years after ‘My Heart is Loaded’, Sigma Research published their Plus One study which looked at HIV sero-discordant relationships among black African people in England. Many of the problems identified a decade earlier remain true today – fears around disclosure, and experiences of hostility; in many cases verbal assault or complete rejection from partners when disclosure occurs; fear of abandonment by an HIV negative partner, difficulties in their relationships and sex lives. In particular, the study found ‘A significant number of women ... (both with and without diagnosed HIV) seemingly occupied a position of limited power within their relationships, which made it difficult for them to attain happiness’.<sup>89</sup>

NAT held a roundtable on Women and HIV in 2012 where one important theme was the importance of widening the opportunities for women to test for HIV. The PozFem report ‘Women, HIV and Sexual Health’ also focuses on this question. This is not to decry the immense success of ante-natal testing in diagnosing women living with HIV. It would be wrong, however, to rely solely on this intervention to reduce late diagnosis amongst black African women. Many women at the NAT roundtable and

<sup>87</sup> The LASS Women’s Programme is one example of such support

<sup>88</sup> see Positively UK and Women’s Health & Equality Consortium. (2013) ‘Commissioning Effective Services for Women living with HIV’

<sup>89</sup> Sigma Research (2012) ‘Plus One Study’, see Executive Summary



in the PozFem consultation spoke of the trauma of receiving a positive diagnosis during pregnancy. And of course there will be many women living with undiagnosed HIV who will not become pregnant. There was a call for the implementation of the routine testing recommendations outlined in the preceding section of this report – this is perhaps an underappreciated reason to improve routine HIV testing in the NHS, to diagnose more women with HIV outside the ante-natal clinic, where they may find it less difficult to cope with the new diagnosis and feel more in control of the process. It is a gender-sensitive approach to HIV testing.

It is essential that HIV positive women enjoy the same sexual and reproductive rights as other women, and that those rights are fully met, to a high standard. An issue for many women living with HIV has been access to assisted conception to ensure there is no transmission risk to an HIV negative sexual partner. PozFem in an overview of policy issues mentioned the ‘major hurdles’ in finding accessible and affordable assisted conception services if you are living with HIV.<sup>90</sup> Since PozFem’s analysis guidance has developed taking account of the preventive impact of HIV treatment, which enables ‘natural’ conception with almost no risk to the HIV negative partner. NICE in 2013 published a revised clinical guideline on fertility which takes account of treatment as prevention where the male sexual partner is HIV positive.<sup>91</sup>

In 2010 NAT surveyed public knowledge and attitudes to HIV. We asked whether people thought the following statement was true, ‘There are no effective ways of preventing a pregnant mother with HIV from passing HIV on to her baby during pregnancy and childbirth’. Twelve percent were certain this was true, 34% felt it was true and a further 26% did not know. Only 7% were (correctly) certain this was false and 20% felt it was false.<sup>92</sup> This is an ignorant public context in which HIV positive women have to make their conception choices. Women told PozFem of a sense of disapproval even from some healthcare professionals as well as a minority of readers of an HIV activist magazine around the desire to conceive. We have heard others



**The THT ‘HIV and Poverty’ report found 43% of applicants to the Hardship Fund were black African women despite constituting only 23.3% of the population of people diagnosed with HIV.**

90 PozFem UK ‘Women, HIV and Sexual Health in the UK’

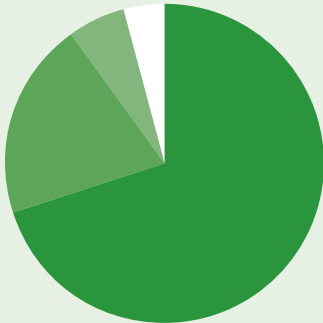
91 NICE Clinical Guideline 156 ‘Fertility’ 2013 see section 1.3.10

92 NAT. (2011) ‘HIV: Public Knowledge and Attitudes, 2010’, p.16



### Homerton Hospital HIV clinic female service users - Survey of Intimate Partner Violence

Of 198 service users:



● African	70%
● Black and not born in Africa	20%
● White	6%
● Other	4%

Of all respondents:



● Had experienced intimate partner violence (IPV) over their lifetime	52%
● Had experienced IPV in the last year	14%
● Had experienced IPV while pregnant	14%

speak of similar disapproval around accessing contraception, as though the person with HIV should not be having sex at all, or only with a condom.

Sadly, this ignorance can exist also within African communities affected by HIV. In the Plus One study, over half of those interviewed questioned whether it was possible to have HIV-free children if one partner had HIV, while a few still held concerns about whether sex (even protected) could ever be safe enough to prevent them from acquiring HIV. It would seem unlikely that these issues had not been covered in the HIV clinic – but there is clearly a problem of communication for many people, confirmed by some of the respondents we spoke to. AHPN organised a conference in September 2012 on African Women and HIV which agreed some specific asks, including, ‘When of reproductive age, we need better information about our treatment options and access to safer conception and contraception services’. Linked to that was a call ‘for health professionals to ensure they communicate effectively with us, ensuring all relevant information is given and understood and that we are meaningfully involved in decision-making’.<sup>93</sup>

The inclusion in the BHIVA Standards of Care for People Living with HIV 2013 of Standard 8 on ‘Reproductive Health’ is very welcome, including auditable outcomes around documented discussions, care pathways, care plans, reporting requirements and surveys of patient experience.

One of the quality statements in Standard 8 states, ‘All mothers known to be HIV positive should have access to the full range of interventions which have been shown to reduce the risk of onward HIV transmission, including free infant formula milk for those who are unable to afford it’. However, free formula milk is not consistently available across the UK. We have heard of some difficulties for some African women living with HIV who are destitute or extremely poor (often because they have no recourse to public funds) in accessing free formula milk.

Another matter which has recently received overdue attention is the experience of gender-based violence amongst HIV positive women. Homerton Hospital surveyed by questionnaire 198 women HIV clinic service users – 70% of respondents were African, 20% black and not born in Africa, 6% white and 4% other. Of respondents 52% had over their lifetime experienced intimate partner violence (IPV), 14% had experienced it in

93 AHPN/Ffena. (2012) ‘African Women and HIV’



the previous year, and 14% when pregnant.<sup>94</sup> IPV could take the form of humiliation, fear, rape or physical assault. There was no association with immigration or socioeconomic status, educational background or substance misuse. Associations were with younger age, with experience of mental health problems and being black but not African. But of course given that a large majority of respondents were black African it is clear that in this study IPV was clearly experienced by significant numbers of black African women also.

Respondents spoke of violence in the context of disclosure of HIV status, of difficulties negotiating safer sex, and in relation to economic and housing dependence. Violence might also take the form of threats to disclose the women's HIV status if she did not comply with the demands of the sexual partner. There were also threats to accuse women of criminally transmitting HIV to the sexual partner or others. In many instances these acts should be understood as an example of hate crime. Whilst above all else an issue of rights and dignity, there is a harm additionally around HIV prevention as the fear of violence prevents disclosure and the ability to have the safer sex you might want, this of course being true whether the woman is HIV positive or not.

The Sophia Forum undertook a piece of work exploring the potential for a national investigation into violence as a cause or a consequence of HIV for women in England.<sup>95</sup> They found few organisations which support people with HIV are collecting data on women's experience of gender based violence (GBV) and few GBV support organisations collected data about women's HIV status. They identified a need for far more data collection and research on the issue. The authors of the Homerton study recommended 'universal screening' for IPV amongst women attending HIV clinics including ante-natal care, and greater awareness raising of IPV amongst healthcare professionals. The Sophia Forum recommended further mapping of support services available for women with HIV who experience GBV, the development of good practice guidance for support services on how best to meet these needs, training

packages to help challenge GBV cultural norms, multi-sectoral collaboration, and research, for example to identify how best to screen for GBV and in what settings.

We would also restate the gendered aspect of HIV-related poverty so starkly evidenced in the recent report from THT on 'HIV & Poverty' where, as has been cited earlier in this report, 43% of applicants to the Hardship Fund were black African women despite constituting only 23.3% of the population of people diagnosed with HIV. The report cites as probable reasons for this elevated need among black African women the lower socio-economic status of people from BME communities, experience in some instances of gender-based violence, and 'costs for caring for children', particularly where they may be separated from the father.

### Recommendations

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- 72 Routine HIV testing in the NHS, as recommended by BHIHVA, BASHH and NICE, should be implemented to support the experience of women around HIV diagnosis.
  - 73 Guidance on needs assessments should be available to local authorities around the support needs of people living with HIV which includes specific and discrete attention to the needs of women living with HIV, including black African women.
  - 74 BHIVA should in the near future audit HIV clinics against Standard 8 'Reproductive Health' in the Standards of Care for People living with HIV. NHS England commissioners of HIV specialised services should ensure service specifications and their implementation meet Standard 8 on 'Reproductive Health'. The current development by BHIVA of Patient Reported Experience Measures (PREMS) should consider inclusion of measures around reproductive health advice, support and services for women living with HIV.
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94 See British HIV Association 'HIV Medicine' Volume 13 Suppl 1 April 2012 Dhairyawan R et al 'Intimate partner violence in women living with HIV attending an inner city clinic in the United Kingdom: prevalence and associated factors'

95 Sophia Forum. (2012) 'HIV + GBV'



**We have heard of some difficulties for some African women living with HIV who are destitute or extremely poor (often because they have no recourse to public funds) in accessing free formula milk.**

75 All local authorities should have arrangements in place to fund free formula milk for HIV positive mothers unable to afford it, to support them in avoiding breast feeding their newly born children.

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76 Further research is needed on the prevalence of gender-based violence amongst women living with HIV, including black African women.

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77 Work should be undertaken to secure clinical and HIV sector consensus on how best to screen for gender-based violence amongst women living with HIV – even in advance of such a consensus, HIV and ante-natal clinics and relevant voluntary sector organisations need to be alerted and sensitised to this issue.

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78 Police and prosecuting authorities need to be trained in the specific issues relating to gender-based violence and HIV. There should be wider appreciation that gender-based violence against a woman living with HIV can be hate crime and should be treated as such in the recording, investigation and prosecution of such crimes. There should be an understanding that non-consented disclosure of someone's HIV status or the threat to do so may be a criminal offence, as may be malicious allegations around reckless or intentional transmission of HIV.

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K

## BLACK AFRICAN MSM

It is of course wrong to characterise the black African HIV epidemic in the UK as exclusively heterosexual. The tendency to do so is itself discriminatory and marginalising for black African MSM. There were, in 2012, 94 black African MSM diagnosed with HIV, the highest number ever and 3.1% of the total number of MSM diagnosed that year – and since the beginning of the epidemic 863 black African MSM have been diagnosed with HIV.

As we shall see, there is an issue as to the degree of under-reporting of MSM sexual activity amongst black African men. The statistics need, therefore, to be treated with caution, especially in estimating the extent of HIV prevalence and incidence amongst black African MSM. Nevertheless, 'Mayisha II' found that 5.8% of the black African male respondents reported same-sex partners only.<sup>96</sup> In Bass Line 2008-09 exclusive homosexual attraction was reported by 3.7% of male respondents.

Respondents were also asked about sexual partners in the last year.<sup>97</sup> 3.5% of male respondents said they had had only same-sex partners but a further 7.8% of men said they had both male and female sexual partners in the last year. Like all studies there

are limitations around the sample, but they do demonstrate significant rates of same-sex sexual behaviour amongst black African men.

There has been little research done on the experiences of black African MSM. A piece of qualitative work was done by Homerton University Hospital with a small sample of eight black African MSM and published in 2007, entitled "I count myself as being in a different world": African gay and bisexual men living with HIV in London'.<sup>98</sup>

Many of the issues faced were common to other African men and women with HIV, for example isolation from family, fear of death, and in some instances poverty and fears relating to immigration status. But being gay or bisexual and African also brought additional challenges. For example, fears of removal to their country of origin were not only around access to HIV treatment and HIV stigma but also fear of persecution or even death as a result of their sexual orientation. Fears to disclose and experience of social isolation, already substantial as a result of having HIV, were

96 Sadler K E et al. (2007) 'Sexual behavior and HIV infection in black-Africans in England: results from the Mayisha II survey of sexual attitudes and lifestyles', *Sex Transm Infect*, 83:523-529

97 Sigma Research. (2009) 'Bass Line Survey: 2008-09', section 2.1

98 Doyal L et al Homerton University Hospital NHS Foundation Trust. (2007) 'I count myself as being in a different world': African gay and bisexual men living with HIV in London'





compounded and complicated further by homophobia within African communities and rejection linked to their sexual behaviours.

Some participants regretted the lack of services or groups specifically for black African MSM though it was acknowledged there was an issue of whether enough people would want to attend such groups. A further element of social isolation was the attitude within their churches/mosques to same-sex sexual behaviour – it was considered sinful. Again there is this double-stigma and isolation as a result of being gay as well as having HIV. Overall, there are accounts of ‘constant juggling required to balance different aspects of the men’s lives ... The tensions between being African and being gay were especially acute and sometimes provoked negative feelings of a life lived in secrecy’.<sup>99</sup>

The MESH project analysed a national sample of ethnic minority MSM, including 76 black African MSM. It provides useful information in a number of areas. Black African MSM were the ethnic group most likely to say they were bisexual (33% compared with an overall average for MSM of 14%) and to have had sex with a woman in the previous 12 months (17% compared with 9% overall). They had the lowest percentage (shared with some other BME groups) on being in a relationship with a man (25% compared with 40% overall).

Black African MSM were significantly more likely than MSM overall to believe (rightly) that new HIV treatments made people with HIV less infectious (39% compared with 18% overall). They were more likely to have had an HIV test. The MESH study found that ‘The odds of self-reported HIV infection in MSM from all black ethnic groups combined were similar to those of white British MSM in both univariable and multivariate analysis’. In their study 10.7% of black African MSM reported being HIV positive compared with 12.7% of white British MSM. The researchers accept that this is a convenience sample but, given the high rate of HIV

“ There was discussion of the ‘triple whammy’ of homophobia, racism and HIV stigma, and the toll this took on the lives and well-being of black African MSM. Such pressures were immensely isolating and there was a real need for voluntary sector mobilisation specifically for black African MSM, and for those in that group who are living with HIV.

<sup>99</sup> Doyal L et al Homerton University Hospital NHS Foundation Trust. (2007) ‘I count myself as being in a different world’: African gay and bisexual men living with HIV in London’, p.18



testing amongst black MSM, did not believe that there is significant undiagnosed HIV in this group compared with white British MSM.<sup>100</sup>

There was no difference between different ethnic groups of MSM analysed as to the percentage who reported unprotected anal intercourse in the previous three months. This has also been reported in other countries such as the US where assortative sexual mixing within ethnic groups has been identified as one factor in the elevated levels of HIV amongst African American MSM when compared with white MSM. In the UK, however, it does not seem clear that HIV positivity rates are significantly higher amongst black African MSM than the overall MSM population. Whilst there is more assortative sexual mixing amongst black MSM in the UK than would have been the case were their partners chosen at random, it remains the case that the very significant majority of sexual partners of black MSM are white British.<sup>101</sup>

The project also analysed attitudes amongst ethnic minority MSM to sexual health clinics. There is a high satisfaction rate amongst black African MSM in the service received in sexual health clinics. There was, however, a degree of elevated concern, when compared with white British MSM, for example, at confidentiality in the clinic and the risk of other people in their community finding out about their sexual orientation. Whilst the paper authors noted there were limitations relating to the relevant question, it was also the case that ‘men in most ethnic minority groups were more likely than white British men to say that the person they saw in the clinic assumed that they had sex with women’.<sup>102</sup>

Discussions held by NAT in preparation for this report confirmed much of what has emerged from the above research. A key issue was the detachment of sexual identity from sexual attraction/behaviour. Even the term ‘bisexual’ was questioned – many black African MSM would identify as ‘straight’ but have sex with men, whilst

also having or wanting sex with a woman and to start a family. This has implications both for prevention and for treatment and care.

It was claimed that greater understanding of HIV and how transmission occurs are important – men are simply told ‘use a condom’ and if they fail to do so then give up on safer sex. We need to inform men not just about this one prevention tool but about HIV itself and wider issues of health promotion and safer sex.

As was noted in the MESH study, there was a sense that black African men in sexual health clinics could too often be assumed to have sex exclusively with women, and whilst questions of sex of partners might be routinely asked, it was probably necessary to identify some more effective and acceptable questions to elicit more candid responses. Assuming incorrectly that a man had not had sex with another man could well mean an inappropriate or inadequate sexual health screen. Furthermore, it contributes to an under-assessment of the scale of need amongst black African MSM.

HIV prevention and health promotion materials for MSM were thought often to be inappropriate for black African MSM. It was claimed that the visuals and language used were very ‘gay identity’ focused, and highly eroticised – and that many black African MSM would be uncomfortable picking up or being seen with such literature.

There was discussion of the ‘triple whammy’ of homophobia, racism and HIV stigma, and the toll this took on the lives and well-being of black African MSM. Such pressures were immensely isolating and there was a real need for voluntary sector mobilisation specifically for black African MSM, and for those in that group who are living with HIV.

100 Elford et al. (2012). ‘HIV Infection Among Ethnic Minority and Migrant Men Who Have Sex With Men In Britain’, *Sexually Transmitted Diseases*, 39(9):678-686

101 Ibid

102 McKeown E et al. (2012) ‘The experiences of ethnic minority MSM using NHS sexual health clinics in Britain’, *Sex Transm Infect*, 88:595-600



For second generation young black African MSM growing up in the UK, disapproval within the family of being gay could mean either they left home voluntarily or were forced out, and as a result were very vulnerable to exploitation, homelessness and poverty.

In terms of engaging black African MSM both for prevention and support purposes, it was felt that more could be done with gay businesses and clubs which do specifically cater for black MSM. There were also organisations such as the UK Lesbian and Gay Immigration Group (UKLGIG) who were supporting many black African MSM as they navigated the UK's immigration processes. It would be good to link up with them around information on HIV and on sexual health services. There would be some black African MSM who have arrived with undiagnosed HIV and who would benefit from an HIV test. More generally, many black African MSM come from countries where same-sex sexual behaviour is criminalised – the idea that there might be health services for them and that you could tell a doctor or nurse that you had sex with other men was unimaginable.

### Recommendations

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- 79 More research, and with larger cohorts or samples, needs to be funded and conducted amongst black African MSM in the UK, disaggregated from other black, African and MSM groups.
  - 80 In particular, further research is needed on HIV prevalence and incidence, and on prevention needs amongst black African MSM.
  - 81 Appropriate prevention materials should be available for men who have sex with men but who do not identify as gay or bisexual and may be uncomfortable with 'gay scene' media.
  - 82 BHIVA and BASHH should work with relevant communities and organisations to determine how within sexual health and HIV clinics to improve identification of and support for black African MSM through appropriate questions and approaches.
  - 83 Public Health England should work with HIV Prevention England and MSM health promotion organisations to determine whether any distinct prevention interventions are needed for black African MSM and, if so, what they might be.
  - 84 Local authority commissioners, especially in areas with significant African populations, need to commission prevention interventions which target black African MSM.
  - 85 Awareness needs to be raised of the sexual health and wider social needs of second generation black African MSM.
  - 86 Further collaboration is needed between HIV voluntary sector organisations, gay businesses which cater for black African MSM and the UK Lesbian and Gay Immigration Group in order to engage black African MSM with prevention and support services.
  - 87 Resources should be made available for community-based services/organisations specifically to provide for black African MSM.
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L

# BLACK AFRICAN YOUNG PEOPLE LIVING WITH HIV

The cohort of HIV positive children and young people accessing HIV paediatric care stands at just over 1,000. Of this group, 80% are identified as black African.<sup>103</sup> Fifty per cent of children and young people living with HIV were being seen for care at London clinics, 39% in the rest of England, 4% in Scotland, 1% in Wales, 5% in the Republic of Ireland, and less than 1% in Northern Ireland. Whilst official projections predict numbers to remain stable for the next five years, it is anticipated that numbers will begin to decline thereafter,<sup>104</sup> if not before. In this section we focus on some of the policy issues relating to young people with HIV, noting that the vast majority of this group are of black African ethnicity and so effective policy in this area will meet the needs of young black African people affected by HIV. We have looked earlier at the prevention needs of young people from black African communities so in this section we will focus on young people living with or affected by HIV.

It is well documented that young people with HIV often have significant needs. There may well be social and economic challenges – we have seen how black African people are disproportionately affected by deprivation – but also sometimes neurocognitive or psychological needs, difficulties in adherence to HIV medication, problems with the immigration system, to name just some of the challenges faced. They may well be in lone parent families and not have access to wider family support structures. There are often issues around ‘secrecy’ of HIV within the family setting which places additional pressures on the young person.<sup>105</sup> This combination of complex needs, in the context both of HIV and of black African ethnicity and migrant experience, can require a great deal of expert support from a number of different services and professionals. In that context we highlight below just a few of the areas where policy action may help improve quality of life.

<sup>103</sup> Collaborative HIV Paediatric Study (CHIPS) Annual Report 2012/2013. Available at: [http://www.chipscohort.ac.uk/documents/CHIPS%20Annual%20Report%202012-13%20final\\_for%20Website.doc](http://www.chipscohort.ac.uk/documents/CHIPS%20Annual%20Report%202012-13%20final_for%20Website.doc)

<sup>104</sup> Collaborative HIV Paediatric Study (CHIPS) Annual Report 2012/2013. Available at: [http://www.chipscohort.ac.uk/documents/CHIPS%20Annual%20Report%202012-13%20final\\_for%20Website.doc](http://www.chipscohort.ac.uk/documents/CHIPS%20Annual%20Report%202012-13%20final_for%20Website.doc)

<sup>105</sup> see for example Campbell T et al. (2013) ‘HIV+ children and their families in the UK’ Perspectives in Public Health



### Sexual and reproductive health

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The need for HIV paediatric services to support the sexual and reproductive health of young people with HIV is specified in the HIV paediatric service specification.<sup>106</sup> HYPnet/CHIVA have also developed 'Guidance on the Management of Sexual and Reproductive Health for Adolescents Living with HIV (2011)'. The guidance clearly states that all PHCP (paediatric healthcare professionals) who are responsible for giving sexual health and relationships advice should receive training. In addition it should be delivered before sexual maturity and as part of a discussion around negotiating and managing relationships, not just the biology of sex and sexual health. Similarly the CHIVA Standards of Care at Standard 8 on 'Sexual Health, Secondary HIV Prevention & Reproductive Health' sets out essential elements of high quality provision.

The criminalisation of reckless and intentional HIV transmission is an especially difficult context within which young people with HIV have to start understanding their sexuality and beginning sexual relations with others. Whilst no case involving a defendant under 18 has as yet come to court, NAT has come across some cases where there are initial police investigations of young people with HIV as a result of a complaint. Given possible criminal liability for HIV transmission, it is clear there is a significant responsibility on services to provide appropriate support.

For young adolescent girls there are challenges around reproductive health and appropriate support around contraceptive choices. For those young people with HIV with learning difficulties or neurocognitive impairments expert guidance will be needed on how to meet these needs.

The CHIVA Standards of Care emphasise the importance of the support being provided not only by the HIV paediatric clinic but also by sexual health services and the voluntary sector, within the context of the Multidisciplinary Team.

Respondents told us that parents also face difficulty talking about sex and relationships at home, whilst recognising that this is an important conversation to be had. There may be particular religious and cultural sensitivities which affect how sex and relationships are discussed at home. These sensitivities may present barriers, but they must also be recognised if parents are to be effectively supported in talking to their children about sex and relationships within the context of HIV.

Respondents also mentioned the increased affiliation of young people of African origin affected by HIV with gangs. This may present significant sexual health and unplanned pregnancy risks due to the culture of sexual violence and other forms of sexual behaviour associated with gang-related activities. The extents to which these behaviours present an HIV transmission risk are unknown within a UK context.

### Social care

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We have already recounted the significant challenges many African families face in terms of poverty and dealing with the immigration system. To that must be added the complexity of addressing HIV within the family. This can include naming of HIV to children living with the condition, and to children not living with the condition, ensuring confidentiality is maintained and negotiating external disclosure, coping with HIV stigma within the family, addressing care responsibilities that fall to spouses and to children – and these are just some of the challenges cited.

There is increasing emphasis on a 'whole family approach' to social care need and recent outcomes from this emphasis have been sections of the new Children and Families Act 2014 which impose statutory duties on local authorities in relation to young carers (which can be very relevant to HIV). There are also provisions in the Care Bill currently going through Parliament for a 'whole family approach' to the assessment and support of adults.

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<sup>106</sup> NHS England – 2013/14 NHS Standard Contract for Specialised HIV Services (Children) – Section B, Part 1 – Service Specifications.



These welcome developments need, however, to be combined with an understanding of how HIV impacts on a family and family relationships, and in particular the needs arising from HIV stigma. There are fewer HIV specialist social workers now employed by local authorities, with most people having to rely on assessments undertaken by generic social workers. This only underlines the need for all social workers to have appropriate training around HIV and its social as well as health impacts, and not just for the individual but for the family unit and its functioning. Joint Strategic Needs Assessments similarly should, in considering HIV support needs for the local population, employ a whole family approach appropriately.

Services need to clearly advertise themselves as 'HIV-competent' and 'HIV-friendly' – to ensure that adults and young people feel confident to describe HIV-related need and that this is properly considered in social care assessments. As was stated earlier, social care departments will also need to navigate the difficult balance of maintaining confidentiality around HIV status for their clients, including within the local authority, whilst at the same time ensuring that colleagues who need to know do know, with service user consent. We heard from some of respondents of the fatigue of having to 'tell your story' repeatedly to different local authority staff and providers.

### Schools and education

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Because of concerns over responses to disclosure of HIV in the family, many schools will be unaware that they have pupils living with and affected by HIV. Whilst there is no obligation and sometimes no need for children or families to name their HIV in educational settings, schools may in fact be well placed to respond to some of the issues and challenges which families face. The forthcoming guidance for school governors, arising from the Children and Families Act 2014, on supporting children with medical conditions, should help to ensure that this takes place. In addition, the Public Sector Equality Duty should ensure that schools respond to the needs of HIV positive children.

Best practice for schools with regards to HIV is outlined in various documents published by CHIVA, NCB and NAT.

A key way for a school to ensure that it is a supportive environment for young people living with or affected by HIV is for HIV to be well taught within the school curriculum. At present HIV is usually taught within SRE (sex and relationships education), which is itself delivered within PSHE (Personal, Social, Health and Economic education) and the National Curriculum for Science – but there is not a clear statutory requirement for all schools across the UK to teach SRE and even where it is taught there are real concerns on variation in its quality. A statutory requirement for key facts about HIV to be taught to all children within SRE is needed, and for such information to include both information on transmission and safer sex, but also the effectiveness of treatment, the realities of living with HIV and the unacceptability of HIV stigma. Young people living with or affected by HIV above all need HIV to be taught as a condition we all live alongside in UK society rather than something which could not possibly be affecting anyone within the classroom. We have heard too many accounts of HIV being taught in a way which a young person living with or affected by the condition finds upsetting and marginalising.

### Young people with HIV and the wider policy agenda

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When considering the policy needs of young people, including those from black African communities, who are living with HIV, we have to acknowledge that it is difficult to ensure their concerns are consistently addressed by policy makers and decision-makers because their numbers are so small.

For example, the Chief Medical Officer in the 2012 report 'Our Children Deserve Better: Prevention Pays', refers to the importance of supporting children and young people with long-term conditions but fails to mention HIV in that context, though especially relevant to the needs the report then sets out.

The reality is that organisations who work with and for young people living with HIV need to identify policy opportunities and then get the needs of this group of people on the agenda of national and local government, as well as the Children's Minister, the Children's Commissioner, the Chief Medical Officer and many other relevant organisations and officials. They should also engage with wider young people's



advocacy charities to build effective alliances and get the needs of young people with and affected by HIV referred to and taken into account. There is already good practice in this area with impressive work on HIV by the Children's Society, the National Children's Bureau and Barnardos amongst others.

Whilst the numbers of young people living with HIV are small nationally, and of course even smaller in any one local authority, the 'whole family approach' cited above, which now has statutory support, does provide an important chance to get the needs of this group attended to. The number of families living with HIV i.e. with at least one family member living with the condition, is significant, especially in high prevalence areas, and of course the majority of them will be black African. Thus the whole family approach can ensure that the needs of young people both living with and affected by HIV are appropriately captured and addressed when they arise within the family setting.

### Recommendations

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- 88 The implementation of standards set out in the HYPnet/CHIVA Guidance on the Management of Sexual and Reproductive Health for Adolescents Living with HIV (2011) and CHIVA Standards of Care Standard 8 should be a matter of priority. These services should be appropriately commissioned and resourced, with effective coordination between NHS England and local authority commissioners. We recommend regular audits of sexual and reproductive health support, with account taken of evidence such as rates of STIs and unintended pregnancies in this group.
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- 89 HIV clinics should ensure specific support for parents so that they are empowered to have appropriate conversations about sex and relationships within the context of HIV, with their children. Such support should be culturally sensitive and tailored to the individual needs of each parent.
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- 90 All social workers need some basic training around HIV, and in that context should be taught about how HIV impacts on the family unit and the social care needs which then arise, including caring responsibilities, disclosure and 'HIV naming' issues, intra-family tensions, and risks of social isolation. The FACS assessment for local authority social care support needs to adopt a whole family approach and take account of the impact of HIV within the family unit.
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- 91 Both SRE (Sex and Relationships Education) and PSHE (Personal, Social, Health and Economic education) should be a statutory requirement in all schools. In relation to HIV, guidance should require that all transmission routes and safer sex are appropriately taught, as well as the effectiveness of HIV treatment and the unacceptability of HIV stigma. Most importantly, schools should be advised that there is a significant possibility that one or more young people at their school have HIV or are from a family affected by HIV – so HIV must be taught not as something 'out there' that happens to others, but as a condition which we all live alongside in UK society.
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- 92 HIV-related organisations should bring the needs of young people living with and affected by HIV to the attention of decision makers when they are considering relevant generic policy issues. They should also form alliances with broader young people's advocacy organisations to ensure the needs of these young people are addressed.
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- 93 Local authorities should within their Joint Strategic Needs Assessments (JSNAs) adopt the whole family approach as part of their needs assessment around HIV – this will ensure the needs of young people both living with and affected by HIV are captured and addressed as they arise in the family setting.
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- 94 NAT should provide a briefing on the whole family approach and its potential to address the needs of families and young people living with and affected by HIV.
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# AFRICAN COMMUNITY LEADERSHIP AND CAPACITY

## Research

Some respondents said that more needs to be done to translate effective policies and services from African countries to the UK, including lessons around scale and style of intervention and use of the media. TAC (the Treatment Action Campaign) in South Africa was held up as one good example from whom we could very possibly learn.<sup>107</sup>

We were also told that more research should be commissioned into the HIV-related needs of African men and women in the UK – too often voluntary sector organisations were expected to undertake research themselves into their service users and the impact of their services from limited resources. The recent successful and innovative commissioning by Lambeth, Southwark and Lewisham of research into the ‘chemsex’ phenomenon amongst MSM was cited as a speedy and valuable initiative which should be mirrored for African communities. Important work has been done in the past by the African HIV Research Forum and it would be good for similar initiatives to be taken forward in coming years.

## Capacity of the African community sector

Many spoke of the important role of black African people themselves in any effective response to HIV in African communities, and in this context the importance of African community groups. We heard, however, that even before the current financial crisis this sector had been ‘shaky’ in terms of financial and organisational stability, and that since 2008 a large number of such organisations had folded.

One respondent said that a black-led organisation did not appear to be sustainable with an annual turnover of less than £750,000. There was a real lack of money from black communities going into prevention amongst BME groups – black businesses and philanthropists needed to be identified and challenged to meet these community needs.

<sup>107</sup> For a description of an attempt in the UK to apply lessons from African interventions see Chinouya M and O’Keefe E ‘Pachedu-Zenzele (2008) in the Diaspora: Promoting Sexual Health amongst Zimbabweans in England’, *International Migration*, 46(5)





“ **Some respondents felt that for a step change to take place in engagement of black African men and women on HIV and sexual health issues we also need an effective sector with visible black leadership. This is not to deny the impressive work focused on African communities done by a wide range of more generic HIV organisations.**

Another said there was a real issue with the maturity and stability of the African voluntary sector in the UK. But it is very important to develop such African civic infrastructure. It is such an infrastructure which enables the work you do with one person to have far greater reach and impact in the wider community.

Other African community organisations continued to exist but had widened their initial HIV focus and remit in an attempt to broaden possible funding streams – this could, however, mean that organisations became de-specialised and de-skilled.

It was also claimed that as an increasing number of immigration cases were resolved and people secured residency status in the UK, they began to work all hours and had less time or interest in engaging with community or HIV-related activities.

AHPN has done a great deal at a national level to coordinate and support African community organisations working on HIV, and more recently the Ffena network of African people living with HIV has become an important forum for engaging individuals.

The needs of non-Anglophone communities – for example French or Portuguese speaking – were highlighted. National and local strategies should address these needs and ensure language issues do not become a barrier to accessing services and support.

It was claimed by some respondents that there is a lack of black leadership on HIV issues. Some respondents felt that for a step change to take place in engagement of black African men and women on HIV and sexual health issues we also need an effective sector with visible black leadership. This is not to deny the impressive work focused on African communities done by a wide range of more generic HIV organisations.

It was debated whether African community workers were or were not best placed to meet health promotion needs – it was pointed out that often Africans were suspicious of other Africans, including, indeed often especially, those from their own country of origin, and this was a typical phenomenon in migrant communities. More important perhaps than the community or ethnic origin of a worker was their qualification to do a job well.



It was noted in discussion that there are a very large number of African men and women employed within the NHS and there is potential both for them to benefit from NHS services as they see their value first hand, and also make the NHS a place more welcoming to and supportive of African communities. However, many African healthcare workers report facing inequalities within the NHS and this is something that AHPN has sought to investigate and address.

It was felt there was a failure by the statutory sector to tap the public health resource of the African voluntary sector. The voluntary sector could and should be more robustly integrated into commissioning decisions. The large and integrated sexual health contracts currently being developed and tendered did not seem to have much room for community contribution and some services as a result were falling through the gaps.

There was a call for services to abide by the GIPA principle (Greater Involvement of People living with HIV and AIDS) – the meaningful involvement of people living with HIV in needs assessment and in the design, planning and delivery of services. The diversity of people with HIV, including black African people with HIV, needs to be recognised in the implementation of the GIPA principle. At the African Woman and HIV conference they called for ‘the greater involvement of African women living with HIV, in all areas and at all levels including design, implementation and leadership: as patient representatives, in clinical and social research, in service delivery and in projects’.

A significant issue raised was the lack of effective cross-boundary commissioning, especially in London. Voluntary sector services tend to be open access – people in need are not turned away. In a city such as London people tend simply to travel where they find a service they like and which meets their need – they don’t think in terms of borough boundaries. The result, however, is that voluntary sector services may be short-changed since they might only be paid for those service users with the ‘right’ postcode i.e. those from commissioning local authorities. The voluntary sector organisation itself will in effect be subsidising other local authorities who fail to commission necessary support services.

### Recommendations

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- 95 Funding, leadership and coordination are needed to identify, encourage, catalyse and share research projects around the many issues highlighted in this report, and to translate findings from sub-Saharan Africa to a UK context.

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- 96 Black African philanthropists and businesses should be challenged to support charities meeting the health and wider needs of black African people in the UK. Public Health England and local authorities have a role in forging links and setting out the needs to be met.

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- 97 The capacity of African HIV voluntary sector organisations has recently diminished significantly. Further work is needed from black African communities and organisations to identify the reasons for this and rebuild this sector to promote the well-being of UK African communities.

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- 98 In urban and near-urban areas especially there should be consideration of cross-boundary commissioning of support services for people living with HIV.

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