Unheard Voices Project

A literature review of studies on the needs of Black communities living with and impacted by HIV

Working together

ONE VOICE NETWORK

NATIONAL AIDS TRUST

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Introduction

The HIV epidemic in the UK is one of stark inequalities. While the virus itself may not discriminate, people from marginalised and socially excluded communities are disproportionately affected.

Amongst the heterosexual population, this means people from Black communities above all. Black people are more likely to acquire HIV and to be diagnosed late, often leading to serious ill health and risking premature death. Black communities are also known to have lower levels of awareness of HIV prevention technologies than other populations at risk, exacerbating existing trends. Despite clear evidence of this however, there has been a consistent failure to end these inequalities.

This literature review is part of a collaborative project between National AIDS Trust, the UK's HIV rights charity, and One Voice Network (OVN), a collective of Black-led community organisations focused on improving the health and wellbeing of Black communities in the UK affected by HIV. The project aims to address structural inequalities by ensuring that Black communities living with HIV can hold decision-makers to account, influence policies, and become part of the decision-making process. To do so, this literature review sought to deepen understanding of the inequalities faced by Black communities living with or at risk of HIV.

Available literature was reviewed according to four key themes:

- **HIV testing, treatment and care**
- **Primary HIV prevention**
- **Funding and service provision**
- **Community involvement**

We found evidence of inequalities across each theme. Key barriers to a more equal state of affairs include the impact of HIV stigma on Black communities, inequities in access to interventions and support, socio-economic hardship and wider determinants of health, particular difficulties experienced by migrant populations, lack of cultural competency and representation in HIV messaging and campaigns, and insufficient funding for and involvement of Black communities in HIV work.

A range of solutions are proposed in the literature to address these barriers and help to end inequalities. These include increased access to HIV testing and prevention, improved targeting and tailoring of resources and campaigns, greater community involvement and engagement throughout the clinical and voluntary HIV system, increased access to wider health and socio-economic support, an end to hostile environment faced by migrants, national and local efforts to reduce stigma, and increased and sustainable funding of services aimed at Black communities.

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1. When discussing HIV data it is important to acknowledge at the outset that comparisons between Black communities and other populations not always straightforward. In the UK, the groups most affected by HIV are gay and bisexual men and people of Black African ethnicity. These are often described as 'key populations.' This means that comparing a given metric between Black populations and White (or other) populations is not always the most useful comparison. Instead, it may be more useful to compare key populations directly, or to compare specific groups within wider populations, for examples White heterosexuals and Black heterosexuals. We have attempted to use the most appropriate comparison in each instance but rely on available analysis.
2. Public Health England (PHE), 2019, HIV in the United Kingdom: Towards Zero HIV transmissions by 2030, 2019 report [https://www.gov.uk/government/publications/hiv-in-the-united-kingdom]
3. See ethnicity data from 2011 census at: https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/population-of-england-and-wales/latest
4. UK Health Security Agency (UKHSA), Country and Region HIV data tables to end December 2020. Tables No. 2: 2021 [https://www.gov.uk/government/statistics/hiv-annual-data-tables]

HIV testing, treatment and outcomes

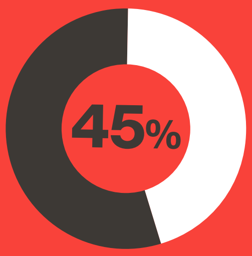
2.1 Testing

Nationwide data on HIV testing and diagnoses is published annually by the UK Health Security Agency (formerly Public Health England) as part of its HIV surveillance reporting.

Due to the impact of COVID-19 on HIV and HIV reporting, we have considered data from 2018, 2019 and 2020 (data from 2021 will not be published until late 2022). This enabled us to recognise inequalities that existed prior to the COVID-19 pandemic, as well as the ways that COVID-19 has affected HIV testing amongst different demographics in different ways.

In 2019, 45% of new HIV diagnoses in the UK were among Black, Asian and Minority Ethnic communities.[2] 26% were among Black ethnicities specifically, despite people of Black ethnicities making up only 3.3% of the UK population in the last census.[3] HIV thus has a clearly disproportionate impact on Black populations.

In 2019



of new HIV diagnoses in the UK were among Black, Asian and Minority Ethnic communities.

Recent years have seen a decline in new HIV diagnoses nationally, including amongst people of Black ethnicities. This decline however is not equally distributed. In the 5-year period from 2014-2019, new HIV diagnoses amongst people of White ethnicity in the UK declined by 42%, while people of Black African ethnicity saw only a 37% decline in diagnoses.[4] In England, these figures were 47% and 36% respectively.[5]

In England, the number of Black African heterosexuals tested for HIV increased by 3% from 2015 to 2019.[6] In 2019, HIV test coverage (the proportion of people tested for HIV at specialist sexual health services among eligible attendees) was higher among Black African heterosexuals than among non-Black African heterosexuals (73% vs. 63%), but lower than Gay and Bisexual Men (87.2%). Among Black African heterosexuals, HIV test positivity among men fell to 0.3% in 2019 but remained at 0.5% among women. This compares to an overall HIV test positivity rate of 0.2%.

Of people who attended specialist sexual health services but did not test for HIV, 46% were not offered a test and the remainder declined testing. Heterosexual women were more likely than heterosexual men to decline a test (25% vs 13%). Few gay and bisexual men declined testing (4%), in contrast to 20% of Black African heterosexual women and 9% of Black African heterosexual men (Figure 2). High rates of declined tests, in addition to the 15% of Black African heterosexual women who were not offered an HIV test, resulted in over a third of Black African heterosexual women attendees not being tested at specialist sexual health services.

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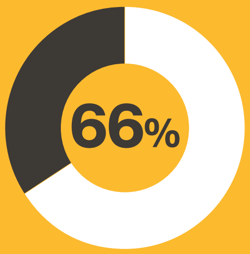
5. UHSA, National HIV surveillance data tables to end December 2020. Tables No. 1: 2021 [[https://www.gov.uk/government/statistics/hiv-annual-data-tables]
6. Ibid.
7. UHSA, National HIV surveillance data tables, op. cit. Table 2b.
8. PHE, 2019, HIV in the United Kingdom: Towards Zero, op. cit.
9. UK Health Security Agency, 2021, HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report [https://www.gov.uk/government/statistics/hiv-annual-data-tables]
10. National Institute for Health and Care Excellence (NICE), 2011, Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England: Barriers to HIV testing – Final full report; NICE, 2015, HIV testing: increasing uptake among people who may have undiagnosed HIV - Evidence review on: Factors which help or hinder HIV testing among people who may have undiagnosed HIV [https://www.nice.org.uk/guidance/ng60/evidence]

Black people are also more likely to be diagnosed late than their conterparts, with accompanying consequences for health.

Black African (50%), Black Caribbean (48%) and Black Other (47%) were the ethnicities most likely to be diagnosed late in 2019, compared to a rate of 39% for White ethnicities.[7] Again, there are significant differences between genders: in 2018, 66% of Black African men who acquired HIV via heterosexual contact were diagnosed late, compared to 50% of Black African heterosexual women.[8]

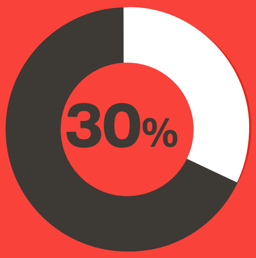
The COVID-19 pandemic has had a disruptive impact on HIV testing. In 2020, the number of people who tested for HIV at a sexual health service (SHS) in England fell by 30% from 1,320,510 in 2019 to 927,760.[9] This decline was not equal between population groups. Among gay, bisexual and other men who have sex with men, the number having an HIV test at SHS fell by 7% from 157,710 in 2019 to 146,900 in 2020. By contrast, the number of heterosexuals tested for HIV fell sharply by 33% (from 1,142,950 in 2019 to 760,260 in 2020). Similar drops in testing were observed among Black African heterosexuals (34% for men and 24% for women) and White heterosexuals (43% and 30%, respectively). The proportion of heterosexuals offered an HIV test at SHS in 2020 reduced from 83% in 2019 to 60% in 2020 (87% and 67%, respectively, among Black African heterosexuals).

In 2018



of Black African men who acquired HIV via heterosexual contact were diagnosed late.

In 2020, there was a



decrease in the number of people who tested for HIV at a sexual health service in England.

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11. Ibid.
12. NICE, 2011, Increasing the uptake of HIV testing… among black African communities living in England, op cit.
13. Mohammed H et al., 2017, 'Refusal of HIV testing among black Africans attending sexual health clinics in England, 2014: a review of surveillance data' Sexually Transmitted Infections 93(3):217-220 [https://sti.bmj.com/content/93/3/217.long]
14. National AIDS Trust & Fast-Track Cities London, 2021, HIV: Public Knowledge and Attitudes [https://www.nat.org.uk/files/hiv-public-knowledge-and-attitudes-pdf]
15. National AIDS Trust, 2020, Community HIV testing: Intervention design toolkit [https://www.nat.org.uk/nat-topic/community-testing]; ECDC, 2018, Public health guidance on HIV, hepatitis B and C testing in the EU/EEA - An integrated approach [https://www.ecdc.europa. eu/en/publications-data/public-health-guidance-hiv-hepatitis-b-and-c-testing-eueea]; Deblonde J et al., 2010, 'Barriers to HIV testing in Europe: a systematic review' Eur J of Public Health 20: 422–432.

2.1.1 Barriers

Barriers to HIV testing experienced by Black people in the UK have been well researched.

This has included independent academic research as well as voluntary sector-led and publicly funded research. The resulting literature has identified a number of key barriers discussed below.

High levels of HIV stigma within the UK's Black African population are cited by the National Institute for Health and Care Excellence (NICE) as a significant barrier to HIV testing among this population.[10] As is discussed in more detail in section 3.1, findings of national surveys and other forms of research suggest that Black communities are particularly affected by HIV stigma. Evidence reviews conducted by NICE in 2011 and 2015 found that this can deter people from testing due to fear of individual, intra-community and external consequences of an HIV diagnosis.[11] Perceptions of HIV as a fatal disease result in fear of death; community stigma results in fear of social isolation and exclusion; and societal racism results in fear of prejudice from non-Black communities.

Another previously identified barrier to testing is a lack of perceived personal risk of acquiring HIV. NICE's 2011 evidence review found that this was due to associations between HIV and stigmatised behaviours, severe illness, and other communities.[12] Research into the reasons for refusal of HIV testing among black Africans in sexual health clinics supports this but highlights differences in risk perception within this population: risk perception is lower amongst heterosexuals and those born in the UK than LGBT people and those born in high prevalence countries.[13] More recently, research conducted by National AIDS Trust and Britain Thinks in 2021 found that Black people were in fact more concerned about getting an STI than White people or gay and bisexual men.[14] This suggests an increase in self-perception of sexual health risk, but did not refer to HIV specifically.

Even where people are aware of the importance of HIV testing, literature shows that clinical sexual health services are not always accessible or acceptable to populations at increased risk, including Black communities.[15] Reasons for this include stigma and concerns about being seen, limited knowledge of the sexual health system, and previous negative experiences of healthcare that deter engagement. Experience of racist or discriminatory attitudes and perceptions of a lack of linguistic and/or cultural competency in mainstream healthcare settings further contribute to this.[16]

Migrants face particular barriers to accessing sexual and wider health interventions, including HIV testing. To give an indication of the scale and relevance of this demographic to this review, in 2018, 69% of people who acquired HIV through heterosexual contact were born outside of the UK, and 47% in a country of high HIV prevalence.[17] Of the latter group, 81% were of Black African ethnicity. Literature demonstrates that migrants face both structural and individual barriers to testing. At the structural level, although HIV testing is free to everyone in the UK regardless of immigration status, hostile environment policies and a lack of access to information about healthcare entitlements result in concerns about migration status, financial costs, and data sharing.[18] In addition to this, migrants experience language barriers, unfamiliarity with the healthcare system, and competing priorities resulting from their socio-economic position.[19] Different cultural norms, attitudes and behaviours around HIV testing and wider preventative healthcare can also play a role.[20]

Underpinning some of the above barriers are wider socio-economic factors and a lack of resources and political will. Social and economic disadvantage disproportionately affects Black communities in the UK, including Black communities living with HIV.[21] This is known to impact upon access to healthcare generally, and evidence points to this including HIV testing. For example, rates of test refusal are higher amongst those living in more deprived areas.[22] Lack of resources and will to address the barriers to testing identified above will be dealt with more thoroughly in section 4, but in summary literature suggests that the advocacy and resources required to target relevant populations appropriately is not available.[23]

In 2018

of people who acquired HIV through heterosexual contact were born outside of the UK

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[16] Shangase P et al., 2015, 'Barriers to accessing HIV services for Black African communities in Cambridgeshire, the United Kingdom' J Community Health 0(1):20-6 [https://pubmed.ncbi.nlm.nih.gov/24878614/]; NICE, 2015, HIV testing: increasing uptake among people who may have undiagnosed HIV, op. cit.

[17] PHE, 2019, HIV in the United Kingdom: Towards Zero HIV transmissions by 2030, op. cit.

[18] National AIDS Trust, 2021, HIV and migration: Understanding the barriers faced by people born abroad living with HIV in the UK [https://www.nat.org.uk/sites/default/files/publications/FINAL%20HIV%20and%20migration%20report%20June%202021.pdf]

[19] Deblonde J et al., 2010, 'Barriers to HIV testing in Europe: a systematic review' Eur J of Public Health 20: 422–432 [https://pubmed.ncbi.nlm.nih.gov/20123683]; NICE, 2011, Increasing the uptake of HIV testing… among black African communities living in England, op cit.

[20] Ibid.

2.1.2 Solutions

Literature suggests a range of evidence-based solutions to the barriers identified above, as well as additional strategies to support increased testing amongst Black populations.

Due to the scope of this review the following does not comprise an exhaustive list, but rather focuses on solutions for which there is most evidence.

Strong emphasis is placed on the importance of increased opportunities to test, and consequent normalization of HIV testing. Literature suggests that opt-out testing (i.e. the routine provision of HIV testing across the NHS on an opt-out rather than opt-in basis) is both effective and acceptable to Black communities, particularly in primary care.[24] This could help to address barriers such HIV stigma, lack of perceived HIV risk, and alienation from sexual health services. Increased testing would not only reduce levels of undiagnosed HIV, but also help put an end the disproportionately high rates of late of diagnosis amongst this population. Further evidence on the impact of opt-out testing will be generated by the implementation of the Government's 2021 HIV Action Plan.[25]

Community-based HIV testing, though much smaller in scale, also has an important role to play in Black communities. A previous evidence review conducted by National AIDS Trust to inform the development of community HIV testing toolkits found that community testing overcomes many of the barriers identified above and is effective in reaching those who do not engage in sexual health services, including those of Black ethnicity.[26] Evidence supporting this and a breakdown of the ways in which community testing overcomes barriers can be found in the aforementioned toolkits, but in summary the act of 'taking testing to where the community is' and the provision of tailored and culturally-competent interventions are central to their success.

Both in clinical and community settings, community involvement is identified as a factor that can support HIV testing amongst Black communities. Mobilising community members and resources to deliver outreach, education and testing interventions increases engagement in those interventions and also helps to tackle HIV stigma and enable wider sexual health promotion.[27]

> **There is significant evidence of the importance of testing campaigns being tailored to and led by members of the community, and the role that positive Black role models can play in tackling stigma.**

There is significant evidence of the importance of testing campaigns being tailored to and led by members of the community, and the role that positive Black models can play in tackling stigma.[28] A 2015 evidence review by NICE found a consensus that in dealing with the problem of HIV among immigrants specifically, religious and community leaders need to do more than they are currently.[29]

HIV education is also key to addressing barriers to testing. Knowledge and attitudes towards HIV amongst the Black population is explored in detail in section 3, but in short increased awareness of HIV is vital to support uptake of testing, particularly around transmission risk and the benefits of earlier diagnosis and treatment.[30] The literature is clear that educational messaging and campaigns must be culturally competent and appropriately tailored to the relevant community.

Testing strategies must also reflect local need and target relevant populations effectively. This requires analysis of and response to ethnic differences in HIV outcomes locally, taking into consideration the differences in need within broad demographic categories such as 'Black African.'[31] Some literature has suggested that identification of need also consider sub-groups within giving ethnicities, for example 'women over 65' or 'college educated men.'[32]

Finally, barriers to testing may also be addressed by the use of novel testing technologies. Although online/self-testing appears to less popular amongst people from Black communities than other key populations, research by the Terrence Higgins Trust has found that enhanced promotion aimed at Black Africans and the option to 'Click & Collect' tests increased uptake and addressed barriers around confidentiality and privacy.[33] Partner notification, whereby people receive an invitation to test from a sexual health clinic following the STI/HIV diagnosis of a sexual partner (who remains anonymous), is also known to be effective in securing uptake of testing amongst Black Africans.[34]

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[21] UK Race Disparity Audit. Available at: https://www.gov.uk/government/publications/race-disparity-audit; Public Health England, 2020, Positive Voices: The National Survey of People Living with HIV, Findings from the 2017 survey [https://www.gov.uk/government/publications/hiv-positive-voices-survey]

[22] Mohammed H et al., 2017, 'Refusal of HIV testing among black Africans', op. cit.

[23] Deblonde J et al., 2010, 'Barriers to HIV testing in Europe: a systematic review' Eur J of Public Health 20: 422–432.

[24] NICE, 2016, HIV testing: increasing uptake among people who may have undiagnosed HIV (guideline NG60) [https://www.nice.org.uk/guidance/ng60]; HIV Commission, 2020, How England will end new cases of HIV: Final report and recommendations [https://www.hivcommission.org.uk/final-report-and-recommendations/]

[25] Department of Health and Social Care, 2021, Towards Zero: the HIV Action Plan for England - 2022 to 2025 [https://www.gov.uk/government/publications/towards-zero-the-hiv-action-plan-for-england-2022-to-2025]

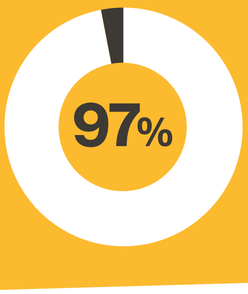
2.2 Treatment and care

Of people receiving HIV specialist care in the UK in 2019, just over a quarter were Black African (28.7%), 2.8% were Black Caribbean and 2.2% identified as Black Other.[35] 5.7% were of 'Other/Mixed' ethnicity.

These statistics demonstrate that the impact of HIV on Black people is complex, with Black Africans significantly overrepresented compared to other Black ethnicities. Gender is also significant, with Black African women nearly twice as likely as Black African men to be living with HIV (51 per 1000 compared with 26 per 1000 respectively).[36]

Of people seen for HIV care and receiving antiretroviral therapy (ART) in England in 2019, 97% were virally suppressed.[37] This is defined as having a viral load count below ≤200; people who are virally suppressed cannot pass on HIV to others via sex (this is referred to as 'Undetectable = Untransmittable', or U=U). Rates of viral suppression were largely consistent between people of different ethnicities at 98% for White people, 97% for people of Black African or Black Other ethnicity, and 96% for Black Caribbean people.

In 2020, in England



of people seen for HIV care and receiving antiretroviral therapy were virally suppressed.

This data is supported and expanded upon by the findings of a recently published study exploring ethnic differences in HIV clinical outcomes amongst heterosexuals in the UK.[38] Most study participants were of Black African ethnicity (64.4%), followed by white (19.1%), Black Caribbean (6.3%) and black other (3.7%). More than half of the Black African and Black other ethnic groups were women.

The study found that people from BAME groups had a lower CD4-count upon presentation than the white group, particularly amongst Black African and South Asian participants. This supported the findings of a previous study of clinical HIV outcomes amongst men who have sex with men (MSM).[39] People of Black ethnicities also spent a lower proportion of time engaged in care than people of other ethnicities, in line with findings of other UK studies which have found lower rates of engagement with care following diagnosis, higher rates of disengagement from care and more irregular clinic attendance amongst this population.

Associations between ethnicity and treatment initiation were less clear. While the aforementioned study of MSM specifically found that people of Black ethnicities were less likely to start treatment than their white counterparts, more recent research found no significant ethnic differences and no association between ethnicity and time (from treatment initiation) to viral suppression. This supports the findings of previous London-based studies and is reassuring, suggesting that once people are linked into care there are no significant ethnic disparities in starting treatment and becoming virally suppressed.[40] Black individuals were however more likely to experience viral rebound (where viral load returns to a non-suppressed level after viral suppression; this can be caused by drug resistance or poor adherence to HIV treatment).

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[26] National AIDS Trust, 2020, Community HIV testing: Intervention design toolkit, op. cit.; Croxford S et al., 2019, Community-based HIV testing in Europe: a systematic review (Poster), HepHIV 2019 Conference, 28-30 January 2019, Bucharest, Romania [https://www.eurotest.org/Portals/0/PS4_04.pdf]

[27] NAT, 2020, Community testing: intervention design toolkit; NICE, 2016, HIV testing: increasing uptake, op. cit.

[28] National AIDS Trust, 2014, HIV and Black African Communities in the UK [https://www.nat.org.uk/sites/default/files/publications/NAT-African-Communities-Report-June-2014-FINAL.pdf]; NICE, 2016, HIV testing: increasing uptake, op.

[29] NICE, 2015, HIV testing… Factors which help or hinder HIV testing, op. cit.

[30] Fakoya I et al., 2019, 'HIV testing and Sexual Health among Black African Men and Women in London, United Kingdom' JAMA Network Open 2(3):e190864 [https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2728620]; NICE, 2016, HIV testing: increasing uptake (guideline NG60), op. cit.

[31] APPG on HIV & AIDS, 2022 [awaiting publication], Nothing about us without us: Addressing the needs of Black, Asian and Minority Ethnic communities in relation to HIV

> **Black people living with HIV in the UK are more likely to experience social and economic hardship than their white counterparts.** [41]

2.2.1 Causes/barriers

Literature identifies a number of factors likely to contribute to ethnic differences in clinical HIV outcomes. Many of these were discussed in a recent study by Dhairyawan R et al., which we would like to recognise as significantly informing this section.

Black people living with HIV in the UK are more likely to experience social and economic hardship than their white counterparts.[41] This is consistent with the experience of Black people in the UK more broadly as a result of structural racism. In context of HIV, social and economic hardship can impact upon physical and mental health, access to care, and viral rebound.[42] Good clinical outcomes rely on access to and continued engagement with care, and are therefore hindered by social and economic disadvantage.

HIV stigma can also impact upon clinical outcomes amongst people living with HIV. Stigma is associated with poor treatment adherence and can lead to disengagement from healthcare services.[43] A recent qualitative study to identify barriers to treatment uptake and adherence in people living with HIV from Black African and Caribbean communities also found that beliefs linked to stigma and shame could influence perceptions of the necessity of treatment as well as fears of discrimination should their treatment (and by implication HIV status) be discovered.[44]

Related to HIV stigma, evidence pertaining to Black Africans in the UK has found that poor treatment adherence is associated with a lack of confidence in treatment, medical mistrust, and worries about not being taken seriously by healthcare providers.[45] This is supported by evidence from the US which found that barriers to Black people engaging in care include the perception that patients are excluded from the decision-making process.[46] Concerns about the short- and long-term side effects of HIV treatment are also highlighted throughout the referenced literature.

The disproportionate impact of poor mental health on people living with HIV can further impact clinical HIV outcomes.[47] Black people living with HIV in the UK are marginalised not only on the basis of their HIV status but also on the basis of race; research into ethnic disparities in mental health amongst the general population has found that people from Black and minority ethnic backgrounds are more likely to be diagnosed with mental health problems and less likely to engage with or experience good outcomes from treatment.[48] In the context of HIV specifically, evidence shows significantly higher rates of psychosocial need amongst Black African and Caribbean women compared to their white counterparts, yet comparatively low rates of diagnosis.[49]

Difficulties migrants face in accessing healthcare may also contribute to issues with treatment adherence and engagement with care. As discussed in section 2.1.1, migrants living with HIV in the UK experience a range of barriers to testing, treatment and care. These include restrictive immigration and 'hostile environment' policies, a lack of access to information about healthcare entitlements, language barriers, poverty (which is often related to restrictions on the right to work and inability to access public funds), mental health problems and the intersection of HIV stigma and discrimination with broader xenophobia and hostility towards migrants.[50] Added to barriers experienced by this population are a lack of political will and the absence of Black representation in decision-making processes.[51]

[32] Fakoya I et al., 2019, 'HIV testing and Sexual Health' op. cit

[33] Terrence Higgins Trust, 2019, 'Reducing barriers to HIV testing among black African communities – Self testing pilot' (Presentation) [https://www.bhiva.org/file/5ca756a5a39fd/GeorgeHalfin.pdf]

[34] Mohammed H et al., 2017, 'Refusal of HIV testing among black Africans', op. cit.

[35] PHE, 2020, Trends in HIV testing, new diagnoses and people receiving HIV-related care, op. cit.

[36] Ibid.

[37] UHSA, National HIV surveillance data tables: Table No. 1: 2021, op. cit.

[38] Dhairyawan R et al, 2021, 'Differences in HIV clinical outcomes amongst heterosexuals in the United Kingdom by ethnicity' AIDS 35: 1813-1821 [https://pubmed.ncbi.nlm.nih.gov/33973878]

[39] The UK Collaborative HIV Cohort Study Group, 2012 'Uptake and outcome of combination ART in men who have sex with men according to ethnic group: the UK CHIC Study' JAIDS 59:523–529 [https://doi.org/10.1097/QAI.0b013e318245c9ca]

2.2.2 Solutions

A range of recommendations have been proposed to address inequalities in treatment and care and the factors that cause them.

As with testing, literature suggests that disaggregation of broad ethnic categories in data collection and improved recording of ethnicity data in clinics would be of benefit.[52] This would enable heterogeneity within categories to be identified and better understanding of who is lost to care to be developed. This would, in turn, support informed responses to local inequalities in access and outcomes.

Awareness of ethnic differences in clinical access and outcomes is also recommended on the part HIV clinicians and other healthcare professionals working with people living with HIV.[53] Providers should be aware that Black people living with HIV may need additional support to remain engaged in care and on treatment, and this requires culturally competent and holistic assessment of needs. Additional support may involve adherence support from specialised pharmacists, access to peer and mental health support, and referrals to services that can provide support with issues such housing, benefits, and employment. Better assessment is also 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.[54]

Re-engagement of people living with HIV who have disengaged from care is also vital. For obvious reasons robust surveillance data on these populations does not currently exist, but data from Elton John AIDS Foundation's HIV Social Impact Bond (SIB) demonstrates the impact of concerted re-engagement activity on the Black community. The SIB funds opt-testing in hospitals, HIV screening and re-engagement efforts in primary care, and community-led outreach and linkage to care.[55] Data from the programme shows that of those reconnected to care, the majority were from Black communities.[56] As investment in re-engagement seems to particularly benefit Black people living with HIV it is therefore important to achieve equitable outcomes for this population.

To combat medical mistrust, concerns about not being taken seriously, and a lack of cultural competency, meaningful involvement of people living with HIV is encouraged at all stages of research, policy, service design and evaluation.[57] This must include people from Black communities throughout.[58] Literature also suggests that further research to investigate and address barriers to treatment and care should take a community participatory approach.[59]

To support engagement with care and adherence to treatment, people living with HIV must have access to mental health support that is both HIV literate and culturally competent.[60] Providers must understand the ways in which HIV can impact upon mental health and how this intersects with ethnicity, inequalities in access and outcomes must be fully investigated and addressed, and services must actively seek to improve diversity and representation.[61]

To address barriers faced by migrants, the hostile environment must be dismantled in healthcare settings so that migrants regain trust in the health system, and it is essential that migrants are made aware of their HIV healthcare entitlements and have access to accurate, up-to-date information available in key languages.[62] Given the lack of proactive testing by some migrants, opt-out testing should be implemented where possible across all healthcare settings to reduce missed opportunities to diagnose and treat HIV. HIV support services are essential in supporting migrants living with HIV in the UK, and should be funded and available in every area in order to provide culturally specific support to address the specific and complex needs of migrants living with HIV in the UK.

> **To support engagement with care and adherence to treatment, people living with HIV must have access to mental health support that is both HIV literate and culturally competent.[60]**

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40. Ibrahim F et al., 'Uptake of antiretroviral treatment among people living with HIV in London: ethnicity, gender and sexual orientation' Sex Transm Infect 2008; 84:176–178; Saunders P et al., 'Does gender or mode of HIV acquisition affect virological response to modern antiretroviral therapy (ART)?' HIV Med 2016; 17:18–27
41. Burch LS et al., 2016, 'Socioeconomic status and treatment outcomes for individuals with HIV on antiretroviral treatment in the UK: crosssectional and longitudinal analyses' Lancet Public Health 1:e26–e36.
42. Dhairyawan R et al, 2021, 'Differences in HIV clinical outcomes', op. cit.
43. Burch LS et al., 2016, 'Socioeconomic status and treatment outcomes', op. cit.; Katz IT et al., 2013, 'Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. J Int AIDS Soc 16 (3 Suppl 2):18640.
44. Glendinning E et al., 2019, 'A qualitative study to identify perceptual barrier to antiretroviral therapy (ART) uptake and adherence in HIV positive people from UK Black African and Caribbean communities' AIDS Behav. 23(9): 2514–2521 [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6766469]

Wider HIV prevention

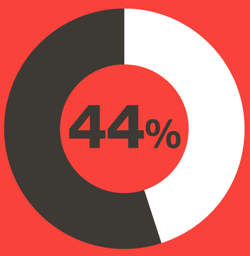
3.1 HIV/awareness and attitudes

Understanding Black populations' knowledge and attitudes towards HIV and sexual health is important to inform HIV prevention efforts.

At a national level, data on knowledge and attitudes has been periodically collected via surveys conducted by organisations including Sigma Research and National AIDS Trust. Some of this data has focused on Black Africans rather than Black populations more broadly, but as the former group accounts for the vast majority of Black people affected by HIV in the UK this data is highly relevant.

In the most recent nationwide African Health and Sex Survey (2013-2014), HIV awareness, and particularly awareness of HIV prevention strategies, was found to be lacking.[63]

In the survey



of respondents were not aware of the concept of treatment as prevention, and more than a third were not aware that HIV medication is freely avaliable.

Nearly three-quarters (72.7%) of respondents were not aware of the high prevalence of HIV among black African people living in England, indicating a failure of public health messaging to reach this community. More than two-fifths (44.2%) were not aware of the concept of treatment as prevention (TasP), and more than a third (35.8%) were not aware that HIV medication is freely available to any individual in the UK who needs it. Younger respondents, and those with lower levels of education, were significantly less likely to know that HIV treatments work better if taken before people become ill.

These findings supported the limited knowledge of HIV prevention strategies found by a 2011 UK study of African people in sero-discordant relationships.[64] Despite the nature of their relationships, nearly a third were unaware of PEP and a further third were unaware of how it worked or how they could access it. A quarter of participants had no knowledge of the concept of TasP (treatment as prevention), and half had some knowledge but would not personally rely on it. It should be noted that this survey preceded the Partner studies that established the evidence that U=U, and therefore TasP did lack the certainty that it offers today.

Several of the surveys above also asked about sexual health practices in order to assess behaviour as well as attitudes. The 2008-09 Bass Line Survey (a precursor to the 2013-14 African Healthcare and Sex survey), found significant evidence of sexual risk amongst Black African people living in England.[65] Perhaps most notably, 10% of respondents reported unprotected sex with someone definitely or probably of a different HIV status to themselves. A third reported condom failure in the past year (compared to 13% of MSM in Gay Men's Sex Survey 2008), and a 1/3 felt unsure about whether they could talk easily about safer sex and HIV with new partner. 10% of both HIV positive and negative respondents did not feel they were in control in terms of exposure to HIV risk.

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45. Ibid.; Spiers J et al., 2016, 'The experience of antiretroviral treatment for black West African women who are HIV positive and living in London: an interpretative phenomenological analysis.' AIDS Behav, 20:2151–2163.

46. Freeman R et al., 2017, 'Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: a qualitative exploration.' Int J Equity Health 16:54

47. APPG on HIV and AIDS, 2019, The Missing Link: HIV and mental health [https://www.appghivaids.org.uk/s/The-Missing-Link-Web-version.pdf]

48. Rethink Mental Illness, 2020, 'Black, Asian and Minority Ethnic (BAME) mental health factsheet' [https://www.rethink.org/advice-and-information/living-with-mentalillness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health/]

49. Solomon D et al., 2021, 'Ethnic inequalities in mental health and socioeconomic status among older women living with HIV: results from the PRIME Study', Sexually Transmitted Infections 0:1–4 [https://sti.bmj.com/content/sextrans/early/2021/05/05/sextrans-2020-054788.full.pdf]

In 2013-2014

of respondents indicated that they did not always use condoms during sexual intercourse.

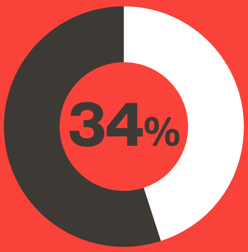
In the 2013-14 African Healthcare and Sex survey, 11.5% of respondents indicated that they did not always use condoms during sexual intercourse with a regular partner who they either knew to have a different HIV status to themselves, or whose status they were unaware of. A quarter (26%) had experienced condom breakage or condom slippage (condom failure) in the previous 12 months, and a quarter of those who had sex with men agreed they would worry what people would think of them if they carried condoms. Almost a quarter (23.9%) did not know that using the right size condom on the penis can reduce the likelihood of it breaking or slipping off; this was more commonly the case among those never tested (31.4%) and those with lower levels of education (47.7%).

More recently however, research conducted by NAT and Britain Thinks into public knowledge and attitudes relating to HIV suggests a more complex, and arguably optimistic, picture.[66] Consistent with previous research, Black people remained more likely (28%) to have lower than average knowledge of HIV transmission than White people (23%). However, across a variety of metrics Black people demonstrated higher levels of HIV knowledge/awareness than White people, if still lower levels than gay and bisexual men (GBM).

For example, Black people were more likely than White people to have heard something about HIV in the last 6 months (60% vs 33%), to personally know someone living with HIV (26% vs 7%), and to be aware of U=U (28% vs 16%) and PrEP (39% vs 26%).

In terms of behaviour, Black people were more likely (19%) than White people (8%) and less likely than GBM (30%) to report higher risk sexual behaviours (i.e. sex with more than one partner, condomless casual sex, or chemsex). However, Black people were more likely (34%) to disagree with the statement “I am not personally worried that I might get an STI” than both White people (14%) and GBM (32%). Black people were also more likely (25%) to report getting a sexual health test in the past 18 months than White people (5%) or GBM (22%). Interpreting this statistic in light of the missed opportunities to test Black people detailed in section 2 suggests that in too many instances sexual health tests are not including HIV.

“I am not personally worried that I might get an STI”



of Black people were more likely to disagree with the statement than both White (14%) and GBM (32%).

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50. National AIDS Trust, 2021, HIV and migration, op. cit.

51. Dhairyawan R et al, 2021, ‘Differences in HIV clinical outcomes’, op. cit.

52. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.;

53. Dhairyawan R et al, 2021, ‘Differences in HIV clinical outcomes’, op. cit.

54.

55. See: https://www.eltonjohnaidsfoundation.org/what-we-do/what-we-fund/uk-social-impact-bond/

56. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.

57. UNAIDS, 2007, ‘The greater involvement of people living with HIV (GIPA)’ Policy Brief [https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf]

58. NAT, 2014, HIV and Black African Communities, op. cit.

The research found that Black people are less likely than White people to agree that society is more positive towards people living with HIV than in the past, but more likely (39% vs 32%) to fully agree that they have sympathy for all people living with HIV, regardless of how HIV was acquired. Black people were not more likely than White people to associate HIV with having had lots of sexual partners but were more comfortable discussing associations between HIV and the LGBT community.

Black people were more likely than White people to:

- Completely agree that if someone in their family told them they had HIV it would not negatively impact the relationship (39% vs 36%)
- Completely agree that if a neighbour told them they had HIV it would not negatively impact the relationship (37% vs 34%)
- Completely agree that their employer should not have to tell them if a colleague is living with HIV (26% vs 22%)

It should be noted that LGBT people scored significantly higher than both Black and White people as a whole for each of these statements.

Finally, in terms of attitudes towards policies regarding HIV, Black people are slightly more likely than White people to support:

- All healthcare workers receiving training so they know up to date information about HIV in the UK today (95% vs 91%)
- Relationships, Sex and Health Education (RSHE) including more information about HIV (95% vs 89%)
- PrEP being made available via GPs as well as sexual health services (91% vs 81%)
- HIV tests being included as part of any standard NHS blood test (82% vs 72%)
- People living with HIV being able to foster and adopt children (67% vs 56%)

HIV stigma has been discussed elsewhere, but is worth briefly highlighting the findings of the 2015 Stigma Survey regarding disclosure.[67] Twice as many individuals from BAME backgrounds did not disclose their status to their main sexual partner as non-BAME participants (10% vs. 5%). While the decision as to whether to not to disclosure is an entirely personal decision one made for various reasons, and the burden for HIV prevention does not fall solely on those living with HIV, disclosing to a sexual partner enables that partner to better consider their own HIV prevention options.

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59. Dhairyawan R et al, 2021, 'Differences in HIV clinical outcomes', op. cit.
60. BHIVA, British Psychological Society & Medical Foundation for AIDS and Sexual Health, 2011, Standards for psychological support for adults living with HIV [https://www.bhiva.org/standardsforpsychologicalsupport]
61. NAT, 2021, HIV and mental health: Improving generic NHS talking therapy services for people living with HIV in England [https://www.nat.org.uk/sites/default/files/publications]
62. NAT, 2021, HIV and migration, op. cit.
63. Sigma Research and London School of Hygiene & Tropical Medicine, 2014, African health and sex survey 2013-14: headline findings [http://sigmaresearch.org.uk/files/report2014c.pdf]
64. Sigma Research, 2011, Plus One: HIV sero-discordant relationships among black African people in England, reports available at: http://sigmaresearch.org.uk/projects/item/project49
65. Sigma Research, 2009, Bass Line 2008-09: Assessing the sexual HIV prevention needs of African people in England [http://sigmaresearch.org.uk/reports/item/report2009h]

3.2 Messaging and campaigns

It is clear from the surveys above, as well as literature on testing and PrEP (see sections 2.1 and 3.3), that HIV messaging and campaigns are not always effective in reaching or impacting Black communities.

Several reasons have been suggested as to why this is and what can be done to address it. How messaging is 'targeted' and who is represented are key issues. Traditionally, HIV campaigns have tended to centre White, gay male narratives, using imagery and language which Black communities may not feel represented by or able to relate to.[68] This can alienate people from campaigns from the outset. Representation and cultural competency are therefore widely acknowledged as vital, ensuring that HIV prevention activities target population groups in proportion with need. However, singling out Black communities and making them 'feel targeted' can itself have negative consequences, including deterring people from engaging with services.[69] Previous research by NAT found that singling out Black Africans as the one ethnic group among heterosexuals at risk of HIV resulted in HIV being associated with Blackness, contributing to both HIV stigma and racism.[70]

The unacceptability of campaigns that single out Black Africans is apparent in the literature. Analysis of one media campaign found that using only Black people in campaign materials resulted in negative feedback from the community.[71] When people from White ethnicities were added to the campaign, negative feedback was reversed. Who is represented and spoken to also needs to go beyond broad labels of Black and White, and instead reflect the diversity and intersectionality of Black communities.

Campaigns such as Sholay Love, a campaign run by NAZ focusing on the South Asian community, and The Requisite Project, a PrEP campaign run by Prepster and The Love Tank aimed at queer men of colour, demonstrate the effectiveness of such an approach.[72]

What seems to be most important then is that messaging and campaigns feel tailored and relatable, and are designed with the needs of the target population in mind. This requires not only representation, but a community-owned approach. Black-led organisations have noted that often national and regional campaigns may feature Black faces but have not been developed by Black communities.[73] This can result in representation feeling tokenistic rather than authentic. An alternative approach is exemplified by GMFA's Me. Him. Us. campaign, developed by BAME gay and bisexual men for BAME gay and bisexual men.[74] This was highly successful and could be emulated elsewhere, ensuring that campaigns are developed by and acceptable to Black communities.

Campaigns such as Me. Him. Us and HIV Testing Week's It Starts With Me have demonstrated that mass media can be effective in delivering HIV prevention for Black populations. However, literature highlights the continued importance of resources being dedicated to 'hands-on' behavioural and informational interventions.[75] This includes in-person and online outreach, traditional and non-traditional forms of media, and the engagement of faith groups and other community leaders.[76] Such interventions are typically delivered by voluntary-sector organisations that are embedded within their local communities and adept at engaging them effectively.

The importance of health promotion activities being community-led, culturally competent and delivered using multiple channels is supported by a Public Health England resource on sexual health promotion for people from Black Caribbean backgrounds.[77] In addition to providing advice for commissioners, providers and third sector organisations on how to effectively tailor messaging and campaigns, it emphasises the importance of workforce training and development, collaboration with local partners, and community involvement and co-production.

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66. National AIDS Trust & Fast-Track Cities London, 2021, HIV: Public Knowledge and Attitudes [https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf]
67. Stigma Index UK, 2015, The People Living With HIV Stigma Survey UK 2015: Black, Asian and minority ethnic participants [http://stigmaindexuk.org/reports/2016/BAME.pdf]
68. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
69. NICE, 2016, HIV testing: increasing uptake [guideline NG60], op. cit.; Ibid.
70. NAT, 2014, HIV and Black African Communities, op. cit.
71. Ibid.
72. See campaigns at https://www.naz.org.uk/sholaylove; and https://prepster.info/requisite/
73. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
74. See: https://www.gmfa.org.uk/mehimus-why-we-created-me-him-us

PrEP

3.3.1 Uptake

Pre-exposure prophylaxis, or PrEP, is a drug that can be taken by HIV-negative people to prevent acquisition of HIV. When taken as prescribed, PrEP reduces the risk of acquiring HIV via sexual contact by almost 100%.[78] Currently PrEP comes in tablet form, but different delivery methods such as injectables and implants are being researched.

In England, PrEP is provided for free by the NHS via sexual health clinics. It can also be accessed online via private pharmacies or overseas vendors at a financial cost. Initially, PrEP was made available via the NHS to only 26,000 people in as part of the IMPACT trial, which ended in July 2020.

To be eligible for PrEP via the trial, people had to be HIV-negative and in one of three groups:

1. **Gay and bisexual men and trans women who had had condomless sex in the previous three months and anticipated doing so in the next three months.**
2. **Sexual partners of people living with HIV who have an unsuppressed viral load and where condoms are not used.**
3. **People who do not fit into either group above but whose situation is clinically assessed and considered to be at a similarly high risk of HIV acquisition. This could include, for example, people who travel to and have sex in countries with a high prevalence of HIV, or people who have unprotected sex here in the UK within social networks of people from such countries.[79]**

While some Black people may fit into each of the criteria above, evaluation data shows that the vast majority of trial participants were White, cisgender gay and bisexual men.[80] Overall, just 3% of participants were Black (African or Caribbean), despite Black people accounting for almost a quarter (23%) of new HIV diagnoses in 2019.[81] Amongst heterosexuals recruited to the trial, just 11% of cisgender women and 19% of cisgender men were Black African. To put this into context, Black African people accounted for 38% of new HIV diagnoses amongst heterosexuals in 2019.

Among cisgender gay and bisexual men recruited to the trial, the biggest single non-White ethnicity was Asian at 5%.[82] Very few trans women or men were of Black African or Caribbean ethnicity. Just under a third of trial participants were born outside the UK, the majority of whom (with the exception of trans women and cisgender heterosexual men) identified as White.

Since the autumn of 2020, PrEP has been available through routine NHS commissioning at specialist sexual health services in England. The UK Health Security Agency (UKHSA) has announced the development of a national framework to monitor and evaluate the delivery of routinely commissioned PrEP in England using a series of indicators.[83] These will be published within existing surveillance outputs from 2022 onwards to support the delivery of PrEP at a national, regional and local level.

In Scotland, PrEP is available through sexual health clinics. Scotland was the first country in the UK and one of the first in the world to provide PrEP via sexual health clinics as a standard provision of its national health service, and has done so since 2017. The most recent publicly available demographic data on PrEP users in Scotland, from a 2019 evaluation of the first two years of the roll-out, found that almost all people prescribed PrEP were men who have sex with men (98% of the total).[84] Two-thirds of people were recorded as White Scottish or British, with a further 12% recorded as White other, Irish or Polish. The reporting collapses ethnicity and nationality such that the proportion of people identifying as Black is not available, but 0.4% of people reported being of African ethnicities.

In Northern Ireland PrEP is available through sexual health clinics but data on ethnicity is not published. This is also true of Wales, but a 2019 parliamentary question revealed that from July 2017 to March 2019, <10 individuals taking PrEP in Wales were of Black ethnicity.[85] This accounted for less than 1% of all PrEP users.

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75. NAT, 2014, HIV and Black African Communities, op. cit.
76. NAT, 2020, Community testing: intervention design toolkit, op cit.
77. PHE, 2021, Promoting the sexual health and wellbeing of people from a Black Caribbean background: an evidence-based resource [https://www.gov.uk/government/publications/promoting-the-sexual-health-and-wellbeing-of-people-from-a-black-caribbean-background-an-evidence-based-resource]
78. See https://www.aidsmap.com/about-hiv/pre-exposure-prophylaxis-prep
79. See: https://prepster.info/impact/5things/
80. Sullivan A et al., 2021, ‘The HIV pre-exposure prophylaxis (PrEP) IMPACT trial: baseline demographics, coverage and first regimen choice’ (Presentation) Fifth Joint Conference of the British HIV Association (BHIVA) and the British Association for Sexual Health and HIV (BASSH) [https://www.aidsmap.com/news/apr-2021/englands-big-prep-implementation-trial-releases-its-enrolment-data-young-people-under]

3.3.2 Barriers to PrEP access for Black communities

Research has identified a number of barriers to accessing PrEP for Black communities in the UK.

Chief among them is a lack of knowledge and awareness of PrEP within these communities. A 2020 review by HIV Prevention England (HPE) of available research and health promotion programme data found that knowledge of PrEP is very low among Black African people in England, particularly compared to gay and bisexual men. Face-to-face and online surveys conducted by HPE in 2019 found that only 22% and 53% (respectively) of Black African respondents were aware of or had heard of PrEP previously. This compared to 84% of gay and bisexual men.[86]

> **In some cases where people did report hearing about PrEP they had confused it with PEP (post- exposure prophylaxis) or believed to be for gay and bisexual men only.**

Research into PrEP awareness amongst sexually active Black African and Caribbean women in Glasgow and London found similarly low levels of knowledge.[87] While nearly all of the research participants displayed good knowledge of how HIV is transmitted and were aware of the role of condoms in preventing infection, few knew about biomedical prevention strategies such as PrEP or U=U. Limited self-perception of risk also presented as a barrier, with participants acknowledging that PrEP could be a valuable intervention for women but unlikely to consider themselves at risk. This perception of PrEP as not personally relevant was also identified in the analysis conducted by HPE.[88]

Community and institutional stigma also play a role. In the research focusing on women, participants described how widespread HIV stigma made talking about HIV challenging for fear of being perceived as 'infected.'[89] Many believed that this stigma would deter women from seeking out sexual health services more generally. Some women were afraid of visiting sexual health services out of fear of being seen, thus impacting upon access to PrEP and other sexual health support. Institutional stigma also prevented some participants from seeking out sexual health services. Despite satisfaction with the NHS in general, women in Glasgow reported institutional racism, receiving delayed or substandard care due to their race. There were fewer reports of this from participants in London, but some also felt that race played a role in how they were treated.

[81] PHE, 2020, Trends in HIV testing, new diagnoses and people receiving HIV-related care, op. cit.

[82] Sullivan A et al., 2021, 'The HIV pre-exposure prophylaxis (PrEP) IMPACT trial', op cit.

[83] UKHSA, 2021, HIV testing, new HIV diagnoses, outcomes and quality of care, op cit.

[84] Health Protection Scotland, 2019, Implementation of HIV PrEP in Scotland: Second Year Report (https://www.hps.scot.nhs.uk/web-resources-container/implementation-of-hiv-prep-in-scotland-second-year-report/)

[85] See https://record.assembly.wales/WrittenQuestion/78441

[86] HIV Prevention England, 2020, 'PrEP knowledge, attitudes and usage among Black African communities in England' [https://www.hivpreventionengland.org.uk/2020/07/30/prep-knowledge-attitudes-and-usage-among-black-african-communities-in-england/]

[87] Nakasone SE et al., 2020, 'Risk perception, safer sex practices and PrEP enthusiasm: barriers and facilitators to oral HIV pre-exposure prophylaxis in Black African and Black Caribbean women in the UK' Sexually Transmitted Infections, 96:349-354 [https://sti.bmj.com/content/96/5/349]

> **This wider failure of PrEP messaging to reach Black communities effectively has allowed incorrect associations to flourish.**

Where Black communities are aware of PrEP, medical mistrust and doubts about PrEP's effectiveness prevent some people from accessing it. Terrence Higgins Trust's Takudzwa Mukiwa has explained that historic medical racism and malpractices committed by the pharmaceutical industry have led to people from Black communities being cautious about new medicines.[90] This is particularly true of 'Western' medication perceived as being targeted at marginalised groups. Doubts about the effectiveness of PrEP and concerns about side effects and the trustworthiness of the PrEP messaging has also been highlighted by research.[91] This wider failure of PrEP messaging to reach Black communities effectively has allowed incorrect associations to flourish. Media representations of PrEP as a 'gay men's drug' have led those from other communities to assume that it is not for them, while references to PrEP as a 'promiscuity pill' have further stigmatised it.[92]

Research conducted by Public Health England and Prepster in 2018 revealed a lack of PrEP-related health promotion targeted at Black communities.[93] A mapping exercise gathered information on more than 100 health promotion activities conducted by community organisations and the NHS around PrEP. Most activities did not focus on providing health promotion to one specific group but rather targeted a number of key populations. Gay and bisexual men were included in the largest number of activities, as well as the largest number of activities focused on a specific population group. There were no activities focussed solely on heterosexual men and only two focussed solely on transgender individuals. While there were a number of activities which included women as a target group, none targeted BAME women alone.

Specific barriers experienced by Black gay and bisexual men are important to consider given the potential of PrEP to reduce the disproportionate impact on HIV on this group. Research suggests that in addition to barriers common to other groups, Black gay men experience difficulties talking openly with friends about the type of sex they have (particularly those in heterogenous friendship groups) or with sexual partners about PrEP (due to emphasis on condom use).[94] This prevents open discussion and maintains a certain taboo around PrEP use.

Black gay men also experience intersecting marginalisation on the basis of both race and sexuality; racism from members of the gay community can isolate or exclude Black gay men from LGBT spaces and thus limit exposure to PrEP messaging.[95] Racist stereotypes of Black gay men as sexually dominant and promiscuous also impacts PrEP use as this language is also used about PrEP users, and therefore risks further discrimination. Similarly, HIV stigma and homophobia within Black communities can deter people from accessing services due to concerns around visibility and confidentiality. As a result, research has suggested that community-based interventions may not be advantageous for this group.[96]

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88. HIV Prevention England, 2020, 'PrEP knowledge, attitudes and usage', op cit.

89. Nakasone SE et al., 2020, 'Risk perception, safer sex practices and PrEP enthusiasm', op cit.

90. Mukiwa T, 2020, '2020 was a huge year for PrEP. Why don't black men know about it?' GQ Magazine [https://www.gq-magazine.co.uk/lifestyle/article/prep-black-men]

91. HPE, 2020, 'PrEP knowledge, attitudes and usage', op cit.; Nakasone SE et al., 2020, 'Risk perception, safer sex practices and PrEP enthusiasm', op cit.

92. Mukiwa T, 2020, '2020 was a huge year for PrEP. Why don't black men know about it?', op cit.

93. Guerra L et al., 2018, 'Getting PrEP to those who need it' UK Health Security Agency Blog [https://ukhsa.blog.gov.uk/2018/10/31/getting-prep-to-those-who-need-it/]

94. Witzel TC et al., 2019, 'What are the motivations and barriers to pre-exposure prophylaxis (PrEP) use among black men who have sex with men aged 18-45 in London? Results from a qualitative study.' Sex Transm Infect. 95(4):262-266 [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6585870/]

3.3.3 Facilitators to PrEP acces for Black communities

A range of literature supports the need for improved community engagement around PrEP to facilitate uptake. Community surveys conducted by HIV Prevention England found that once Black African people know what PrEP is and how it works, a majority would be willing to use it under certain circumstances.[97] Improving Black communities' understanding of HIV risk and confidence in PrEP's effectiveness is therefore key to facilitating access.

One means of doing so is via well-targeted media campaigns. At a national level, HIV Prevention England's PrEP Protects campaign demonstrated the potential to reach Black people in significant numbers using a multi-channel approach.[98] The campaign engaged people using social media, influencers and digital advertising, and utilised Black health professionals on the basis of research suggesting this would increase trust. Of those who took the campaign's PrEP self-assessment tool and self-reported their ethnicity, 68% were Black African and 7% were of other Black ethnicities. Despite the COVID-19 pandemic prohibiting face-to-face meetings and workshops to promote the campaign – methods previously shown to be preferable to internet interventions for Black Africans – the campaign was nonetheless effective in reaching its target population.

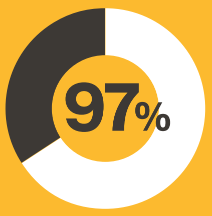
For some Black people, provision of information about PrEP may not be sufficient to overcome barriers. Engagement via community organisations and events can therefore be an effective means of increasing PrEP acceptability. A study which surveyed attendees at two primarily Black football tournaments found that while awareness of PrEP was low, once educated a majority of participants indicated willingness to use it.[99]

This rose to 100% of participants identified as being in the highest risk behaviour groups. The authors concluded that better targeting of PrEP messaging is needed, utilising methods such as events-based outreach and engagement with local faith groups.

Collaborating with community-based organisations can facilitate engagement and has been shown to be similarly effective in overcoming barriers to understanding and awareness.[100] Some projects have utilised 'PrEP Champions' and 'peer mobilisers,' ensuring that PrEP promotion is peer- and community-led.[101] This is supported by research findings which suggests that conversation about PrEP within Black communities is important to help break down stigma and facilitate supportive relationships, particularly in light of the mistrust some have of health professionals.[102] PrEP role models are therefore recommended as one solution to normalise such conversations.

Research into PrEP motivators for Black gay and bisexual men specifically demonstrates the need for services to be discreet, efficient and culturally-competent.[103] Research participants tended to prefer services that were conveniently located but, due to confidentiality concerns, removed from primarily 'Black areas.' Similarly, contrary to the ethos of community-based health services, a preference was found for receiving services from people of different cultural backgrounds to themselves. Staff must however be attuned to the specific barriers faced by this group and affirmative of their identities. Having trained PrEP peer-navigators working in sexual health clinics has also been recommended.[104]

In 2020, in England



of people seen for HIV care and receiving anti-retroviral therapy were virally suppressed.

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95. Ibid.

96. Nutland W et al., 2018, 'What qualities in a potential HIV pre-exposure prophylaxis service are valued by black men who have sex with men in London? A qualitative acceptability study' International Journal of STD & AIDS 29(8):760-765 [https://journals.sagepub.com/doi/full/10.1177/0956462418755224]

97. HPE, 2020, 'PrEP knowledge, attitudes and usage', op cit.

98. Kifetew CA et al., 2021, 'HIV pre-exposure prophylaxis and Black people in England: addressing heath information inequities through a national campaign' Fifth Joint Conference of BHIVA and BASHH (abstract O015) [https://www.aidsmap.com/news/may-2021/black-africans-uk-have-limited-knowledge-prep-despite-ongoing-risk]

99. Ekong N et al., 2018, 'Awareness of pre-exposure prophylaxis (PrEP) in the black and minority ethnic (BME) community; a questionnaire survey in Leeds, UK' Fourth Joint Conference of BHIVA with BASHH (Poster) [https://www.bhiva.org/file/BlTipNrWekDjZ/P71.pdf]

Funding and service provision

The funding and provision of services that support Black people living with risk of HIV, and people living with HIV more broadly, has declined in recent years.

In England, sexual health is funded largely through Local Authorities via the public health grant. Analysis published by the Health Foundation in 2021 revealed that despite an increase in funding between 2019/20 and 2020/21, the public health grant has been cut by 24% in real terms per capita since 2015/16 (equivalent to a reduction of £1bn).[105] When considering sexual health services specifically, the analysis found a 14% cut in spending during a period in which STI diagnosis rates (if not HIV diagnosis rates) did not decline.[106]

NAT has previously conducted evaluations of UK spending on HIV prevention specifically. The most recent of these, concerning the period between 2015/16 and 2016/17, found that HIV prevention funding was diminishing fast.[107] In addition to a UK-wide drop in year-on-year spending of 12%, in England's high prevalence local authorities spending dropped by almost a third (29%) in two years, and in London by over a third (35%). This is notable given the disproportionately large Black population in London.[108]

NAT's analysis also found that health promotion contracts are becoming less specific in their target groups, with reductions in spending largely seen in targeted services. Between 2015/16 and 2016/17, funding for BME (Black and minority ethnic)-targeted health promotion contracts dropped by more than 50% in London, and by 9% in the rest of England. Services that targeted a range of groups were therefore left accounting for a much higher proportion of contracts across the UK.

These contracts usually specify that the service should be for people at increased risk of HIV, and often specifically reference MSM and/or BME groups, but how much of the service cost is dedicated to work targeting specific groups is unclear.[109]

Investment in HIV prevention for Black and minority ethnic groups is generally much lower outside of London.[110] This can in part be explained by population differences, but also reflects the existence of fewer organisations specialising in sexual health work with BAME communities outside of major cities.[111] In the absence of infrastructure for specialist services, generalised sexual health services may be contracted to do work with BME groups alongside the other groups they work with, but may not be equipped to meet their specific needs.

On the other hand, NAT's analysis found that, contrary to the overall trend, in 2016/17 BAME-targeted HIV prevention investment in high prevalence local authorities outside of London increased compared with 2013/14 and 2014/15. Due to an absence of comparative analysis since it is not possible to say conclusively whether this level of investment has been maintained, but evidence presented to the APPG on HIV & AIDS' recent inquiry into HIV and BAME populations suggests that it has not.

The inquiry found that the number of BAME-led HIV and sexual health agencies across the UK declined from approximately 40 in 2014 to just 11 in 2021, with none in Wales, Scotland or Northern Ireland.[112] A previous report on HIV and Black African communities from 2014 suggests that even prior to 2014 the UK's African community sector lacked financial and organisational stability, with a large number of organisations folding from 2008 onwards.[113] In addition to the decommissioning of services, remaining organisations reported having to widen their remit in order to broaden possible funding streams. This risks organisations becoming de-skilled and de-specialised.

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[100] Kasadha B, 2021, 'PrEP Messaging for Black Women Must Include Compassion and Respect' TheBodyPro (feature) [https://www.thebodypro.com/article/prep-messaging-black-women-compassion-respect]

[101] APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.

[102] Witzel TC et al., 2019, 'What are the motivations and barriers to pre-exposure prophylaxis (PrEP)' op cit.; Nakasone SE et al., 2020, 'Risk perception, safer sex practices and PrEP enthusiasm', op cit.

[103] Nutland W et al., 2018, 'What qualities in a potential HIV pre-exposure prophylaxis service are valued', op cit.

[104] Witzel TC et al., 2019, 'What are the motivations and barriers to pre-exposure prophylaxis (PrEP)' op cit.

[105] Finch D et al., 2021, 'Why greater investment in the public health grant should be a priority' The Health Foundation [https://www.health.org.uk/news-and-comment/charts-and-infographics/why-greater-investment-in-the-public-health-grant-should-be-a-priority]

Further impacts of funding cuts reported by the APPG on HIV & AIDS include severely reduced organisational capacity and increased staff burnout, as well as the loss of community workers who had built up critical skills and experience in delivering services to Black communities.[114] This affects trust in providers to fulfil their obligations to the communities they support. Community organisations also reported a reduction in the level of interactions and working relations between Black, Asian and Minority Ethnic communities and statutory sector agencies, with an inevitable loss in quality and quantity of HIV services available to the community.[115]

Further to funding decreases resulting from cuts to public health spending, problems have been highlighted with regards to commissioning practices. The APPG report being provided with many examples of community organisations not receiving financial support due to biased commissioning practices. Previous research by NAT also found evidence of a perceived failure of the statutory sector to tap the public health resource of the Black voluntary sector, and reported that the development and tendering of sexual health contracts involves little scope for community contribution or engagement.[116]

> **It has been recommended that the Black voluntary sector is robustly integrated into comminsioning decisions, and consultations on sexual health strategies made more inclusive.**

Commissioning models need to reflect the diversity of communities and organisations involved in frontline work. Funding also needs to be democratised (i.e. need to fund a broader range of organisations/community groups of various sizes); presently, large organisations often hold the funds and then commission outwards or remunerate service users of smaller organisations on an individual basis. This is not adequate or sustainable and may reduce accountability.

It is clear that greater funding and support is needed for organisations that are led by and/or meet the sexual and wider health needs of Black communities. Organisations have called for funding to be ring-fenced, long-term and sustainable, and for consideration to be better given to the support and advocacy needed to enable Black people living with HIV to live well.[117] Some have called for Black philanthropists and businesses to have an increased role, though there should not be expectation that Black communities be solely responsible for meeting their own needs.[118]

Recent literature has identified the need for consultations on sexual health strategies and commissioning intentions to be inclusive of all communities living with HIV, and for commissioning models to reflect the diversity of communities and organisations involved.[119] A review of commissioning practices could support improvement in this regard.

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106. Ibid.

107. National AIDS Trust, 2017, UK Investment in HIV prevention 2015/16 and 16/17: Examining UK expenditure on primary HIV prevention and HIV testing [https://www.nat.org.uk/publication/uk-investment-hiv-prevention-201516-and-201617]

108. See London population statistics at: https://www.trustforlondon.org.uk/data/geography-population/

109. National AIDS Trust, 2017, UK Investment in HIV prevention 2015/16 and 16/17, op cit.

110. Ibid.; APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.

111. National AIDS Trust, 2017, UK Investment in HIV prevention 2015/16 and 16/17, op cit.

112. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.

113. NAT, 2014, HIV and Black African Communities, op. cit.

Meaningful involvement and co-production

An issue that is often discussed in the HIV sector is a lack of meaningful involvement of Black people and Black-led organisations in research, policy-development, decision-making, and service delivery and design. Available literature on this is limited but relevant findings can be found in the community insights report above.

Traditionally, research into the HIV-related needs of Black people in the UK has often been left to voluntary-sector organisations.[120] Though such organisations may have useful data to draw upon based on the profile of their service users, research activity is rarely funded and small organisations are unlikely to be equipped with the skills necessary to meet professional research standards. Literature has also highlighted the lack of involvement of Black people, and Black people living with HIV, in clinical trials.[121] This can result in research failing to consider or understand the impact of drugs or other interventions on Black people, and therefore risks exacerbating health inequalities.

A recent APPG inquiry into HIV and BAME communities found that meaningful involvement of Black communities in HIV work is also lacking. In the case of Black people living with HIV this is contrary to the GIPA (Greater Involvement of People Living with HIV & AIDS) principle recognised as important in realising the rights and responsibilities of people living with HIV.[122] Service providers may wish to involve community members in service design and delivery but without dedicated funding this is not always feasible.[123]

Instead, the APPG reports expectations on Black community members and organisations to provide labour without remuneration. In additional to financial barriers, community members may not consider the issues relevant to their personal experience or possible to prioritise.

Research also describes a failure of the statutory sector to tap the public health resource of the voluntary sector.[124] Black-led members of the latter have called for a need to recognise the existence of unconscious biases and discrimination towards Black communities and Black-led organisations working in HIV. Where inclusion does occur, literature suggests that it is often tokenistic rather than meaningful.[125] Proposed solutions to this include decision-makers embracing partnership work and co-production, and greater scope for community involvement in the development of sexual health contracts.[126]

Even within the voluntary sector, community members have pointed to the underrepresentation of Black people in positions of influence. Marc Thompson, a gay Black man and leading HIV activist, has pointed to the dearth of Black CEOs within the HIV sector, excepting those at specifically Black organisations.[127] This inequity should be acknowledged, alongside efforts to empower Black communities and arm them with the skills and confidence to challenge and influence HIV policy.[128] Policy organisations must also better promote and include Black communities in their work, acknowledging and addressing past barriers to participation.

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114. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
115. Ibid.
116. NAT, 2014, HIV and Black African Communities, op. cit.
117. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
118. NAT, 2014, HIV and Black African Communities, op. cit.
119. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
120. NAT, 2014, HIV and Black African Communities, op. cit.
121. Pepperrell T et al., 'Phase 3 trials of new antiretrovirals are not representative of the global HIV epidemic' Journal of Virus Eradication 6:70-73 [https://ncbi.nlm.nih.gov/pmc/articles/PMC7213067/pdf/jve-6-70.pdf]

Conclusion

This literature review set out to explore existing evidence relating to inequalities experienced by Black communities in the context of the UK's HIV epidemic. Black communities, and particularly people of Black African ethnicity, are disproportionately affected by HIV in the UK. Yet while this has long been acknowledged, recent progress experienced by other key populations, namely gay and bisexual men, has not always been shared by Black communities. Black people remain more likely to be diagnosed late, for example, and to have lower levels of awareness of HIV prevention technologies. To end these inequalities, it is important to understand the causes, barriers and solutions that have been identified.

Data on HIV demonstrates an overrepresentation of Black people amongst new HIV diagnoses despite lower HIV test coverage amongst this population. The literature shows there is a clear need for increased opportunities to test that are acceptable to Black communities, lower rates of missed and declined tests, and earlier diagnoses. Barriers identified include high levels of HIV stigma, issues accessing services, and wider socio-economic factors. Migrants also experience specific barriers accessing healthcare due to hostile environment policies. A range of solutions were identified, including the provision of testing on an opt-out basis and in a wider range of settings, greater community engagement and involvement, and more effectively targeted and community-led campaigns.

With regards to HIV treatment and outcomes, the literature demonstrates that while there are no significant ethnic disparities in starting treatment and becoming virally suppressed, Black people spend a lower proportion of time engaged in care and are more likely to experience viral rebound. Barriers identified to equitable outcomes include the disproportionate impact of social and economic hardship due to structural racism, alienation from healthcare providers, mental health needs and competing priorities. A number of solutions were identified, including better connections between HIV services and wider care and support, increased cultural competency of healthcare providers, and a dismantling of the hostile environment.

Beyond testing and treatment, wider HIV prevention needs were also identified, such as improved access to and awareness of prevention technologies, and improved HIV knowledge and understanding.

Historically prevention efforts have focused largely on gay and bisexual men, and too little has been done to address the impact of community stigma and institutional racism on Black access to HIV prevention. Solution identified by existing literature include tailored and culturally competent campaigns, a diversification of PrEP access, targeted stigma reduction efforts, peer networking and women-specific messaging.

Less literature is available regarding service provision, but what there is makes clear that cuts to HIV funding in recent years have been particularly felt by organisations led by or focused on Black communities. Commissioning practices are considered to lack transparency and inclusivity, and there is concern that the value of the voluntary sector is inadequately recognised or drawn upon. Services that remain open have had to be stripped back, resulting in them becoming de-skilled or de-specialised. Literature identifies a need for increased public and sexual health funding across the board, ring-fenced and long-term funding to be made available, more contracts targeting specific demographics, and commissioning practices that do not disadvantage Black-led organisations.

Limited literature is available regarding meaningful involvement of Black communities in the work of the UK's HIV sector. The literature there is however indicates insufficient opportunities (and funding) for Black community members to be involved in service design, delivery, or policy-development. Issues identified include unconscious bias and discrimination within the HIV sector, underrepresentation of Black communities in research and of Black people in leadership positions, and expectations of community organisations to provide labour without remuneration. The literature suggests a need for greater involvement of Black people in HIV-related research, increased partnership work and co-production, and greater scope for community involvement in the development of sexual health contracts.

122. UNAIDS, 2007, 'The greater involvement of people living with HIV (GIPA)', op cit.
123. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
124. NAT, 2014, HIV and Black African Communities, op. cit.
125. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.
126. Ibid.; NAT, 2014, HIV and Black African Communities, op. cit.
127. Thompson M, 2022, 'Marc Thompson on stigma and how to really tackle HIV inequalities' NAT blog [https://www.nat.org.uk/blog/marc-thompson-stigma-and-how-really-tackle-hiv-inequalities]
128. APPG on HIV & AIDS, 2022, Nothing about us without us, op. cit.