



Terrence Higgins Trust submission: APPG inquiry on addressing the needs of Black, Asian, and Minority Ethnic Communities in relation to HIV

July 2021

About Terrence Higgins Trust

[Terrence Higgins Trust](#) is the UK's leading HIV and sexual health charity, offering support, information, and advice services for those living with HIV and affected by HIV or poor sexual health.

Our vision is a world where people with HIV live healthy lives free from prejudice and discrimination, and good sexual health is a right and reality for all.

We were one of three founder organisations of the independent HIV Commission that reported in December 2020, had equity at its heart and tackling health inequalities in HIV at its core. It's recommendation to get new cases of HIV down by 80% by 2025 set KPIs in England for key population, including Black African people (numbers of diagnosis in 2019: 466, target for 2025: <100, target for 2030: <18).

Introduction

This is an extremely timely and important inquiry by the APPG and we welcome the opportunity to input our evidence to members, as well as providing oral evidence on 1 July. The communities this inquiry is looking at face high levels of social, health, and economic inequalities, all of which exacerbate poor sexual health outcomes, including the risk of HIV transmission. After gay and bisexual men, Black African heterosexual men and women are the most heavily impacted by HIV in the UK and yet the declines seen in new cases of HIV among the former are not being seen at the same rate among the latter.

While there has been a decline of 15% in new cases of HIV among Black African heterosexuals in 2019, there was a small increase in 2018. Progress is also impacted by gender, with falling cases more pronounced in men (24%) compared to women (9%).¹

¹ [HIV in the United Kingdom: Towards Zero HIV transmissions by 2030](#), Public Health England, 2019

The recent report by the UK Government's Commission on Race and Ethnic Disparities (Sewell report) fell far short of expectations and Terrence Higgins Trust signed an [open letter](#) to the Prime Minister organised by the Runnymede Trust, outlining our shared concerns.² Despite overwhelming evidence, including from the Government's own Race Disparity Unit, that HIV is a health inequality that is disproportionately shouldered by Racially Minoritized Communities, the report made no reference to the disparities these communities experience in regards to HIV. This was a missed opportunity to recognise, take action and begin to root out the racial inequalities that exist in the UK's HIV epidemic.

While this APPG inquiry will not have the same tools and resources at its disposal that the Sewell report did, we hope it will provide bold and evidenced recommendations to address race equity in the HIV response where the Sewell report failed to do so. This must include tackling racism, discrimination, and barriers Racially Minoritized Communities experience in accessing services.

All four UK nations have made commitments to end new cases of HIV by 2030, with work by health departments underway to produce plans to help deliver this. Health Ministers in England have also pledged to achieve an 80% reduction in new cases by 2025, among all population groups affected by HIV. Public Health Minister, Jo Churchill, reaffirmed this equity point in a letter to Dame Inga Beale.³ In England, the Department of Health and Social Care is due to publish its national HIV Action Plan by the end of 2021. The findings of this inquiry will be crucial to lobby for focused commitments relating to Racially Minoritized Communities within this plan.

Our submission is divided into five sections: data collection, HIV testing, prevention, quality of life for people living with HIV, and working in partnership with other organisations.

Key recommendations

- The HIV Action Plan in England and strategies in Scotland and Wales to end new cases of HIV by 2030, should have a specific focus on the needs of Racially Minoritized Communities in regard to prevention and living well. Progress on addressing current inequalities that disproportionately impact these communities should be detailed in annual reporting.
- Public Health England/UK Health Security Agency should produce more granular data linked to HIV, ethnicity, age, gender, and migration status so a greater understanding of intersectional issues impacting Racially Minoritized Communities affected by HIV can be understood.
- There should be increased funding made available to support increased HIV testing in all parts of the UK, this should prioritise opt-out HIV testing in areas with high or very high HIV prevalence. In England, money should be provided in the up-and-coming Comprehensive Spending Review by the Treasury to fully fund the national HIV Action Plan for England, including supporting the expansion of testing in other parts of the NHS that people from Racially Minoritized Communities are more likely to access. The Barnett consequences of this funding should be an

² [Sewell Reports : Runnymede Responds](#), Runnymede, 2021

³ Letter to Dame Inga Beale, dated 16 February 2021

opportunity for the other UK nations to take action towards the same ends. In addition, there should be a one-off national campaign to encourage everyone to know their HIV status.

- PrEP should be made available in other parts of the NHS across the UK, including pharmacies and GP surgeries. Funding should be made available by governments to support community outreach projects that work with Racially Minoritized Communities to increase awareness of PrEP, in a culturally appropriate way and one that challenges misinformation about PrEP. Health Education England, NHS Education Scotland, and Health Education and Improvement Wales should ensure there is regular training and development for all frontline NHS staff to better support Racially Minoritized Communities living with HIV. This should include measures to address unconscious bias, racism, and the importance of inclusive language, as well as focusing on cultural competencies.
- Health Education England, NHS Education Scotland, and Health Education and Improvement Wales should ensure there is regular training and development for all frontline NHS staff involved in HIV testing (including sexual health clinics, A&E, and GP surgeries). This should include measures to address unconscious bias, racism, and the importance of inclusive language, as well as focusing on cultural competencies to better support people from Racially Minoritized Communities.
- All government strategies to end new HIV cases by 2030 should have a focus on ensuring people living with HIV can enjoy fulfilling and healthy lives, this must include a recognition of the specific challenges Racially Minoritized Communities living with HIV experience, and action to address these. As demonstrated in the high rates of applicants to Terrence Higgins Trust Hardship Fund by people from Racially Minoritized Communities, there is an urgent need to tackle the root causes of social inequalities, including poverty, poor housing and structural inequalities that disproportionately impact these communities require cross-governmental working. Progress on tackling these inequalities should be included in annual reporting on work to end the domestic HIV epidemic

About our evidence

As well as drawing on existing reports and data, our evidence has been informed by the experiences of our frontline services – including health promotion, HIV testing, and financial and welfare support – to communities across England, Scotland, and Wales.

Evidence in our submission has also been informed by the work of the HIV Commission, which was founded by Terrence Higgins Trust, alongside Elton John AIDS Foundation and National AIDS Trust.

The HIV Commission sets out the actions that are needed for the UK Government to meet its commitment to end new cases of HIV by 2030.⁴ It also aims to support work being undertaken in Wales and Scotland to set out national plans to end HIV transmission. A key focus of the Commission was the

⁴ [HIV Commission final report](#), 2020

inequities experienced by Black, Asian, and other Minority Ethnic communities with KPIs being set for reductions in new diagnoses of HIV among Black African women and men.

In 2020, Terrence Higgins Trust made a public commitment to addressing the sexual health inequalities faced by Black people.⁵ This includes working with staff and service users from Black, Asian, and Minority Ethnic Communities to co-produce meaningful change. An immediate outcome of this was the establishment of a Racial Diversity Working Group for staff members from those communities to join. Members of the working group fed directly into this submission, including identifying several of our recommendations.

As well as being of interest to the APPG's inquiry, language has been an area of focus for Terrence Higgins Trust and its Racial Diversity Working Group. In line with its recommendation, Terrence Higgins plans to move away from using the term 'BAME' as it is no longer fit for purpose, doesn't reflect the significant diversity of experiences within a single acronym, and is not a category that our colleagues identify with. Internally, we are now using the term Racially Minoritized Communities. Where possible we try to be clear on the specific community we are referring to. However, the current national HIV data use terms such as 'Black African', so we have used a combination of terminologies throughout our submission to ensure consistency with other reports.

There is currently no consensus among Racially Minoritized Communities on what is the appropriate language to use. However, this underlines the immediate need for a larger piece of work to take place across civil society, supported by the Government and in partnership with those communities, to identify solutions.

Latest statistics on Racially Minoritized Communities and HIV⁶

- Over the past 10 years in the UK, there has been a gradual decline in diagnoses in Black African heterosexuals from 1,764 in 2010 to 581 in 2019. Between 2018-2019 there was one of the most notable drops in diagnoses for some time, with a 15% drop in diagnoses (from 683 down to 581).
- Reductions in new diagnoses have been slower and not as rapid as in other communities, for example, gay and bisexual men have seen a fall of 47% in new cases since 2015.
- 25,679 Black African heterosexual people were receiving HIV care across the UK in 2019, 26% of all those receiving care. Current PHE data does not include representation of gay and bisexual men who are also Black African, to be included within these figures.
- An estimated 28,200 Black African men and women are living with HIV in the UK in 2019, 5% of whom were undiagnosed. Late diagnoses continue to be a significant issue in this population, with 50% of all Black African heterosexual diagnoses in 2019 being diagnosed late. The UK Government's own Race Disparity Unit recognises that late HIV diagnosis is a health inequality

⁵ [Black Lives Matter](#), Terrence Higgins Trust, 2020

⁶ [HIV in the United Kingdom: Towards Zero HIV transmissions by 2030](#), Public Health England, 2019

that disproportionately impacts Racially Minoritized Communities.⁷ However, there is little indication of how this feeds into wider action by the UK Government to tackle this inequity.

- Black African men have seen no change in diagnoses. From 2018-19 'Black other' men have only seen a 5% drop. It is worth noting, however, that the number of diagnoses in these groups is small. The largest decline has been observed in Black Caribbean men dropping 21% in the past year and 57% since 2014.
- Black African women accounted for 39% of all women diagnosed, followed by White women accounting for 28%. The greatest decrease was seen in women of 'Black other' and Black African ethnicity with a drop of 8% and 6% respectively. Asian women were the only group of women to see an increase (8%) in the last year, although numbers in this group are low and overall have dropped by 40% since 2014.
- Overall, testing in Black African heterosexuals has increased 3% from 2015. However, 20% of Black African heterosexual women and 9% of Black African heterosexual men declined to test in sexual health clinics. Combined with the 15% of Black African heterosexual women not being offered a test, this means over a third of Black African heterosexual women are not being tested at a sexual health clinic.

1. Data collection

- The UK has some of the best HIV data surveillance systems in the world. Annual UK-wide reporting by Public Health England (PHE), including data tables and spotlight reports, is an invaluable resource to better understand the domestic HIV epidemic and inform services. Separate data is published by authorities in Northern Ireland, Scotland, and Wales, however, there is either limited or no data on ethnicity within these HIV data sets. Under current proposals by the UK Government, we expect responsibility for publishing national HIV data sets will lie with the UK Health Security Agency, with health promotion activity for England moving from PHE to the Office for Health Promotion at the Department of Health and Social Care.
- Despite the world-leading UK-wide HIV surveillance data, there remains a challenge in the lack of granular data available about different populations affected by HIV, including Racially Minoritized Communities. As we look at what needs to happen to end new cases of HIV within the decade, this need grows even greater. Speaking at the launch of the HIV Commission report on 1 December 2020, the Chancellor of the Duchy of Lancaster promised annual reporting on the progress made to achieve the 2025 and 2030 goals on HIV however, no further details have been provided on this yet.⁸
- There are several challenges in how the current HIV data sets record the experiences of Racially Minoritized Communities that need to be addressed. Firstly, there is an inconsistency in terminology and categories used to identify populations within national HIV data sets, and secondly, many ethnic groups are missing from these data sets. Data on 'BAME' populations

⁷ [HIV infection with late diagnosis](#), Ethnicity Facts and Figures, UK Government

⁸ [Government and Opposition back HIV Commission recommendations](#), HIV Commission, 2020

tend to predominantly focus on Black African, Black Caribbean, and Asian men and women. While other ethnic groups are often included in the ambiguous and stigmatising 'other' or 'mixed' categories within data sets. This is particularly notable in the absence of consistent HIV data about Latino populations. Thirdly, there is limited visibility of the intersectionality between ethnicity, gender, and sexual orientation when it comes to HIV. For example, the ethnic profile of gay and bisexual men living with HIV is not included within statistics on 'BAME' populations, and statistics on 'BAME' populations only included heterosexual men and women. Current national HIV data sets are therefore erasing the visibility of gay and bisexual men from Racially Minoritized Communities.

- Data from PHE obtained by National AIDS Trust showed in 2019, 62% of new HIV diagnoses in the UK were among people born abroad, with the majority of people born abroad diagnosed with HIV between 2009 and 2018 likely acquired HIV while living in the UK.⁹ Despite this, there is only limited data on migrants and asylum seekers within national HIV data sets. Migration is an issue of increasing significance to inform HIV interventions, such as HIV testing.
- Reporting on the experiences of women affected by HIV from Racially Minoritized Communities is also limited. Research by Terrence Higgins Trust and Sophia Forum found women affected by HIV (including those from Racially Minoritized Communities) are often left out of research, decision making, and service design and delivery.¹⁰ As part of a series of recommendations, we called on PHE to produce a spotlight report on women and HIV – this was subsequently published by PHE in 2019¹¹. This was an important first step, but further analysis and granular data are required to better understand the drivers of why Black African women, in particular, continue to be disproportionately impacted by HIV in the UK.
- Data on trans people and HIV has only been collected in England since 2015 - the impact of HIV among trans people before 2015 remains largely unknown. A code for sexual health clinics to record trans people's attendance was introduced, however, the HIV Commission learned that the use of this code is yet to be fully implemented. The experiences of trans people from Racially Minoritized Communities is even more of an unknown and should be better reflected within HIV data. Anecdotal evidence suggests that this population is some of the most minoritized and disenfranchised within society.
- The experiences and identities of groups within Racially Minoritized Communities are not being properly represented within current national HIV data sets. While the catch-all term 'Black African' is useful in epidemiological terms, it does not reflect the diversity within these communities and what HIV interventions and language is most acceptable and appropriate to people in these populations, based on either nationality or sexual orientation.
- There are no systematic mechanisms in place for local and national public health, and clinical oversight bodies to address equity issues that the current national HIV data sets identify.

⁹ [Press release](#): HIV and migration: Understanding the barriers faced by people born abroad living with HIV in the UK, National AIDS Trust, 2021

¹⁰ [Invisible No Longer](#), Terrence Higgins Trust and Sophia Forum, 2017

¹¹ [HIV: women in the UK](#), PHE, 2019

Recommendations

- Public Health England/UK Health Security Agency should produce more granular data linked to HIV, ethnicity, age, gender and migration status so greater understanding of intersectional issues impacting Racially Minoritized Communities affected by HIV can be understood.
- National HIV data on gay and bisexual men from Racially Minoritized Communities should be reflected within data sets based on ethnicity. National data sets on gay and bisexual men should include a breakdown of ethnicity in order to better understand the HIV epidemic using an intersectional approach.
- Public Health Wales and Public Health Scotland should publish national HIV data that includes statistics on ethnicity.
- To have a more robust and consistent data set about different ethnic groups, all national HIV data sets should use the same ethnic group categorisations. This would prevent the sometimes ambiguous terms such as 'other' being used in reporting and ensure proper representation of different Racially Minoritized Communities in data sets. We recommend alignment with the ethnic groups published by the UK Government, which is used in census data, as a starting point.¹²
- Public Health England should produce further insight reports on the experiences of Racially Minoritized women affected by HIV, with input from third sector organisations to inform its findings.
- Sexual health services across the UK should collect more consistent data about trans people affected by HIV, including rates of HIV test offer and take up.
- The PHE Health Equity Assessment Tool should be used more consistently by local and national public health, and clinical oversight bodies to plan, inform and assess HIV services in England to ensure they are addressing local health inequities that predominantly impact people from Racially Minoritized Communities.¹³

2. HIV testing

- In 2019, there were 549,849 missed opportunities to test for HIV in sexual health clinics in England, with an overall coverage of HIV testing in sexual health services at 65%. Of the 549,849 people not tested for HIV, 46% were not offered a test and the remainder declined testing.¹⁴ There are no national data sets on missed opportunities to test for HIV in these settings in Scotland and Wales. Of the missed opportunities to test for HIV in sexual health clinics in England, 75% were women; women are both less likely than men to be offered a test, and less likely to accept one when offered. Few gay and bisexual men declined testing (4%), in contrast to 9% of Black African heterosexual men and 20% of Black African heterosexual women.

¹² [List of ethnic groups](#), UK Government

¹³ [Health Equity Assessment Tool](#), Public Health England, 2020

¹⁴ [Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019](#), Public Health England, 2020

Combined with the 15% of Black African heterosexual women not being offered a test, this means over a third of Black African heterosexual women are not being tested at a sexual health clinic.

- The majority of women testing for HIV in sexual health clinics are White (72% in 2017), with testing rates lower in other ethnic groups, with Black African women most likely not to be offered an HIV test and also decline a test. Factors including structural racism within healthcare settings and a lack of staff confidence to have conversations about HIV with people from ethnic minority communities can contribute to people not having an HIV test.
- Since 2011, NICE has recommended that all sexual health clinics offer and recommend an HIV test to everyone who attends for testing or treatment.¹⁵ Guidelines by BASHH, BHIVA, and BIA also recommend opt-out testing at sexual health services, and recommends 'for many clinical settings, opt-out testing is the most effective method to increase testing coverage.'¹⁶ BASHH, BHIVA, and BIA define opt-out testing as: Opt-out testing means that attendees are informed that they will be automatically tested unless they actively decline.¹⁷
- The HIV Commission recommended introducing opt-out HIV testing in key areas of the NHS in England, with areas of high or extremely high local HIV prevalence being a priority. The HIV Commission recommended that introducing opt-out HIV testing in GP surgeries in areas of high or extremely high levels would help to increase testing to those less likely to access a sexual health clinic, which includes women, Black communities, and other ethnic minorities.¹⁸
- There are several reasons why people decline an HIV test, this can range from incorrect personal HIV risk assessments to the perception of stigma. Anecdotal evidence has also shown that the integration of sexual health services with other services such as reproductive health, in England has resulted in capacity issues with women who are accessing a contraception consultation/procedure, not then being offered an HIV test due to time pressures in a clinic.
- The HIV Commission identified gaps in routinely accessible widespread HIV testing as the single most important intervention and identifies Black African's as one of the key populations for targeted prevention interventions.¹⁹
- A report by Terrence Higgins Trust and the British Association for Sexual Health and HIV found that Black communities experience the highest rates of STIs and HIV.²⁰ It notes the role of intersectionality on the equalities reported, citing the links between socioeconomic, sociodemographic, and ethnicity in poor sexual health outcomes. The stigma associated with poor sexual health was identified as a key barrier to accessing services among all demographics but one survey in the south of England found that Black British, Black Caribbean, Black African and Black 'other' communities showed a preference for sexual health interventions being

¹⁵ [HIV testing: increasing uptake among people who may have undiagnosed HIV](#), NICE, 2016

¹⁶ [BHIVA/BASHH/BIA Adult HIV Testing guidelines 2020](#), BHIVA, 2020

¹⁷ Ibid

¹⁸ [The HIV Testing Traffic Light](#), HIV Commission, December 2020

¹⁹ [HIV Commission final report](#), 2020

²⁰ [State of the Nation report](#), Terrence Higgins Trust, BASHH, February 2020

available through the GP (60.5% of respondents).²¹ The survey concluded that the stigma associated with sexual health services made accessing services through the GP a more viable option.²²

- Migrants face significant barriers to testing despite the fact they are disproportionately impacted by HIV. A report by National AIDS Trust on the barriers migrants face accessing HIV testing, treatment, and care revealed that many migrants are not testing proactively for HIV with most being diagnosed only after seeking emergency treatment.²³ The 'hostile environment policy of the UK Government has significantly contributed to migrants and asylum seekers being deterred from accessing healthcare, including sexual health services. Terrence Higgins Trust services spoke of recent worries of migrants they support, including data sharing between NHS services and the Home Office. Sexual health services sit outside this protocol – it remains a challenge to reassure people that this is the case and data will not be shared.
- The UK has a range of other HIV testing opportunities outside of sexual health clinics and the introduction of home-testing brought by a change in legislation does provide people with even more flexibility to choose how and where they test. However, access to self-sampling or self-testing services varies across the UK. In England, not all local authorities provide free self-sampling HIV tests all year round. Moreover, Terrence Higgins Trust services have stated that some service users from Racially Minoritized Communities would prefer to see HIV testing made available within other support settings, for example, women's health groups.
- Data from Terrence Higgins Trust, It Starts With Me self-assessment HIV test tool²⁴ found that testing outside of sexual health clinics was popular among Racially Minoritized Communities. There was good tool uptake among users from a Racially Minoritized Community, 7,264 since December 2017. Of these, 66% preferred to test themselves rather than have someone else test them. Of those who preferred a self-test or self-sampling, 92% preferred to read the results themselves (self-test instead of self-sampling). There is an even greater preference among heterosexual people of Black African ethnicity to test themselves (73.4%) and of these, 96.5% prefer a self-test.
- As part of a wider free HIV self-test kit programme – to the most at-risk communities – Terrence Higgins Trust ring-fenced 3,000 kits for Black African users from May-December 2018. This included an option to deliver to any address or via a Click and Collect service at 4,000 collection points. There was enhanced promotion aimed at Black African communities. The results confirmed higher uptake of a Click and Collect delivery option among Black African users (14% v 10% overall users). Although a relatively small sample (54 orders), 17% of Black African women aged 50-64 used Click and Collect. There were also notably higher rates for gay and bisexual men from Pakistani backgrounds (29%), Indian backgrounds (24%), and Chinese backgrounds

²¹ Smith, A. & Rajeev, S. (2014) 'A Sexual Health Needs Assessment: Black and Minority Ethnic Communities living in Hampshire, Southampton and Portsmouth', <https://www.letstalkaboutit.nhs.uk/media/1109/bme-needs-assessment-v3-0215.pdf>,

²² Ibid.

²³ [HIV and migration report](#), National AIDS Trust, June 2021

²⁴ [Which test?](#) It Starts With Me

(19%). A full ethnicity breakdown of HIV self-test kit orders (including paid for orders) since 2016 is available as an appendix.²⁵

- Data from the national HIV Prevention England programme (more detail within the Prevention section) which promotes HIV community-based tests (point-of-care) and self-sampling kits in collaboration with Public Health England. Since 2016, this Terrence Higgins Trust programme has achieved:
 - 126,838 self-sampling kits ordered (annual average of 25,368).
 - According to Public Health England, 8% of all orders were from people from a Black African ethnic background from 2016-2019. Black African people made up 18% of reactive results.
 - 13,930 point-of-care/community-based tests (annual average of 2,786)
 - Nearly 44% of all community tests were delivered to people from Black African or other Racially Minoritized communities. On average, more than a third of these individuals were first-time testers.

Recommendations

- There should be increased funding made available to support increased HIV testing in all parts of the UK, this should prioritise opt-out HIV testing in areas with high or very high HIV prevalence. In England, money should be provided in the up-and-coming Comprehensive Spending Review by the Treasury to fully fund the national HIV Action Plan for England, including supporting the expansion of testing in other parts of the NHS that people from Racially Minoritized Communities are more likely to access. The Barnett consequences of this funding should be an opportunity for the other UK nations to take action towards the same ends. In addition, there should be a one-off national campaign to encourage everyone to know their HIV status.
- There should be a fully funded one-off national campaign to encourage everyone to know their HIV status by health departments across the UK.
- The introduction of opt-out HIV testing across the NHS in parts of the UK where there is very high and high HIV prevalence should be a priority by governments.
- Long-term and sustainable funding should be made available by governments to support community HIV testing initiatives. Tendering by local government should include a requirement for projects to be co-produced by service users, including design, implementation, and ongoing reviews of a service to ensure it meets the needs of users.
- Where appropriate and there is support from a community, HIV testing should be integrated within other local support services, for example, new parent support groups and women's health groups.
- Inspections of healthcare settings (for example by the Care Quality Commission in England or Healthcare Improvement Scotland) where current opt-out HIV testing guidelines, including NICE and BHIVA/BASHH/BIA, are applicable, should be audited to ensure this is taking place. Where the guidelines are not being followed, this should be referenced in inspection reports, with recommendations to address these gaps.

²⁵ See Appendix 1

- Health Education England, NHS Education Scotland, and Health Education and Improvement Wales should ensure there is regular training and development for all frontline NHS staff involved in HIV testing (including sexual health clinics, A&E, and GP surgeries). This should include measures to address unconscious bias, racism, and the importance of inclusive language, as well as focusing on cultural competencies to better support people from Racially Minoritized Communities.
- All parts of the UK should have free at-home self-sampling HIV testing available all year round, this should also include options to Click and Collect at pick-up points. There should be a long-term aspiration by governments and health authorities to go one better and provide free home-testing to those at the highest risk of HIV, including people from Black African backgrounds.

3. Prevention

- Terrence Higgins Trust currently manages the HIV Prevention England (HPE) programme, which is a national HIV prevention programme and funded by Public Health England. HPE delivers a programme of HIV prevention work for those most affected by HIV in England, mainly gay and bisexual men and Black African people.
- The flagship activity of the HPE programme is National HIV Testing Week which usually takes place in England in November and has been running since 2015. HPE works with a number of local activation partners to deliver National HIV Testing Week in their part of England. In Scotland and Wales, Terrence Higgins Trust supports separate HIV testing week initiatives. In England, National HIV Testing Week targets gay and bisexual men, and Black African people to encourage uptake of HIV testing and increase awareness of HIV, including PrEP, condoms, the different ways to test (at home, self-sampling, community testing, or at a sexual health clinic) and PrEP. National HIV Testing Week 2020 was postponed until February 2021 and saw record numbers of people order HIV self-sampling kits provided by Public Health England.
- To build meaningful relationships with Racially Minoritized Communities, HPE has attended a series of outreach events, including offering HIV testing, at African cultural events, including Africa Nations Cup and Kenya in the Park. The visibility of HIV testing at these events has helped address stigma and increase awareness of HIV among attendees.
- Throughout the year, HPE uses social marketing to reach communities, this includes targeted advertising on social media platforms, working with media outlets that specialise in news coverage for Black African communities, and dating apps. It costs significantly more to prompt Black African communities to order an HIV test via digital platforms than it does to reach White gay and bisexual men. However, there is limited recognition of equity and the different funding required to engage with Racially Minoritized Communities affected by HIV and the different routes of engagement required. The need for targeted approaches to HIV prevention messaging will become even more acute to find the 6,700 people who remain undiagnosed in the UK.
- The experience of HPE working with social influencers, such as celebrities and faith leaders - many of whom are not associated with the 'HIV sector' – has been hugely beneficial in engaging Racially Minoritized Communities about HIV prevention campaigns, who otherwise could not be

as receptive to traditional campaigning messages from sexual health services or HIV organisations. For *It Starts With Me* and *National HIV Testing Week*, independent evaluation has consistently demonstrated high levels of target audience campaign recognition and message comprehension. National surveillance data has shown that the campaign is effective at increasing testing.

- Successes of HPE include:
 - **Awareness:** According to an independent evaluation, since 2016, an average of 73% of people from Black African backgrounds have recognized the campaign, while on average 66.5% have been motivated to take an action due to the campaign.
 - **Engagement:** 40,190 (25% of all) uses of the interactive tools on the *It Starts With Me* website were by users from a Racially Minoritized Community. Local activation partners provided face-to-face HIV information to >43,300 individuals from these backgrounds (54.8% of all people engaged), including 10,486 gay and bisexual men from Racially Minoritized Communities and bisexual men and 32,912 heterosexual people of Black African ethnicity.
 - **Behaviour change:** There were 126,838 self-sampling HIV test kits ordered as a result of *It Starts With Me*/National HIV Testing Week promotion. Local partners tested nearly 14,000 individuals from a Racially Minoritized Community and more than a third of these were first-time testers. PHE surveillance has shown steady growth in the numbers of HIV tests since *It Starts With Me* was launched, contributing to an emerging decline in rates of new diagnoses.
 - **Sector impact:** National HIV Testing Week brings the English HIV sector together to promote HIV testing. In an annual survey of participating organisations and clinics, over 90% agreed that the campaign added value to their HIV prevention efforts and that they would support it in the future.
- In October 2020, Terrence Higgins Trust launched the 'PrEP protects' campaign to raise awareness of PrEP among Black African men and women. The campaign was led by those from these communities, the campaign vibrantly showcased the benefits of being proactive about your sexual health. It reached different Black African populations through influencers, relevant Facebook groups, targeted digital ads, and outdoor posters and billboards. A key message of the campaign was that people cannot access something [PrEP] that they don't know about. Just 4% of people accessing the NHS England PrEP Impact Trial were not gay and bisexual men²⁶. The Terrence Higgins Trust campaign received over 4 million clicks online, with nearly 70,000 link clicks to the campaign webpage. The campaign was highly effective at reaching Black African people, with over 1,250 people completing the PrEP self-assessment tool (to help determine if an individual would benefit from PrEP) and 68% of those who specified their ethnicity were Black African people.
- Overall knowledge and awareness of PrEP remain low among Racially Minoritized Communities, in particular among Black African heterosexuals. While rates of White cisgender women and White cisgender heterosexual men were significantly lower than gay and bisexual men on the

²⁶ [Black people left behind as PrEP rolls out](#), Terrence Higgins Trust, 2020

trial, rates among this ethnic group were significantly higher. Data of those who enrolled on the Impact trial showed there were: ²⁷

- 26 Black African cisgender women
- 18 Black African cisgender heterosexual men
- 10 Asian and Asian British cisgender women
- 6 Asian and Asian British cisgender heterosexual men
- 134 White cisgender women
- 56 White heterosexual cisgender men
- Figures for trans people from Racially Minoritized Communities were similarly low in comparison to White trans people: ²⁸
 - 3 Black African trans women
 - 29 Asian and Asian British trans women
 - 1 Black African trans man
 - 9 Asian and Asian British trans men
 - 143 White trans women
 - 80 White trans men
- In Scotland, 99% of people accessing PrEP are male and of that group, 98% are gay and bisexual men.²⁹ This could be as a result of PrEP awareness campaigns that have traditionally focused on reaching UK-born gay and bisexual White men living in urban areas. The increased awareness has resulted in PrEP uptake among this population, which has been highlighted as one of the reasons for the reductions in new cases of HIV among gay and bisexual men. But this creates a serious inequity with progress on PrEP uptake, which is also in part driven by an individual's ability to access PrEP. There are currently three ways that PrEP can be accessed in England, Wales, and Scotland:
 - Free from NHS sexual health clinics (have to meet eligibility criteria for high-risk sex).
 - Generic PrEP can be obtained through some online pharmacies or private clinics at a cost.
 - Another avenue is by buying online from overseas vendors (you can only legally buy medication overseas for personal use and not more than 3 months supply).
- Other Terrence Higgins Trust projects which focus on HIV prevention among Racially Minoritized Communities, include:
 - **Champions of Change project in Bristol.** As part of Unity Sexual Health in Bristol, Terrence Higgins Trust has managed the Champions of Change project. The project works directly with developed community networks, taps into existing community education and mobilisation, and learns directly from our beneficiaries how to best support their needs. Bristol has an above national average late HIV diagnosis of Black African and Black Caribbean communities. The project aims to:

²⁷ Baseline demographics, coverage and first regimen choice of participants in the HIV Pre-Exposure Prophylaxis (PrEP) Impact Trial, Presentation by A. Sullivan et al., HIV Virtual IAS conference, 2021

²⁸ Ibid

²⁹ [Implementation of PrEP in Scotland](#), Health Protection Scotland, 2019

- i. Address stigma.
 - ii. Increase knowledge around HIV and sexual health.
 - iii. Promote condoms and other safer sex methods.
 - iv. Identify and address barriers to accessing services.
 - v. Increase testing.
 - vi. In 2019 - 2020, the project distributed 1,000 condoms in bars, barbers, festivals, and fairs, attended 30 community events, and trained six volunteers. Healthcare staff, statutory services, charities, community groups, medical schools, or anyone working with and for 'BAME' communities can access the training provided by the Champions of Change project.
- **Peer-led services in Luton**, including point of care testing and wider health promotion initiatives.
 - The UK Government has stated that it is actively considering different settings in which PrEP could be made available outside sexual health clinics as part of the HIV Action Plan in England. The current model of PrEP delivery is not reaching all communities who could benefit from PrEP and, in particular, is failing Racially Minoritized Communities, many of whom are already being failed by not even being offered an HIV test at sexual health clinics. In line with other sexual health treatments and the contraceptive pill, PrEP in all NHS settings must also not be subject to a prescription charge. There is an international precedent for making PrEP available outside sexual health clinics, with the states of Oregon, Colorado, and California legislating for PrEP access in a range of different settings.
 - The experience from Terrence Higgins Trust's PrEP Protects campaign is that changing the language to focus more on personal empowerment is an effective way to engage Black African communities in particular about the benefits of PrEP.
 - The COVID-19 pandemic has highlighted the challenges of 'fake news' when it comes to health information. The experience of HPE and wider Terrence Higgins Trust work to engage Racially Minoritized Communities has been to ensure there is regular visibility and persistence. This includes attending large-scale events such as Kenya in the Park or forging relationships with barbershop owners to make space to put information about HIV testing and Terrence Higgins Trust services on display.

Recommendations

- PrEP should be available in other parts of the NHS across the UK, including pharmacies and GP surgeries. Funding should be made available by governments to support community outreach projects that work with Racially Minoritized Communities to increase awareness of PrEP, in a culturally appropriate way and one that challenges misinformation about PrEP.
- HIV prevention messaging should be embedded within wider community support settings, such as women's health groups or GP surgeries.
- The funding and commissioning process for local and national HIV prevention services should embed equity of services for all communities impacted by HIV, including Racially Minoritized Communities.

- Social marketing is a key tool to engage different communities about HIV prevention and lessons learned from the HPE programme should be used to inform future government and NHS messaging about HIV.

4. Quality of life for people living with HIV

- All people living with HIV can experience a range of comorbidities which can vary depending on the time of HIV diagnosis and age. Overall poorer health can exacerbate the risk of comorbidities and quality of life. In the APPG's report on HIV and mental health, people living with HIV are twice as likely to experience poorer mental health, including depression and anxiety than the wider population.³⁰ Prior to this report, the National AIDS Trust 2014 report on HIV and Black African communities highlighted the impact of immigration status/processes, social isolation and ineligibility to meet the care assessment criteria for additional social support in those above 50 years of age, as contributors to poor mental health outcomes. Overall, mental health support for people living with HIV remains patchy, with nearly 40% of HIV clinics not having access to a psychological or mental health professional within their multidisciplinary teams.³¹ Stigma and misinformation about HIV often fuel poor mental health and can result in rejection from friends and family or increased vulnerability to Intimate Partner Violence.³²
- There is a clear link between deprivation and ethnicity in the UK. Statistics from the UK Government revealed that in 2019, people from all ethnic minority groups except the Indian, Chinese, White Irish, and White Other groups were more likely than White British people to live in the most overall deprived 10% of neighborhoods in England.³³ Racially Minoritized people living with HIV, therefore, face a range of additional challenges, including poverty, poor health outcomes, and wider discrimination.
- Migrants and asylum seekers living with HIV face significant barriers to access care and support, despite HIV treatment being free to anyone living in the UK, regardless of immigration status. As described above, migrants and asylum seekers face particular barriers to accessing HIV services and care. The National AIDS Trust found worrying issues linked to the impact of current immigration policies, including charging for healthcare and limited translation services in the NHS for people who do not speak English as a first language.³⁴ Moreover, the report found migrants and asylum seekers experience confusion at how to navigate the health and social care system, coupled with high rates of poverty and poor housing. The so-called 'hostile environment' policies by the UK Government such as data sharing with the NHS and the Home Office have resulted in people being deterred from accessing healthcare and contributed to late HIV diagnoses.

³⁰ [The Missing Link: HIV and mental health report](#), APPG on HIV and AIDS, 2020

³¹ Ibid

³² [HIV and Black African Communities in the UK report](#), National AIDS Trust, 2014

³³ [People living in deprived neighbourhoods](#). UK Government, 2020

³⁴ [HIV and migration report](#), National AIDS Trust, 2021

- Terrence Higgins Trust Scotland provides support for migrant and asylum seeker communities who are living with HIV. The team report that they often work with people from Racially Minoritized Communities but, due to a lack of capacity, this support doesn't go beyond immediate needs, for example, housing or welfare rights issues. This means little work is done to support people to manage their condition and understand their HIV (and/or another blood-borne virus) diagnoses.
- The HIV Commission³⁵ concluded that Racially Minoritized Communities are consistently more likely to experience inequalities in health, including mental health. To tackle this, it recommended:
 - To improve uptake of services, support that is better culturally, linguistically, and faith tailored is needed.
 - Tailored interventions must avoid stigmatising communities.
- Terrence Higgins Trust provides a Hardship Fund (HSF) service to alleviate short-term financial poverty in the lives of adults living with HIV in the UK. The service has run since 2011 and is the only UK-based grant-awarding service for people living with HIV. There is a lifetime award limit of £500 and reapplication is limited to a minimum of 1 year for those on benefits and 6 months for those with immigration considerations. Data from the service covering 2015-2020 shows 3,032 applications, with 2,595 grants awarded, totaling £317,445. The majority of applications are requests for help with basic living expenses such as:
 - Food items
 - Clothing
 - Travel costs to attend clinic appointments
 - Applicants from Racially Minoritized Communities accounted for 81% (2,112) of all awards provided from 2015-2020.
 - During the COVID-19 pandemic (1/04/2020- 31/3/2021), the HSF received 589 applications, of which 563 applications eligible for a grant were awarded, totaling £65,850. Applicants from Racially Minoritized Communities accounted for 61% (345) of all awards provided.
- The trend to move from specialist HIV services towards a more integrated care model does provide opportunities to deliver a more holistic approach to the health of people living with HIV, and better reflect the additional health requirements people may need support with. However, the HIV Commission found that stigma and misinformation about HIV remains prevalent within health and social care settings. This creates barriers to support for people living with HIV.
- Terrence Higgins Trust provides a range of support services for Racially Minoritized Communities living with HIV. A key to the success of these services is ensuring that they are user-led and co-produced so they can meet the needs of the people using them. A three-year programme, [Amplifying our User Voice](#), funded by the National Lottery Community Fund, is helping us better understand what people who interact with our charity want from us. The programme allows

³⁵ [HIV Commission report](#) (2020) *Terrence Higgins Trust, Elton John AIDS Foundation, National AIDS Trust*

service users to help shape the internal workings of the organisation and the services we provide. Services for Racially Minoritized Communities living with HIV that THT provides include:

- **Talking therapies.** Terrence Higgins Trust offers a range of talking therapies for people living with HIV, including free online counseling. We sought to improve these services for women and Racially Minoritized Communities through a co-production approach. Focus groups were held and the majority of participants were living with HIV. There was a recognition of the importance of peer support to create networks of people facing similar issues. The groups made several recommendations, including:
 - Increased advertising of our services through different channels to reach all groups affected by HIV, relying on existing sexual health services risks missing potential users.
 - Effective support groups should have both individual and group support to meet the needs of users.
 - Cultural training is crucial and more training is needed in this area. There are also issues around language barriers.
 - Confidentiality is extremely important, people should have the option to use a pseudonym.
 - Diversity should be recognised in imagery to advertise services and materials should be placed in places of worship and community centres.
 - Specific consideration should be given to women, including support services in the evening so they can manage childcare responsibilities, and support with talking about HIV to family.
- **Addressing the needs of marginalised groups in Brighton and across the Home Counties.** This work supports groups that experience poor health outcomes, including people living with HIV, gay and bisexual men, sex workers, trans people, and Racially Minoritized Communities.
- In Wales, services to support people living with HIV are limited. Subsequent funding cuts and changes in contracts have meant Terrence Higgins Trust has scaled down previous support services, some of which directly supported Racially Minoritized people living with HIV who faced difficulties with talking about HIV and possible rejection from families. Some of the disenfranchised communities living with HIV in Wales are Racially Minoritized Communities and people over 50 years old.

Recommendations

- All government strategies to end new HIV cases by 2030 should have a focus on ensuring people living with HIV can enjoy fulfilling and healthy lives, this must include a recognition of the specific challenges Racially Minoritized Communities living with HIV experience, and action to address these. As demonstrated in the high rates of applicants to Terrence Higgins Trust Hardship Fund by people from Racially Minoritized Communities, there is an urgent need to tackle the root causes of social inequalities, including poverty, poor housing and structural

inequalities that disproportionately impact these communities require cross-governmental working. Progress on tackling these inequalities should be included in annual reporting on work to end the domestic HIV epidemic

- National HIV action plans should include targeted work to ensure migrants and asylum seekers living with HIV can access HIV care and treatment without fear or intimidation by policies from the Home Office. There should be no 'hostile environment' towards these communities in regard to HIV care and treatment (including data sharing), and the Home Office – in partnership with health departments across the UK – should issue explicit guidance making this clear.
- Health Education England, NHS Education Scotland, and Health Education and Improvement Wales should ensure there is regular training and development for all frontline NHS staff to better support Racially Minoritized Communities living with HIV. This should include measures to address unconscious bias, racism, and the importance of inclusive language, as well as focusing on cultural competencies.
- There should be zero tolerance towards stigma and discrimination within healthcare for people living with HIV. Relevant healthcare inspection agencies should assess how services are working to better support people living with HIV, in particular addressing barriers experienced by Racially Minoritized Communities.
- Co-production should be embedded across services for people living with HIV.

5. Working in partnership with other organisations

- Terrence Higgins Trust has been pleased to recently partner with the One Voice Network which works to improve health outcomes for Black communities in the UK, in particular those affected by the HIV epidemic, in calling out the UK Government's discriminatory decision to maintain certain blood donation rules that disproportionately impacts Black communities in England. The restriction relates to a three-month deferral period for anyone who has a 'partner who has, or you think may have been, sexually active in parts of the world where HIV/AIDS is very common' and references 'most countries in Africa'. The question has been removed in both Scotland and Wales but retained in England; while Northern Ireland has postponed changes until September. We wrote a joint letter to the then Secretary of State for Health and Social Care urging the Department to reconsider and instead base the rules on evidence, not outdated and vague criteria.³⁶
- We recognise the importance of meaningfully involving Racially Minoritized Communities in the policy, prevention, and support of people affected by HIV and poor sexual health. The work of our Racial Diversity Working Group has been – and continues to be – crucial in our journey to become an anti-racist, anti-sexist, and more inclusive organisation. We have made progress but acknowledge more work is required to meet these ambitions. We will shortly be appointing a new Director of Equity, Diversity, and Inclusion and are working with a diversity consultancy to drive forward our work in this area.

³⁶ [Terrence Higgins Trust and One Voice Network letter to Secretary of State regarding blood donation rules](#), dated 14 June 2021, Terrence Higgins Trust Twitter

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APPENDIX

Ethnicity breakdown of HIV self-test kit orders from Terrence Higgins Trust since 2016

Asian-Bangladeshi	113
Asian-Indian	661
Asian-Other	883
Asian-Pakistani	463
Black-African	5739
Black-Caribbean	736
Black-Other	222
Chinese	414
Mixed-Other	580
Mixed-White-Asian	350
Mixed-White-Black African	391
Mixed-White-Black Caribbean	555
Other	424
Rather-not-say	608
White-British	33014
White-Irish	1154
white-other	4095