



Report: July 2010

HIV and black Caribbean communities in the UK



Executive summary

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Black Caribbeans make up 1% of the UK population but account for 3% of people living with HIV. HIV prevalence is over four times higher than in the white population. Despite this, a national black Caribbean HIV prevention strategy does not currently exist.

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- **A national black Caribbean HIV prevention strategy should be developed**, initially focused on London where the majority of the UK's black Caribbean population live. Well-researched, targeted and culturally sensitive HIV prevention interventions for black Caribbean people should also be integrated into broader sexual health promotion efforts in areas of the country that have large black Caribbean communities, particularly London, the West Midlands and the North West.
- Although black Caribbeans may be served by organisations working within the National African HIV Prevention Programme (NAHIP), there are no Caribbean-specific partners in the programme, nor HIV prevention work targeted specifically at black Caribbean people.

In the absence of a national strategy, NAHIP should advocate for and support a stream of HIV prevention work at a regional level, targeted specifically at black Caribbean people.
- Whilst the majority of black Caribbean people living with HIV are heterosexual, about one third are gay men or men who have sex with men (MSM). Black Caribbean MSM are not specifically served in England and Wales' MSM prevention programme (CHAPS).

An assessment of the needs of black Caribbean MSM is needed, and CHAPS should consider introducing a stream of HIV prevention work targeted specifically at black Caribbean MSM.
- Black Caribbeans are disproportionately affected by sexually transmitted infections (STIs).

Regional and local STI prevention campaigns targeting black Caribbean communities are needed; NAT supports the call from the Health Protection Agency (HPA) for an STI prevention strategy for the black Caribbean community.
- HPA data on country of birth is available for only 69% of black Caribbeans.

HIV reporters in clinics should ensure surveillance fields reported to the HPA are complete. High quality data allows the HPA to correctly inform funding decisions on sexual health prevention and promotion, as well as to inform the development and monitoring of prevention and treatment guidelines.¹

- Over a quarter of black Caribbeans (30%) are diagnosed late, after treatment should already have begun. UNAIDS has identified 10 Caribbean countries as having an HIV prevalence of over 1%. UK guidelines for HIV testing state that tests should be routinely offered and recommended to all men and women known to be from a country of high HIV prevalence (>1%).

Clinicians must ensure that Caribbean people from these countries are routinely offered and recommended an HIV test, with repeat testing provided to those individuals most at risk.

- The Department of Health (DH) funds organisations which, as part of their wider work, support black Caribbeans at risk of or living with HIV.

FACT

Whilst the majority of black Caribbean people living with HIV are heterosexual, about one third are gay men or men who have sex with men (MSM). Black Caribbean MSM are not specifically served in England and Wales' MSM prevention programme (CHAPS).

Government / Local Government funding is needed to address key issues for black Caribbeans at risk of and living with HIV, particularly in relation to peer support services. Such funding should cover services to help mitigate concerns around the exceptionally high levels of HIV-related stigma and discrimination which exist in the black Caribbean community.

- HIV support organisations report a distinct culture in the black Caribbean community, characterised by high levels of homophobia and strong religious beliefs. Support organisations report their black Caribbean

clients as being particularly fearful of disclosing their HIV status because of the stigma and discrimination that is known to exist within the community. In contrast to black African people, black Caribbeans living with HIV are reportedly less likely to tap into strong support networks after diagnosis.

Actions to address homophobia and HIV-related stigma and discrimination should be developed for this community through engaging and working in partnership with churches and faith-based organisations as well as voluntary sector organisations and the media.

1. These fields include patient details (Soundex, DoB and sex) ethnicity, date of diagnosis, probable route of infection, probable country(ies) of infection, country of birth, year of arrival and CD4 cell count and date.

Defining black Caribbean

FACT

Black Caribbean people make up approximately 1% of the UK's population: at the last Census in 2001, 565,873 of a total population of 58.8 million people defined their ethnicity as black Caribbean.²

1. Defining black Caribbean

According to the Office for National Statistics, in 2001 the Caribbean classification for black people included the following Caribbean and West Indian islands and also Guyana: Anguilla, Antigua and Barbuda, Bahamas, Barbados, Bermuda, Cayman Islands, Grenada, Guyana, Haiti, Jamaica, St Kitts and Nevis, St Lucia, St Vincent and the Grenadines, and Trinidad and Tobago. For people who choose the category 'Other' and write in their answer for ethnicity questions, those who come from the Caribbean and West Indian islands and also Guyana are allocated to the black Caribbean category, apart from those who describe themselves as Puerto Rican, Dominican and Cuban which are coded as Latin American.³

People can describe themselves as

black Caribbean whether they were born in the Caribbean or in the UK. In the last Census, the proportions of non-White ethnic groups born in the UK generally declined with older age. Amongst black Caribbeans, 83% of those aged 25 to 34 were born in the UK, but only 5% of those aged 45 to 64 were born in the UK. The main countries of birth for the UK's black Caribbean population include:

- England (57%)
- Jamaica (23%)
- Barbados, Trinidad and Tobago, and Guyana (each up to 4%)
- Grenada, St Lucia, St Vincent and the Grenadines, and St Kitts and Nevis (each up to 2%).⁴

The term 'black Caribbean' can be ambiguous: whilst Central and South American countries on the Caribbean coast are generally classed as Latin American, there are minority black Caribbean

populations, for example the Garinagu, living along the coasts of countries such as Belize and Honduras.⁵ Lack of clarity on this issue occurred in relation to the UNAIDS/WHO 2008 report on the global AIDS epidemic: the regional summary for the Caribbean makes reference to Guyana (and the 2007 Caribbean summary mentions both Guyana and Belize), but in statistical reporting sections these countries are grouped within the region of Latin America.

Clinicians responding to the Health Protection Agency (HPA) article *Black Caribbean adults with HIV in England, Wales, and Northern Ireland: an emerging epidemic?*⁶ raised the issue that "ethnicity data as they currently stand are likely to underestimate the size of [HIV] in the black Caribbean population... There is a distinct grey area in self defined black British and black Caribbean designations in our clinic attendees."⁷

The health and race organisations contacted for the purpose of this report took the view that people's ethnicity is self-defined: people who consider themselves to be black Caribbean (or 'African Caribbean' or 'Afro-Caribbean') are so. The definition is not limited to Caribbean islands, and can apply regardless of whether someone originated from Jamaica, or from Barbados, Guyana or Belize.⁸

2. Office for National Statistics (ONS)

3. ONS, personal communication

4. ONS: Table ES03: Usual resident population by sex, country of birth and age group.

5. UNHCR: Minority Rights Group International, *World Directory of Minorities and Indigenous Peoples - Belize:*

Garinagu, 2008. Online, available at: <http://www.unhcr.org/refworld/docid/49749d535d.html>

6. S Dougan, L J C Payne, A E Brown, K A Fenton, L Logan, B G Evans, O N Gill, *Black Caribbean adults with HIV in England, Wales, and Northern Ireland: an emerging epidemic?*, *Sexually Transmitted Infections* 2004;**80**:18-23

7. M Hamill et al, *HIV in black Caribbeans*, *Sexually Transmitted Infections* 2004;**80**:420-421

8. Organisations included the Afro-Caribbean Millennium Centre, Black Health Agency and United Anglo Caribbean Society

Data and epidemiological trends

2. Data and epidemiological trends⁹

2.1 Prevalence of HIV infection in the Caribbean

In the Caribbean the overall HIV prevalence is 1.2%, the second most affected region after sub-Saharan Africa. There were an estimated 230,000 people living with HIV in 2007, 20,000 people were estimated to be newly infected with HIV, and some 14,000 died of AIDS.¹⁰

The most affected country in the Caribbean is currently the Bahamas, where HIV prevalence is 3%, and other countries where prevalence has reached or surpassed one percent include the Dominican Republic at 1.1%, Barbados at 1.2%, Trinidad and Tobago at 1.5%, Jamaica at 1.6%, Belize at 2.1%, Haiti at 2.2%, Suriname at 2.4% and Guyana at 2.5%.¹¹

2.2 Prevalence of HIV infection – diagnosed and overall

The prevalence of diagnosed HIV in black Caribbean communities in England is estimated to be 0.3%, compared to 2.9% in black African communities and 0.06% among the white population. Assuming that one third of black Caribbeans infected with HIV remain undiagnosed, the overall prevalence of HIV infection within black Caribbean communities living

FACT

Just under two thirds (64%; 779) of all black Caribbeans newly diagnosed with HIV between 2004 and 2008 were aged between 20 and 39 years. The median age at diagnosis has increased over the past ten years from 33 years in 1999 to 36 years in 2008. This increase was observed amongst black Caribbean heterosexuals (34 years and 37 years respectively); however amongst black Caribbean MSM there was a decline (32 years and 30 years respectively).

in the UK (population estimated at 599,700) is less than 0.5%.

2.3 New diagnoses of HIV

There have been 2,787 cases of diagnosed HIV in individuals of black Caribbean ethnicity reported in the UK since the beginning of the epidemic in the early 1980s. There was a steady increase in the proportion of black Caribbeans diagnosed annually with HIV from 0.7% (14) in 1985 to 4.3% (135) in 1999, falling again to 3.3% (216) in 2008. Black Caribbeans accounted for 3.3% (1,218) of all new HIV diagnoses between 2004 and 2008 in the UK. In contrast, individuals of black African ethnicity accounted for 46% (16,762) of all new diagnoses and 42% (15,419) were of white ethnicity.

The majority of black Caribbean people in the UK live in London (61%), followed by the West Midlands (15%) and North West England.¹² This is reflected in the areas with the highest numbers of new HIV diagnoses for black Caribbeans: London recorded the highest number (827) between 2004 and 2008, followed by the West Midlands (108) and the North West (52). Over the same period, in London 6,358 new HIV infections amongst individuals of black African ethnicity were reported, 1,660 in the East of England and 1,405 in Yorkshire and the Humber. Corresponding figures for individuals of white ethnicity were: London (5,965), the North West (1,778) and the South East Coast (1,112).

9. All data in this section, unless otherwise stated, has been provided by the HPA. NAT would like to thank the HPA for their contribution to this report.

10. Report on the global AIDS epidemic, UNAIDS 2008

11. WHO and UNAIDS Epidemiological Fact Sheets on HIV and AIDS: <http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epifactsheets.asp>

12. Statistics from ONS

Country of birth was provided for 69% (838) of black Caribbeans diagnosed with HIV between 2004 and 2008. Amongst these, one third (32%, 264) of black Caribbeans were born in the UK, and 61% (514) were born in Latin America and the Caribbean. Of those born abroad, there was a median five year gap between their arrival in the UK and their HIV diagnosis. Of black Caribbeans born in Latin America and the Caribbean, 58% (284) reported their probable country of infection as Latin American and the Caribbean, and 37% (181) reported their probable country of infection as the UK. The corresponding figures for black Caribbeans born in the UK were 12% (28) and 82% (190) respectively.

2.4 Risk exposure

2.4.1 Heterosexual contact

A total of 1,774 black Caribbean heterosexuals have been diagnosed with HIV in the UK since the early 1980s. In recent years the proportion of those diagnosed annually who were heterosexual has increased from 60% (81) in 1999 to 75% (152) in 2008. Six out of ten heterosexual black Caribbeans diagnosed with HIV between 2004 and 2008 were women (523/882). Forty six percent (333) of black Caribbean heterosexuals reported their probable country of infection as Latin America and the Caribbean and 43% (310) as the UK. This

compares with 91% (12,719) of black African heterosexuals who reported Africa as their probable country of infection and 7.6% (1059) as the UK.

2.4.2 Men who have sex with men

The annual number of black Caribbeans who acquired HIV through sex between men has remained steady. The proportion amongst all black Caribbean diagnosed who are men who have sex with men (MSM) has decreased from 36% (48) in 1999 to 24% in 2008 (48) due to the rise in infections in black Caribbean heterosexual men and women. However, the disproportionate impact on this small population has been noted.¹³

The majority of MSM diagnosed between 2004 and 2008 reported the UK as their probable country of infection (72%; 118); this is similar to MSM of white ethnicity with 84% (5663) reporting the UK as their probable country of infection.

2.4.3 Other transmission routes

Other transmission routes for Black Caribbeans remain low. Of those newly diagnosed between 2004 and 2008 1.4% (16) reported their probable route of infection as injecting drug use, 0.3% (3) reported mother to child transmission and 0.3% (3) reported being a blood recipient.

2.4.4 Persons accessing HIV-related care

During 2008, 1,776 black Caribbeans accessed HIV related care (representing 2.9% of all persons seen for HIV care). This compared with 22,282 (36%) persons of black African ethnicity and 31,019 (51%) of white ethnicity. This is a slight increase from 1999 when 2.3% (459/20,099) were of black Caribbean ethnicity. The median age of all black Caribbeans accessing HIV-related care has increased from 35 years in 1999 to 39 years in 2008.

In 2008, 70% of black Caribbeans accessing care were receiving antiretroviral therapy, slightly lower than that reported for black Africans (77%) and individuals of white ethnicity (76%). Amongst black Caribbeans with a CD4 cell count of less than 200 (the threshold at which all patients should be on treatment), 15% (21/141) were not on treatment; the respective figures for black Africans and individuals of white ethnicity were 13% (272/2047) and 14% (314/2248) respectively.

2.4.5 AIDS and deaths

Between 2004 and 2008, a first AIDS diagnosis was reported for 112 individuals of black Caribbean ethnicity. The number of new AIDS cases diagnosed amongst black Caribbeans has declined from a peak of 39 in 2003 to 15 in 2008.

13. F Hickson, HIV epidemic among Caribbeans in Britain: half-gay or half-straight? *Sexually Transmitted Infections*, March 2004, <http://sti.bmj.com/cgi/eletters/80/1/2#59>

Seventy four deaths have been reported for individuals of black Caribbean ethnicity. The number of deaths reported for black Caribbeans has been steady with an average of 14 deaths per year reported.

2.4.6 Late diagnosis

Between 2004 and 2008, 30% (287) of black Caribbeans were diagnosed late with a CD4 cell count less than 200 - lower than black Africans, where 42% (5081) were reported late and higher than individuals of white ethnicity (24%; 2860). Amongst exposure groups, late diagnosis accounted for 24% (50) of black Caribbean MSM, compared to 30% (57) of black African MSM and 21% (1807) of white MSM. The corresponding figures for individuals of heterosexual contact were 32% (224), 42% (4920) and 30% (780) respectively.

2.4.7 Previously undetected HIV infection among GUM clinic attendees

Between 2004 and 2008, amongst 17,000 Caribbean born heterosexual men and women who attended an STI clinic and were tested through the unlinked anonymous programme, 0.6% (representing 97 cases) had a HIV infection that had been previously undetected. Of concern, the unlinked anonymous programme found that 49% [95% CI: 33-64] of the 45 men and 25% [CI: 14-39] of the

FACT

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52 women with HIV infections left the clinic still unaware of their infection. In contrast, despite a higher HIV infection detection rate of 2.7% (813/29,666) the rates of undiagnosed infection amongst African born heterosexual men was 22% [CI 17-27] and 33% amongst women [CI: 29-37]. The corresponding figures for UK born heterosexuals attending STI clinics were 26% [CI: 21-32] for men and 24% [CI: 19-29] for women and a 0.2% (623/324,085) detection rate.

Over the same period and across the same STI clinics, the proportion of Caribbean born MSM with previously undetected HIV infection (7.5%; 22/295) was much higher than amongst UK born MSM 3.2% (852/26759). Similarly to heterosexual men, 50% [CI: 28-72] of Caribbean born MSM left the clinic with their infection remaining undiagnosed (compared to 39% [CI: 35-42] of UK born MSM).

2.4.8 Prevalence of HIV infection in women giving birth

The HIV prevalence of Central American and Caribbean born women giving birth between 2004 and 2008 was 0.67% (94/13,980); the prevalence among African born women was 2.48% (2,750/110,795) and among UK born women was 0.04% (430/974,118).

2.4.9 New diagnoses of sexually transmitted infections

Black Caribbeans are disproportionately affected by sexually transmitted infections (STIs). Between 2004 and 2008, black Caribbeans accounted for over a quarter (27%) of gonorrhoea cases among heterosexuals in sentinel GUM clinics in England and Wales. In comparison, individuals of black African and white ethnicity accounted for 6.4% and 48% of heterosexual cases. Among MSM diagnoses with gonorrhoea between 2004 and 2008, 2.8% were of black Caribbean ethnicity, 1.6% of black African ethnicity and 86% were of white ethnicity.

Key policy area

Between 2004 and 2008, 12% (210/1683) of heterosexuals diagnosed with syphilis were of black Caribbean ethnicity, compared to 11% (179/1683) of black African ethnicity and 56% (947/1683) of white ethnicity. Amongst MSM diagnosed with infectious syphilis the corresponding figures were 2% (108/5380) for black Caribbean MSM, 1% (54/5380) for black African MSM and 90% (4823/5380) for white MSM.

Chlamydia screening is conducted on individuals under 25 years across the UK. Between 2003 and 2008, over 3,700 individuals of black Caribbean ethnicity were tested for Chlamydia of whom 15% tested positive - higher than the proportion found positive among black Africans (10%; 1961) and individuals of white ethnicity (10%; 50,093).

2.4.10 Co-infection

Black Caribbeans living with HIV are less likely than other communities to be co-infected with conditions such as tuberculosis (TB) or Hepatitis C.

A recent study on Hepatitis C in an ethnically diverse group of patients in London noted that there is limited information on the prevalence of and risk factors for Hepatitis C virus (HCV) among HIV patients in the UK. Overall, 9% of the study's participants were HIV-HCV co-

infected. The condition was found to be highest amongst IDUs and lowest amongst heterosexual men and women from sub-Saharan Africa and the Caribbean (under 2%). The actual prevalence was 1.1% for black Caribbeans, compared to 16% among white men and women in the study and 2.4% for black Africans.¹⁴

A paper presented at the 2009 British HIV Association (BHIVA) Conference looked at the demographics of TB patients co-infected with HIV. It found that 93% were born outside the UK and that 80% came from sub-Saharan Africa.¹⁵ TB in black Caribbeans living with HIV is significantly lower than in other ethnicities, with black Africans being most affected. A 2007 study showed that more black African patients were diagnosed with TB than any other ethnicity, with 494 cases out of 5,055 (10%) compared to white patients where 185 out of 13,056 were found to be co-infected (1%) and other ethnic groups, in which 126 of 4,960 (3%) of cases were co-infected.¹⁶

3. Key policy areas

3.1 Stigma and discrimination

HIV-related stigma and discrimination is reported to be particularly strong in the black Caribbean community; HIV support organisations cited it as the main

issue of concern for their black Caribbean service users.

In many islands of the Caribbean, sex between men is criminalised. There are extreme levels of homophobia – particularly in Jamaica – and extensive evidence exists of the persecution of people who are gay or living with HIV. For instance, a recent human rights report notes that homophobia “has resulted in violent killings of persons thought to be gay, lesbian, bisexual or transsexual, as well as stabbings, mob attacks, arbitrary detention and police harassment.” Human Rights Watch have published a report looking at homophobia, violence and HIV in Jamaica and the extreme homophobia of the dancehall music scene’s so-called ‘murder music’ has been reported widely.¹⁷

Such homophobia has an impact on people living with HIV, whatever their sexuality. A report from an HIV support organisation’s focus groups with black Caribbeans include comments such as: “with HIV, because it’s seen as a gay thing, there’s a lot of shame, particularly in Jamaica. If someone finds out they are positive, they’re afraid that everyone will assume they are gay, so it’s best to keep it to yourself.” It has been reported that some women with free access to antiretroviral treatment in the Caribbean “failed to show up for

14. AH Mohsen et al, Prevalence of hepatitis C in an ethnically diverse HIV-1-infected cohort in south London. *HIV Medicine* 2005 May;6(3):206-15

15. Rodger A et al, *HIV prevalence and testing practices among tuberculosis cases in London*. Fifteenth Conference of the British HIV Association, abstract O25,

Liverpool, 2009, reported in NAM at www.aidsmap.com/en/news/A6A920D1-997C-4E4B-A4B9-FFDE244653E4.asp

16. Grant A et al, *TB incidence among HIV-infected Africans in the United Kingdom*. Fourteenth Conference on Retroviruses and Opportunistic Infections, abstract

846, Los Angeles, 2007, reported in NAM at <http://www.aidsmap.com/en/news/6CB9163A-0B6D-40B7-B1A8-4CA397500954.asp>

17. Reported in *Pink News* 8 December 2008: Human rights group criticises Jamaica’s homophobic violence

treatment to avoid the stigma of being identified as HIV positive.”¹⁸

Stigma and discrimination towards people living with HIV have been documented amongst healthcare professionals in the Caribbean. The Caribbean HIV and AIDS Health Alliance report that gay men are reluctant to go to healthcare providers because of homophobic laws and attitudes in the country.¹⁹

A study on HIV-related stigma in health services in the Eastern Caribbean concluded that “socially constructed to be physically contagious and socially deviant, PLHA are scorned by some service providers, especially when they are perceived to be gay or bisexual.”²⁰ As might be expected, people’s experiences in the Caribbean appear to have an effect on their fear of disclosing their HIV status.

For instance, support groups noted a different attitude between service users brought up in the UK and those who have more recently arrived from the Caribbean - the latter are even more fearful of stigma and discrimination, having seen evidence of it at home.

The LIVITY project was the first in-depth study of HIV among black Caribbean people in the UK, involving 250 black Caribbeans living with HIV – ‘livity’ is a Rastafarian word for ‘lifestyle’. Participants in the study were very aware of HIV-related stigma and

“With HIV, because it’s seen as a gay thing, there’s a lot of shame... If someone finds out they are positive, they’re afraid that everyone will assume they are gay, so it’s best to keep it to yourself.”¹⁸

attributed it to “a particularly Caribbean combination of fear of contamination, homophobia and ignorance, reinforced by religious beliefs.” A paper emerging from the study found that HIV-related stigma and discrimination affect HIV positive people “emotionally, mentally, financially, socially and physically” with consequences for disclosure and openness. The paper concluded that interventions specifically addressing stigma and discrimination need to be formulated for the UK’s Caribbean population.²¹

Support groups contacted by NAT in relation to this report described a distinct culture in the black Caribbean community (one calling it a “closed community”) to which high levels of homophobia and

stigma and discrimination are associated, which may differentiate it from some other communities affected by HIV. In addition black Caribbeans living with HIV tend not to access support in the way that other affected communities do. One support worker noted that “the current situation is where other communities [affected by HIV] were 15 years ago – there is much to be done to challenge stigma and homophobia.” Faith is a very important part of Caribbean culture, and there is a need to work with faith groups to challenge stigma and homophobia. Some evidence exists of faith groups supporting people living with HIV, for instance donating hardship funds to HIV organisations. Positively Jamaica has held church based events in

18. Both references: Caribbean facing HIV crisis, April 2006, *Positive Nation* issue 121

19. Reported in *Pink News*, 13 March 2009: Gay men in Jamaica ‘face higher levels of HIV due to discrimination’.

20. Rutledge S et al, AIDS stigma in health services in the Eastern Caribbean *Sociology of Health & Illness*, Volume 31 Issue 1, Pages 17 - 34

21. M Anderson et al, HIV/AIDS-related stigma and discrimination: Accounts of HIV-positive Caribbean people in the United Kingdom. *Social Science & Medicine* 67 (2008) 790-798.

East London to raise awareness of, and funding for, HIV efforts in Jamaica.

Support groups talked of the lack of awareness of HIV amongst black Caribbeans in the UK, particularly amongst heterosexual women. One support worker was shocked at the apparent lack of knowledge of HIV amongst black Caribbean clients who had been living with HIV for years. Others highlighted the need for outreach work, particularly amongst young black Caribbeans, to raise awareness of HIV and of the message that you may be more at risk of HIV when you have STIs. The need for such work for areas outside of London was also highlighted.

3.2 The need for targeted prevention and testing strategies

High levels of risky sexual behaviour have been reported amongst black Caribbeans in the UK, which could have an impact on potential HIV transmission, and many studies have identified the need for targeted health promotion.

A study of ethnic variations in sexual behaviour recorded a significant association between ethnic origin and reported STIs over five years with increased risk in sexually active black Caribbean and black African men compared with white men, and black Caribbean women compared with white women.²² Research on

“The current situation is where other communities [affected by HIV] were 15 years ago – there is much to be done to challenge stigma and homophobia.”

HIV support worker

migrant youth in the UK identified the greatest sexual health support needs among black young people, particularly among black Caribbean young men.²³ Other studies, whilst not specific to black Caribbeans, have noted that black and minority ethnic MSM are significantly more likely to report unprotected anal intercourse with casual male partners.²⁴

However, the MESH Project, the largest survey on ethnic minority MSM in the UK, found similar rates of sexual risk behaviour between ethnic groups.²⁵ Despite this, the project, which surveyed nearly 15,000 white and ethnic minority MSM in the UK, found

variations in the prevalence of HIV infection between ethnic groups. HIV prevalence amongst those who identified themselves as Latin American was highest (17%), followed by black Caribbean or Caribbean/mixed (12%), white British and black African (8-9%), Arab (7%), East European and Chinese (4%) and South Asian (3-4%). However, despite having the lowest prevalence of HIV, South Asians reported the highest rates of unsafe sex (15.5%) in the previous three months compared with black men (14.5% all categories), white British men (13.7%) and men from other groups (11.2%).²⁶

22. K Fenton et al, Ethnic variations in sexual behaviour in Great Britain and risk of sexually transmitted infections: a probability survey *Lancet*, April 2005

23. B Teixeira, *Migrant Youth in the UK*, Naz Project London for AIDS & Mobility Europe, September 2006

24. S Soni et al, Black and minority ethnic men who have sex with men: a London GUM clinic experience, *International Journal of STD and AIDS*, 2008

25. J Elford et al *HIV risk behaviour among ethnic minority men who have sex with men living in Britain*, Mexico 2008, abstract TUPE0315.

26. J Elford et al *HIV risk behaviour among ethnic minority men who have sex with men living in Britain*, Mexico 2008, abstract TUPE0315.

There are cultural barriers to the use of condoms in many black Caribbean communities. One HIV support organisation noted that “at home [in the Caribbean] there is a perception that condoms aren’t for protection, they’re to identify you as a gay man or someone with AIDS. The belief that it isn’t natural to wear a condom is brought from the Caribbean. Men simply don’t wear them, and women don’t negotiate.” A black Caribbean man interviewed for a support organisation’s focus group reiterates this view: “if you want to use a condom people assume something must be wrong. Giving out leaflets about this doesn’t make any difference. We need an effective way of getting the message across.”²⁷

Reports of unprotected sex amongst black Caribbean young people are borne out in a 2006 study of pregnancy in Lambeth, which has the highest teenage pregnancy rate in Western Europe and high rates of STIs and HIV. The study found that teenage mothers in the borough are over-represented in the black Caribbean and mixed black Caribbean white minority ethnic groups compared to the proportion of such groups in the general Lambeth population of teenage women. There is also an over-representation of black

Caribbean women for pregnancy terminations.²⁸ More widely, a study of ethnic variations in sexual activity and contraceptive use noted that amongst sexually active single women, black African and black Caribbean women reported levels of contraceptive use that were lower than those reported by white women.²⁹

Existing prevention programmes do not specifically focus on black Caribbean people as a group which is at particular risk of HIV. There is no dedicated black Caribbean STI prevention programme nationally, in spite of the high level of STIs within this community. The HPA has recommended that a black Caribbean STI prevention strategy should be developed.³⁰

There are currently national HIV prevention strategies in place for MSM (the CHAPS project in England and Wales) and for black Africans (NAHIP), but whilst some black Caribbean people may be served by this work, they are not targeted as a specific at-risk group. CHAPS ran a poster campaign five years ago targeting homophobia in black communities, but have not done any specific targeted work for black and minority ethnic MSM since then.³¹ Most of the NAHIP partners are African-led, but some

of these organisations’ audiences may be black Caribbean people, for instance the Pan African and Caribbean Sexual Health Project (PACSH), run by the Ethiopian Community Centre in the UK (ECCUK).³²

However, there are no Caribbean-specific partners in the NAHIP programme, and at the time of writing NAT was not able to identify any HIV prevention work targeted specifically at black Caribbean people.³³ The Naz Project London does run a prevention peer education project for black MSM which includes black Caribbean MSM (40% of participants are black Caribbean MSM).³⁴

Several clinicians and researchers have acknowledged challenges to increasing the uptake of HIV testing. For instance, Boyd et al noted in 2004 that “future educational campaigns designed to promote the uptake of HIV testing among black Africans and black Caribbeans will need to address the multiple barriers to testing, including misperception of risk, stigma and ready access to testing.”³⁵ In 2009, challenges have been recognised for black gay men including a lack of culturally appropriate and accessible services, poor or limited visibility of black gay men in HIV

27. Closet of the Caribbean, *Positive Nation* issue 121

28. A Mohiddin et al, Life as a league table bottom dweller: teenage pregnancy in Lambeth, *Journal of Public Health* 2006 28(4):304-308.

29. Saxena et al, Ethnic variations in sexual activity and contraceptive use: national cross-sectional survey, *Contraception*, September 2006

30. HPA, *United Kingdom HIV New Diagnoses to December 2008, and Sexually transmitted infections in*

black African and black Caribbean communities: 2008 report

31. Terrence Higgins Trust, personal communication

32. Department of Health, ‘Progress and priorities – working together for high quality sexual health’ Review of the National Strategy for Sexual Health and HIV, 2008’. Available for download at <http://www.dh.gov.uk/en/PublicHealth/HealthImprovement/SexualHealth/index.htm>

33. African HIV Prevention Network (AHPN), personal communication

34. See <http://www.naz.org.uk/news/CatalystProjectInformationLetter.doc>

35. Boyd et al, Ethnic differences in stage of presentation of adults newly diagnosed with HIV-1 infection in south London, *HIV Medicine*, March 2005

prevention campaigns, especially in black and gay media.³⁶

The UK guidelines for HIV testing recommend that tests should be routinely offered and recommended to all men and women known to be from a country of high HIV prevalence (>1%).³⁷ Caribbean people from these countries (currently identified by UNAIDS as the Bahamas, Barbados, Belize, Dominican Republic, Guyana, Haiti, Jamaica, Suriname and Trinidad and Tobago) should be routinely offered and recommended an HIV test, with repeat testing provided to those individuals most at risk.

3.3 Immigration and migration patterns

Migrants are disadvantaged in terms of HIV prevention and treatment. Whilst the majority of black Caribbeans in the UK have spent most or all of their lives here, those born in the Caribbean who have more recently arrived may find themselves in a similar, disadvantaged position to the many black African migrants who are living with HIV in the UK.

HIV support groups noticed differences in their black Caribbean clients depending on their migration status. For instance, they report a different attitude between those with secure status who were brought up in the UK and those who have arrived from the Caribbean more recently. The majority of the latter

are even more fearful of disclosure of their HIV status, due to their experience or knowledge of stigma and discrimination at home. Whilst some groups were supporting clients through the immigration application process (and reporting black Caribbeans suffering from stress which was having an impact on treatment adherence), many other clients were people who had entered the country legally but who have overstayed their visa. Being undocumented and unable to work or access benefits, these people rely on family and friends for accommodation and support, and reported problems with shared living around disclosure of HIV status.

Travel to and from the Caribbean has been identified as a factor in the rise of HIV in black Caribbeans in the UK. The phenomenon is not confined to the UK: migrants travelling to their country of origin were described as a 'bridge population' for HIV transmission in a recent Dutch study, which identified in particular older male travellers of Surinamese and Antillean origin being at high risk for cross-border heterosexual transmission of HIV and STIs.³⁸

For the UK, Green's 2004 paper on the *Emerging Epidemic* noted that "continuing high inward migration from the Caribbean and a high incidence of some bacterial STIs among Britain's black Caribbean communities,

suggests a considerable potential for HIV spread." Another study the same year noted that "the outlook is towards an expansion of HIV infection amongst ethnic Caribbeans in the UK, with an existing pool of infection being fed by travel to and from, or the arrival of new migrants from, a high-prevalence area, together with sexual mixing between visiting/migrating and resident communities."³⁹

3.4 Income and poverty

Black Caribbean individuals in general are already disadvantaged compared with the general population: for instance, 25% of working-age black Caribbean households in the UK are workless, compared to 15% of white British households.⁴⁰ Evidence suggests that some black Caribbeans living with HIV in the UK are living in poverty or with unmet social need.

For example, the Crusaid Hardship Fund, which provides practical and financial support to "people with no-one and no-where else to turn" has seen a marked increase of between 40-50% growth in individuals presenting in hardship and self-defining as Caribbean in 2009. The Fund has four levels of assistance, Level 4 being available only to people with no income whatsoever. 29% (17/59) of the grants to black Caribbeans living with HIV in 2008 were Level 4 support (eight women

36. Dennis Carney, *Black Gay Men's Advisory Group: Presentation on Better Engagement with Black Gay Communities*, SWAGNET network meeting on Sexual Health and Black Britain, March 2009

37. UK National Guidelines for HIV Testing 2008, available at www.bhiva.org/files/file1031097.pdf

38. Kramer M A et al, Migrants travelling to their country of origin: a bridge population for HIV transmission? *Sexually Transmitted Infections* 2008;84:554-555

39. G Green et al, The psychosocial and health care needs of HIV-positive people in the United Kingdom: a review (*HIV Medicine*, 2004)

40. Labour Force Survey, ONS, the data is the average for 2006-2008

TABLE ONE

Source of income	Black Caribbean homosexual men (n=26)		Black Caribbean heterosexual men (n=12)		Black Caribbean heterosexual women (n=20)	
	n	%	n	%	n	%
Salary/wage	16	62	5	41.7	8	40.0
Pension	2	8	1	8.3	2	10.0
Unemployment benefits/ income support	5	19	3	25.0	5	25.0
Incapacity/sickness benefit	1	4	3	25.0	1	5.0
Housing benefits	2	8	1	8.3	5	25.0
Disability Living Allowance	5	19	1	8.3	4	20.0
Council tax benefits	2	8	1	8.3	5	25.0
Free travel passes	1	4	3	25.0	3	15.0

and nine men), and 44% (26/59) were Level 3.⁴¹

A study on social and economic hardship amongst people living with HIV in London concluded that a substantial number of people living with HIV in London faced social and economic hardship, particularly black African and other ethnic minority respondents.⁴² Fewer than half of the black Caribbean and white heterosexual men and women who participated in the project were employed at the time

of the survey, and approximately 40% of black Caribbean heterosexual men and women said they did not have enough money to cover basic needs, compared to around 20% for white heterosexuals (16.4% of the men, 27% of the women).

The study revealed that black Caribbeans living with HIV had a range of sources of income (see table one above) (NB - percentages add up to more than 100% because participants could tick more than one source of income).⁴³

Some HIV support groups report that poverty is a problem for their service users. One group had clients at the end of the immigration process who were destitute, and the stress of their situation had been known to cause problems with their treatment adherence.

A support worker explained that people “don’t look at the long-term effects of not taking your tablets when you have children to look after or when you’re worried about not having a roof over your head.”

41. Crusaid, personal communication

42. F Ibrahim, J Anderson, C Bukutu and J Elford, Social and economic hardship among people living with HIV in London (*HIV Medicine*, 2008)

43. Personal communication, J Elford, for disaggregated figures for black Caribbean MSM

3.5 Support organisations for black Caribbeans living with HIV

There are many organisations across the UK offering support to black Caribbean people living with HIV, though for most of them black Caribbeans comprise a small minority of their service users.⁴⁴ Whilst almost all of the support groups contacted for this report in 2009 had black Caribbean clients for their one-to-one support or casework (in some cases just one or two), most did not run Caribbean-specific peer support services. However, some organisations across the country have recognised the need for black Caribbean peer support, for instance:

Freshwinds in Birmingham has 21 clients (all black-Caribbean) in their Bro-Sis project, the majority of whom are Jamaican and at the end of the immigration process, likely to return or be returned to Jamaica. As well as case work and one-to-one support, Bro-Sis assists with the return to the Caribbean by informing clients what services are available there, how to access medication and contact local support organisations to tell them to expect the person who is due to arrive.

Shaka Services in London report that around 21% of their active casework clients are black Caribbean (all of whom were born in the Caribbean), as well as 14% of their non-casework clients. They

received funding from Lambeth, Southwark and Lewisham PCTs for an HIV awareness programme for black Caribbean communities.

Positive East runs a monthly facilitated support group offering peer support and education for black Caribbean MSM. They have a regular attendance of 10 to 12 black Caribbean clients. Six percent of Positive East's total service users are black Caribbean.

Positively Women ran a monthly facilitated peer support group for black Caribbean women and men for two years, but it closed due to lack of funding. There were 15 group members (12 of whom were Jamaican), with 10 to 12 regularly attending. Whilst 7% of their service users are black Caribbean (70 of 1,000), only that smaller number would come to a support group.

Due to relatively low diagnoses, there is a tendency for black Caribbeans to be expected to access black African, MSM or women's support groups. There is some evidence that black Caribbeans may not wish to attend black African groups (due to cultural differences) and there is a concern that black Caribbeans are increasingly choosing not to access support services at all. This concern needs to be addressed through proper needs assessments for the black Caribbean community and the provision of appropriate and culturally specific services where necessary.

4. Conclusions and priorities for action

Whilst the numbers of black Caribbeans diagnosed with HIV are relatively low in comparison to other communities in the UK, levels of HIV are disproportionate to the size of the black Caribbean population in the UK and continue to rise. The high incidence of STIs and level of risk behaviour attributed to both heterosexuals and MSM, as well as travel to and from high prevalence Caribbean countries, creates potential for further increases in the number of black Caribbeans living with HIV in the UK.

Black Caribbean MSM already have a relatively high HIV prevalence and are particularly marginalised, with high levels of stigma and discrimination that exist for anyone living with HIV in the black Caribbean community. This is compounded by homophobia, particularly in Jamaican communities.

Lack of awareness of HIV, or people ignoring the risks, amongst black Caribbeans are contributing factors in over a quarter of diagnoses being made after HIV treatment should have already begun, and there are black Caribbean people, particularly those with insecure residency status, living with HIV in poverty.

To meet the HIV-related needs of black Caribbean communities in the UK, NAT recommends the following activities as priority:

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44. In 2009 the main support organisations, in terms of the numbers of service users for black Caribbean communities across the country include: Terrence Higgins Trust (with local branches across England and

Wales) and in London Body and Soul, Crusaid, Positive East, Positive Place, Positively Women (now Positively UK) and Shaka Services; in Birmingham AB Plus and Freshwinds (the Bro-Sis Project); in Manchester the

George House Trust and Body Positive North West; and in Scotland Waverley Care (though very small numbers of black Caribbeans living with HIV are known to be in Scotland).

Conclusions and priorities for action

Priority activity	With leadership from
Develop and implement a national HIV prevention strategy for black Caribbean communities, which could be initially focused on London where the majority of black Caribbeans in the UK live	Government, pan-London Government
In the meantime, existing HIV prevention programmes focused on MSM and heterosexuals should consider introducing streams of HIV prevention work targeted specifically at black Caribbeans, and wider sexual health promotion efforts should integrate HIV prevention interventions for black Caribbeans in areas of the UK with large black Caribbean communities	CHAPS/NAHIP partners, wider sexual health programmes
Develop regional and local STI prevention strategies for black Caribbean communities, in line with HPA recommendations	SHAs, PCTs
Increase funding at national, regional and local levels for prevention efforts to specifically address the needs of black Caribbeans at risk of HIV and other STIs	Government
Carry out assessments of the HIV and sexual health needs of black Caribbeans and implement strategies to meet these identified needs	Commissioners
Consistently implement the UK guidelines for HIV testing to ensure people from Caribbean countries where HIV prevalence is higher than 1% are routinely offered and recommended an HIV test, with repeat testing provided to those individuals most at risk (high prevalence countries currently identified by UNAIDS include the Bahamas, Barbados, Belize, Dominican Republic, Guyana, Haiti, Jamaica, Suriname and Trinidad and Tobago)	GPs, relevant medical specialties
Increase funding for HIV positive black Caribbean peer support services, and the piloting of innovative anonymous services to help mitigate concerns about disclosure and HIV-related stigma and discrimination which exist in black Caribbean communities	Government
Tackle homophobia and address HIV-related stigma and discrimination in black Caribbean communities	HIV sector, black Caribbean and minority ethnic media, church and faith groups



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About NAT

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.

SHAPING ATTITUDES.
CHALLENGING INJUSTICE.
CHANGING LIVES.

All NAT's work is focused on achieving four strategic goals:

- ▶ Effective HIV prevention
- ▶ Early diagnosis of HIV through ethical, accessible and appropriate testing
- ▶ Equitable access to treatment, care and support for people living with HIV
- ▶ Eradication of HIV-related stigma and discrimination

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