THE ALL-PARTY PARLIAMENTARY GROUP

appg on HIV & AIDS

Nothing about us without us

Addressing the Needs of Black, Asian and Minority Ethnic Communities in Relation to HIV

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The views expressed in this report are those of the group.

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Definitions

Online testing – Ordering your test online to be delivered at home.

HIV self-testing – A test that requires a miniscule amount of blood to put into a test, similar to a pregnancy test. The person will have a short 15 minute wait until they know their own status, there and then.

HIV self-sampling – A test that requires enough blood to fill the collection tube which is approximately 600ml. Then the blood is sent in the post back to a laboratory where the test is performed. The person will then be notified of the result.

HIV - HIV (human immunodeficiency virus) is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). There is currently no effective cure. Once people get HIV, they have it for life. But with proper medical care, HIV can be controlled.

AIDS - AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus. While AIDS cannot be transmitted from one person to another, the HIV virus can.

PrEP - PrEP (pre-exposure prophylaxis) is a medication people can take regularly to prevent them getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV.

PEP - PEP (sometimes called PEPSE) is a combination of HIV drugs that can stop the virus taking hold. It can be used after the event if you believe you may be at risk of HIV transmission.

BAME - Black, Asian and Minority Ethnic communities

HIV-1 & HIV-2 - HIV-1 and HIV-2 are two distinct viruses. Worldwide, the predominant virus is HIV-1. HIV-1 accounts for around 95% of all infections worldwide. HIV-2 is estimated to be more than 55% genetically distinct from HIV-1.

U=U - Undetectable = Untransmittable' (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.

List of Abbreviations

APPG	All Party Parliamentary Group
ART	Antiretroviral therapy
BAME	Black Asian and Minority Ethnic
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
BIA	British Infection Association
CHIVA	Children's HIV Association
DHSE	Department for Health and Social Care
DWP	Department for Work and Pensions
EJAF	Elton John AIDS Foundation
FTC&V	Fast Track Cardiff and Vale
HPE	HIV Prevention England
ICS	Integrated Care System
LGBT	Lesbian Gay Bisexual and Transgender
MSM	Men who have sex with men
NAT	National AIDS Trust
NHIVTW	National HIV Testing Week
PHE	Public Health England
PHW	Public Health Wales
PLWHIV	People Living With HIV
QoL	Quality of Life
SHS	Sexual Health Service
SIB	Social Impact Bond
STI	Sexually Transmitted Infection
THT	Terrence Higgins Trust

Foreword: Florence Eshalomi MP

HIV emerged 40 years ago this month and created an epidemic that still devastates the communities where it was found.

The history of HIV has been largely seen through a white lens, an illness drawing attention for ravaging white men and cultural touchstones like the film Philadelphia, about a gay white man who had AIDS. But we know HIV has been affecting the Black, Asian and Minority Ethnic communities since at least the 1960s. The whitewashing of the epidemic helps explain why today, even as HIV and AIDS rates decline across the UK, Black, Asian, Latinx and others are more vulnerable to HIV infection than white men and women.

We've made big progress in the fight against HIV in the UK since the dark days of the epidemic. New cases of HIV have fallen by over a third in the last five years, with diagnoses among gay and bisexual men nearly halved. The extraordinary advances in HIV treatment mean that the majority of people living with HIV can now expect a normal life expectancy and - even more remarkably - can't pass on the virus.

But that same progress in reducing transmissions isn't being felt across all groups. Diagnoses among women – who account for a third of all people living with HIV – only fell by 4% in 2019, compared with 10% across the general population. Almost half of new HIV diagnoses among heterosexuals in the UK are among Black African men and women – despite making up less than 2% of the British population. These communities are less likely to access the anti-HIV drug, PrEP, which finally became routinely available on the NHS after the government shamelessly dithered and delayed.

We need to reach every community with our HIV response – we need targeted investment, and this includes for those born abroad and living in the UK.

The APPG have called on the Governments of the UK along with the National AIDS Trust, Terrence Higgins Trust, Elton John AIDS Foundation and others to ensure that all four Nations have a HIV Action Plan to deliver the promised 2030 commitment to end new transmissions.

If we are to meet that target then, the voices, experiences and the needs of Black, Asian and Minority Ethnic communities need to be given specific focus and support as part of this action plan process. We cannot end transmissions whilst leaving any group behind.

I represent Vauxhall, an area that has a large Black population, and one of the highest rates of HIV prevalence in the country. I have seen first-hand the inequalities they face day to day. They face additional economic and social barriers such as stigma, income and discrimination. If we are to end HIV in the UK then we must tackle those inequalities and ensure there is equitable and easy access for all to HIV testing, prevention and care.

Flotrence Eshalomi MP
Vice Chair

Foreword: Marc Thompson

Since the beginning of the global HIV pandemic over 40 years ago, people from racially minoritised communities - particularly people of Black African descent - have been disproportionately impacted by HIV worldwide.

I have no doubt that if the AIDS epidemic had affected young, white, heterosexual people at that time, the response across society would have been completely different. The government and health services would have acted a lot more quickly.

The COVID-19 pandemic has highlighted existing health inequalities, across almost every health condition. Therefore, it should be no surprise that these same inequalities will exist across HIV.

Historically, Black led services and organisations have been underfunded and as a result we have often been left out of the conversation at senior and strategic level.
I am shocked to see that there are only eleven Black, Asian and minority ethnic-led organisations in the UK addressing the needs of those communities when it comes to HIV.

When I was diagnosed, HIV positive in 1986, I had a lack of information about how HIV was transmitted, limited access to prevention tools, namely condoms, a sense that HIV did not affect my community of Black men who have sex with men and limited services developed to meet my cultural needs. Flash forward 36 years and these are the exact same reasons why many people from Black, Asian and other ethnic communities continue to be impacted by HIV in the UK. As an activist, health promoter and person living with HIV this is no longer acceptable.

We have had major successes since then and in the UK, we are making great progress to ending new transmissions by 2030. However, these successes are not happening across all communities. People whose first language isn't English, people who are migrants or who don't have a secure immigration status, and people in Latinx and South Asian communities have higher prevention and support needs that are not currently being addressed.

I've been working in HIV and sexual health for over three decades and have witnessed the impact of this exclusion. If we are to ever really make progress and meet the ambitious target by 2030, these lives must really matter, their voices must be heard, and their needs must be acknowledged and recognised.

I welcome this report as it outlines evidence and clear recommendations that the four governments must implement, to ensure the voices of the most marginalised and those from racially-minoritised communities are included in the national HIV response.

I feel that we must fight for all communities, but I make no apologies for putting people of colour at the top - that's because they are so often on the bottom rung of the ladder.

We cannot end the UK HIV epidemic unless all of us have a seat at the table.

Marc Thompson
Director, The Love Tank

Foreword: Dr Rageshri Dhairyawan

I have been fortunate to work as a HIV doctor in an era where life-saving antiretroviral medication is available. The majority of people living with HIV in the UK are living healthy lives on effective treatment, and HIV prevention tools and a variety of testing methods are increasingly accessible. These successes should be celebrated and are down to the efforts of, amongst others, dedicated HIV activists and advocates, healthcare workers, researchers and policy-makers.

However, in my day-to-day clinical practice I still see people who are not benefitting from these advances. On the wards and in clinic, people continue to suffer life-changing disability or die from AIDS-related conditions such as Non-Hodgkin lymphoma and progressive multifocal leukoencephalopathy. These are often people diagnosed late, or not on medication or engaged in HIV care. These are often people from communities which have been marginalised, including racially minoritised groups. Data suggests that people from minority ethnic groups living with HIV in the UK experience significant barriers to HIV testing, taking treatment consistently and staying engaged in care. As these are associated with HIV-related mortality, illness and onwards transmission, it is vital that we understand and work to end these inequalities to ensure more equitable outcomes.

The COVID-19 pandemic has exposed existing and pervasive ethnic health inequalities in the UK, which can be found in almost every area of health. Some of these have existed with little improvement for decades. However, they are not innate or unchangeable; they can be reversed. The COVID-19 pandemic and recent social justice movements have highlighted the impact of structural racism on racially minoritised communities. Structural racism is a root cause of ethnic health inequalities and it is encouraging to see increasing discourse on this, as well as actions being taken to address these inequalities.

I therefore welcome this timely and important report, which sets out the evidence regarding ethnic inequalities in HIV, looks at the gaps and suggests actions at multiple levels to tackle them. It is only through intersectoral working that effective change can be realised. In order that interventions are targeted and acceptable, they must be led by the communities most affected by poor health outcomes. They must also receive the right support to do this. Whilst it is vital to focus on the minority ethnic groups most affected by worse HIV outcomes such as Black Africans, we must also consider other affected groups, such as Asians and Latin Americans.

Ethnic health inequalities in HIV and beyond reduce life expectancy and quality of life for people from racially minoritised groups. This is a matter of human rights and social justice, as well as about meeting targets to end the AIDS epidemic. We have a moral imperative to ensure that these groups who have been historically underserved are not left behind further, and this timely report sets out a strategy to follow. I look forward to a future where clinicians are no longer seeing people with AIDS-defining illnesses on the wards.

Dr Rageshri Dhairyawan
Consultant in HIV Medicine, Barts Health NHS Trust
Honorary Senior Lecturer, Queen Mary University of London

NATIONAL HIV TESTING WEEK
1-7 FEBRUARY 2021

GIVE HIV THE FINGER
A finger-prick test is all it takes.
ORDER A FREE HOME TEST
StartsWithMe.org.uk

GLOBAL HIV COLLABORATIVE

OUR MISSION
We work tirelessly every day to create a world in which every Black person living with HIV gets the equal health outcomes they deserve.
Better healthcare programmes, better treatment, better policy.
www.hiv-collaborative.org

I'M STOPPING HIV.
I'm on treatment.

Sisters are doin' it for themselves
PrEP as part of sexual and reproductive health for women
PREPSTER AND THE LOVE TANK WITH #WANTPREPNOW AND TERRENCE HIGGINS TRUST

CAN'T PASS IT ON
People on effective HIV treatment CANNOT pass on the virus
FACT
www.tht.org.uk

ARE YOU LIVING WITH HIV & THE MENOPAUSE?
BEARDED AND FLUSHED
CREATIVE WRITING WORKSHOPS
THURSDAY 24 JUNE (WEEKLY)
7.00-8.30PM
(ONLINE VIA ZOOM)
To sign up or for more information, email: sekhon@naz.org.uk

FAST TRACK CARDIFF
#DoYouKnow

#CHOOSETO CHALLENGE
82 % OF WOMEN LIVING WITH HIV IN UK ARE BAME
75 % OF WOMEN NEWLY DIAGNOSED WITH HIV ARE BAME
67 % OF WOMEN LIVING WITH HIV ARE BLACK AFRICAN
NAZ
SEXUAL HEALTH FOR EVERYONE

GLOBAL HIV COLLABORATIVE
Website Launch!
WHO WE ARE
A collaborative of HIV activists and experts focused on changing the story of HIV for Black communities on a global scale.
Better healthcare programmes, better treatment, better policy.
www.hiv-collaborative.org

CHALLENGE
PEP (post-exposure prophylaxis) is a treatment that may stop you from developing an HIV infection if you've been exposed to the virus. It must be taken within 72 hours of exposure.
NAZ
SEXUAL HEALTH FOR EVERYONE

empowering
WOMEN KNOW BEST:
What are the best practices in effective, quality HIV support for women in the UK
We want change. We are positive.
POSITIVELY UK
Supported by AbbVie and BHIVA

PEOPLE ON EFFECTIVE HIV TREATMENT CANNOT PASS ON THE VIRUS.
FACT
CAN'T PASS IT ON

After I was diagnosed with HIV my life really changed.
I am now training to be a nurse.

Prepster
TOP, VERS, OR BOTTOM
PrEP WORKS!
To find out if PrEP might be for you, or someone you know visit prepster.info
GET BUSY AT GLASTO?
STI tests are free in the UK and regular check ups are recommended. Vaccinations for HPV and Hep A + B are also available at clinics.
prepster.info/vaxster
NYC DOWNLOW

Brighton & Hove Sexual Health & Contraception Service
PrEP PROTECTS
PrEP is a pill that stops me getting HIV
PrEP is free and confidential
Find out more
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NAZ
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We're back!
WEDNESDAY • 29 SEPT • 6-9PM
AN INCLUSIVE, PEER SUPPORT SINGING GROUP OF PEOPLE LIVING WITH HIV.
FOR MORE INFO CONTACT:
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WWW.NAZ.ORG.UK

NO MORE SILENCE
DATE: 18 MAR 2021 TIME: 6.30PM
VENUE: ZOOM ONLINE
A MONTHLY SPACE FOR BLACK GBTQ+ MEN
WWW.NAZ.ORG.UK

CHALLENGE
These 5 tools can stop HIV transmission:
- Consistent condom use
- Regular STI testing
- HIV treatment
- PrEP (pre-exposure prophylaxis)
- PEP (post-exposure prophylaxis)

SAFE SEX
NAZ
SEXUAL HEALTH FOR EVERYONE

We test for HIV because we look after each other
Testing is easy and confidential. Find an HIV testing service at www.mehimus.org.uk
Me.Him.Us
Charity Number: 1076854 | Company limited by guarantee: 2702133 © LGBT HERO | www.lgbthero.org.uk

Knowing your status is the first step to protecting yourself and others

Gwybod dy statws yw'r cam cyntaf i amddiffyn dy hun ac eraill

#HIVTestingWeek
FAST TRACK CARDIFF

NAZ
LATINX AND PROUD
Vic
Imale
sexy, healthy, queer.

After I was diagnosed with HIV my life really changed.
I became a circus artist
Sadiq
HIV has changed. We help people to come to terms with their HIV diagnosis and get on with life. Support our work now.
#lifereallychanged tht.org.uk
TOGETHER WE CAN

#CHOOSETO CHALLENGE
If your partner has an undetectable viral load, consider using condoms for your own peace of mind.
Condoms prevent the transmission of infections other than HIV.
NAZ
SEXUAL HEALTH FOR EVERYONE

combination HIV & STI PREVENTION

Acknowledgements

Thank you to all of the 26 organisations and individuals who have worked with us throughout the course of the inquiry. This report was compiled by **Mark Lewis**, Senior Policy Advisor to the APPG on HIV and AIDS. If you would like further copies please contact **mark.lewis@parliament.uk**

We would also like to thank **The Love Tank**, **NAZ**, **Lisa Power**, **Terrence Higgins Trust**, **National AIDS Trust**, **Dr Rageshri Dhairyawan** and **BHIVA** for their guidance during this inquiry.

Methodology

The APPG put out a call for written evidence on 14th May 2021 and we received 26 submissions. We also held two oral evidence sessions on 30th June and 1st July 2021. This inquiry deals with the issues faced by the Black, Asian and Minority Ethnic communities in relation to HIV.

While the report recognises that different groups of people have different needs – for instance, diverse Black, Asian and Minority Ethnic communities groups, heterosexual, gay and bisexual men, women, trans, non-binary, gender diverse people, older people, children and young people, people who use drugs and formerly used drugs, people from diverse religious backgrounds, refugees and asylum seekers, and the many people with HIV who have experienced trauma – we use examples which we encountered from our research which do not necessarily reflect the full spectrum of communities within the broader group of people who need to be targeted for HIV testing. The reflections and recommendations however apply to all people at risk of HIV.

Executive Summary

Inequality in HIV care is a matter of serious concern and an issue that is experienced daily by frontline community organisations working directly with Black, Asian and Minority Ethnic (BAME) people living with HIV. Many of the people living with HIV are vulnerable individuals, some experience language, faith and cultural barriers, associated to longstanding stigma, whilst others have complexities such as mental health and social issues that impact their access to health and social care services, leading to poor health outcomes.

Since the 1990s, HIV has been transformed from a terminal virus into a long-term, manageable condition, meaning that people with HIV are living longer, better quality lives. This has been partly attributed to antiretroviral therapy (ART), which prevents the virus from replicating within the body and allows the immune system to repair itself, and the continued innovation that has followed since. Immediately initiating ART is essential as it has been shown to reduce the risk of all-cause morbidity (for example cardiovascular, renal and liver diseases) and mortality, when compared with deferred ART initiation.

A major ask from the organisations who fed into this report was that equity considerations should be given serious weight when designing and delivering HIV testing, treatment and care services in all settings (whether community-based or clinical). It was argued that ‘one-size-fits-all’ does not work when it comes to the Black, Asian and Minority Ethnic communities. Black, Asian and Minority Ethnic service users should be meaningfully involved (including in decision-making processes) from the design phase right through to the delivery phase of any service intended for them.

It was also argued that a holistic approach to care should be provided to all people living with HIV, especially those experiencing socio-economic hardship, so they can lead a dignified life and feel part of the wider society. Enabling them to get the social and psychological support that they need to live well with HIV is key to wellbeing and in preventing onward transmission.

We found that community-led interventions are essential for reaching and improving the health and wellbeing of individuals in Black, Asian and Minority Ethnic communities. It is a route which can alleviate many of the barriers experienced by vulnerable individuals and help ensure that no-one is left behind.

To ensure that this works, the establishment and support of strong partnerships between the HIV and the primary care sector - in particular with community pharmacies and primary care networks - is crucial to get to Zero HIV, especially for Black, Asian and Minority Ethnic groups that are less likely to attend sexual health services. Effective collaborations between primary care and the HIV sector can ensure large-scale information and access to HIV testing and PrEP among the most-affected Black, Asian and Minority Ethnic communities.

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[1] https://www.gov.uk/government/statistics/hiv-annual-data-tables

However, over the past 40 years, we have seen the stigma that surrounds HIV has not improved, as the report published by National AIDS Trust and Fast Track Cities London recently showed.

The media portrayal of HIV and People Living with HIV is important and provides a powerful opportunity to reduce HIV stigma universally. We would urge that a large-scale national anti-stigma mass media campaign is developed and implemented that counteracts well-entrenched fears and negative views in the general public, including towards Black, Asian and Minority Ethnic communities. We would also encourage the use of media that these communities trust.

The campaign should utilise the language around the science and reality of the U=U (undetectable=untransmissible) message and the advantages of HIV PrEP, and would be a massive shift forward from the 1980s campaigns on national TV. This could be a great opportunity for celebrities and community influencers living with HIV from all communities, especially the Black, Asian and Minority Ethnic communities, to be supported to speak out about living positively with HIV, to reduce the fear of stigma and to improve public perception about people who have the virus.

For all this to happen the situation around the data collection needs to be addressed. Currently, some ethnic groups are not effectively captured by the HIV and sexual health data collected by GPs and sexual health clinics, which has implications for reporting, funding and research opportunities. This needs to be improved across the four nations to reflect the different communities within the Black, Asian and Minority Ethnic communities. In the run up to 2030, data collection systems must be able to show even small changes in data trends to target services most effectively to tackle HIV.

A disturbing finding from Fast Track Cardiff and Vale was that there is relatively little known about the needs of Black, Asian and Minority Ethnic people with HIV in Wales. Disgracefully, this is because ethnicity data is not collected nationally; no services, either within specialist or mainstream organisations, systematically target Black, Asian and Minority Ethnic people with or at heightened risk of HIV. There is minimal visibility of this group with the exception of one member of Fast Track Cardiff and Vale. There are, however, a diversity of Black, Asian and Minority Ethnic people living with HIV in Wales. This needs to improve.

By looking exclusively at HIV, this report addresses how inequalities affect a patient population in which Black, Asian and Minority Ethnic vulnerable groups are disproportionately represented. The report makes the following key recommendations:

1. **Opt-out HIV testing across all healthcare settings across the UK.**
2. **More tailored and targeted HIV interventions are needed to reach out to Black, Asian and Minority Ethnic communities.**
3. **A UK wide campaign to educate the general population with equitable Black, Asian and Minority Ethnic representation on the benefits of PrEP needs to be formed and implemented**
4. **Anti-stigma campaigns and interventions to increase understanding, dispel myths and change attitudes towards HIV and HIV testing are needed, to engage with the under-served ethnic minority groups.**
5. **Progress on addressing current inequalities that disproportionately impact these communities should be detailed in annual reporting.**

We recognise that initially it has been seen to be helpful to refer to many different people at once, to use the term Black, Asian and Minority Ethnic. However, this term has now become reductive. By attempting to represent many communities at one time, it simultaneously lacks specificity and ultimately groups a diverse range of people and experiences under dated terminology. For example, while some experiences are shared across communities, health inequalities will inevitably show up differently in a Pakistani community in northern England, Somali community in South Wales, Indian community in Scotland, compared with a Black Caribbean community in central London, as differing determinants of health. The conundrum we have seen during this inquiry of using the term Black, Asian and Minority Ethnic highlights the need to clarify who we want to specifically address, and in what context, and how we refer to people. **Therefore we would urge the four governments to work with a large, diverse range of racial and ethnic communities and organisations, using the principles of co-production and meaningful involvement, to create a consensus around more acceptable terminology to be used by the HIV sector and with communities directly.**

To ensure these inequalities are sufficiently addressed, each of these recommendations should be incorporated into the HIV Action Plans we urge each of the four governments in the UK to develop.

Whilst it is good that we have seen a decline in new cases in populations such as white gay men, we cannot sit and watch late diagnosis rise amongst the Black, Asian and Minority Ethnic communities. If we are to see reductions in these inequalities, HIV needs to be put back on the political agenda, supported by proper investment.

“Nothing about us without us” is not just a phrase, it is a request. Only meaningful involvement of the diverse communities of the UK will end new transmissions on HIV by 2030, combat the stigma, and ensure those people living with HIV have a good quality of life.

Recommendations

Area 1: HIV Testing

1. More tailored and targeted HIV interventions are needed to reach out to Black, Asian and Minority Ethnic communities.
2. Opt-out testing should be implemented across the UK when patients register with a GP, present at A&E or when the NHS takes blood samples across all healthcare settings.
3. All four nations should review their policies and ensure clinical departments are consistently testing for HIV in patients presenting with indicator conditions.
4. Services delivering HIV self-testing to Black, Asian and Minority Ethnic communities in the UK should be provided to support these groups. Where possible, they should be led by BAME organisations and funded appropriately.
5. The four Departments for Health and Social Care along with the HIV voluntary sector need to engage with community-based organisations and faith groups that work within target communities, to enable the facilitation of community testing.
6. Interventions need to take account of the different identities that exist within the Black, Asian and Minority Ethnic communities and interventions need to be tailored and targeted to those specific communities.
7. The four governments should investigate the possibility of implementing a Click and Collect system outside of healthcare settings for people to access home test kits.
8. The NHS in England, Northern Ireland, Scotland and 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).
9. Long-term and sustainable funding should be made available by governments to support Black, Asian and Minority Ethnic community HIV testing initiatives.
10. Where appropriate and where 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.
11. Healthcare settings which have current opt-out HIV testing guidelines 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 any gaps.
12. 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.

Area 2: HIV Prevention

1. A UK wide Campaign to educate the general population with an equitable Black, Asian and Minority Ethnic representation on the benefits of PrEP needs to be formed and implemented.
2. PrEP should be made available in other parts of the NHS across the UK, including pharmacies and GP surgeries.
3. Funding should be made available by governments to support community outreach projects that work with Black, Asian and Minority Ethnic Communities to increase awareness of PrEP and HIV testing in a culturally appropriate way.
4. HIV prevention messaging should be embedded within wider community support settings, such as women's health groups or GP surgeries and non-health settings where people from Black, Asian and Minority Ethnic communities may visit regularly, such as faith organisations and barber shops.
5. Governments, the NHS, Public Health Bodies and the HIV sector need to explore all methods of communication with Black, Asian and Minority Ethnic communities, by working with them to understand what is most effective. This communication should include health promotion to ensure Black, Asian and Minority Ethnic communities have the knowledge to empower themselves to better look after their sexual health.
6. The four governments should deliver access to free infant formula milk for mothers living with HIV and their babies.

Area 3: Quality of Life

1. Anti-stigma campaigns and interventions to increase understanding, dispel myths and change attitudes towards HIV and HIV testing are needed to engage with the under-served ethnic minority groups.
2. Campaigns should include information about U=U to reduce stigma in the wider community.
3. All government strategies to end new HIV cases by 2030 should have a focus ensuring Black, Asian and Minority Ethnic people living with HIV can enjoy fulfilling and healthy lives.
4. There should be zero tolerance towards stigma and discrimination within all healthcare settings for people living with HIV. Relevant healthcare inspection agencies should assess how services are working to better support all people living with HIV.
5. National HIV action plans should include targeted work to ensure migrants and asylum seekers living with HIV can, and know they can, access HIV care and treatment without fear or intimidation by policies from the Home Office.
6. Provide additional funding for organisations providing psychosocial support to Black, Asian and Minority Ethnic groups so that mental health disparities do not worsen.
7. Clinicians should discuss quality of life with their patients, beyond monitoring of blood testing and the perception of an undetectable viral load as the only measure of success.
8. Patients should be at the heart of co-production of their care to ensure meaningful involvement and trust. This must include patients from Black, Asian and Minority Ethnic backgrounds.
9. All patients should have access to peer support which should include, where possible, peer support workers from a variety of ethnic backgrounds.
10. Black, Asian and Minority Ethnic people living with HIV must be better supported to engage in HIV care and take treatment regularly. Clinicians should assess the structural barriers that each individual may face - eg poverty, homelessness, insecure immigration status, food insecurity, domestic violence - and ensure that pathways exist to refer patients to, in order to address these unmet needs.
11. Services should make use of interpreters where possible, to ensure good communication with patients who may not have adequate knowledge of English.
12. Services should provide information about HIV care, testing and prevention in a variety of languages. Consideration should also be taken of how to communicate to patients with low literacy levels.

Area 4: Data, policy, meaningful involvement and co-production

1. Progress on addressing current inequalities that disproportionately impact these communities should be detailed in annual reporting.
2. All four governments should work with a large, diverse range of ethnic communities and organisations, using the principles of co-production and meaningful involvement, to create a consensus around more acceptable terminology to be used by the HIV sector and with communities directly.
3. Any HIV Action Plan developed in England, Northern Ireland, Scotland and Wales to end new cases of HIV by 2030, should have a specific focus on the needs of Black, Asian and Minority Ethnic communities in regard to testing, prevention and living well.
4. Funding should be made available to support increased and diversified HIV testing in all parts of the UK.
5. There should be a UK wide campaign to encourage everyone to know their HIV status with Black, Asian and Minority Ethnic community representation in its development and delivery.
6. All clinicians and frontline staff across health and social care should receive regular training so they are confident in having discussions about HIV, HIV prevention and HIV testing. This training should also focus on the barriers to HIV testing including stigma, racism, transphobia and wider discrimination.
7. Any HIV Action Plan adopted by any of the four governments must include the development of a strategy for recruitment of a diverse workforce, training, and retention of the HIV workforce, in clinical settings, local government and the voluntary sector.
8. Public Health Bodies in England, Northern Ireland, Scotland and Wales should produce more granular data linked to HIV, ethnicity, age, gender and migration status so a greater understanding of intersectional issues impacting the many communities in the Black, Asian and Minority Ethnic community affected by HIV can be understood.
9. More research is needed to provide data on Black, Asian and Minority Ethnic communities so as to better understand their needs. Disaggregated data and research would inform targeting, identify gaps and address barriers to testing more effectively.
10. An audit of public sector data sources in all four nations should be conducted to establish where there are gaps in data collection and how data collection methods can be streamlined. This needs to be consistent across local authorities, Public Health Agencies and the NHS. Data needs to be disaggregated for BAME ethnicities in order to understand the needs of each group and where to target services.
11. The flexibility and granularity of data collection systems must be maximised to meet the changing face of HIV and tackle inequity, including reporting on all communities.
12. Public Health Bodies should produce more granular data linked to HIV, ethnicity, age, gender and migration status so that greater understanding of intersectional issues impacting Black, Asian and Minority Ethnic Communities affected by HIV can be gained.
13. National data sets on gay and bisexual men should include a breakdown of ethnicity to better understand the HIV epidemic using an intersectional approach.

14. Public Health Wales and Public Health Scotland should publish national HIV data that includes statistics on ethnicity.
15. We recommend alignment with the ethnic groups published by the UK Government, which is used in census data.
16. Public Health England should produce further insight reports on the experiences of Black, Asian and Minority Ethnic women affected by HIV, with input from third sector organisations to inform its findings.
17. 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 Black, Asian and Minority Ethnic Communities
18. HIV researchers should ensure that studies recruit a diverse proportion of BAME participants to ensure that the results are representative of the community of PLWHIV. Research should be designed in partnership with the HIV community including people from BAME communities.
19. The four governments should look at ways to support and expand the capacity of Black, Asian and Minority Ethnic voluntary sector organisations to help deliver the programmes and campaigns needed to meet the 2030 target.
20. Migrants' HIV status should not be raised in open court at all without the express wishes of the person in question.
21. The UK Government should end "no recourse to public funds" within the immigration system.
22. The NHS should stop sharing data with the Home Office.
23. Improve both the reporting and response to hate crime by establishing third party reporting centres and victim support programmes based in Black, Asian and Minority Ethnic community organisations.
24. The NHS in England, Northern Ireland, Scotland and Wales should ensure there is regular training and development for all frontline NHS staff to better support Black, Asian and Minority Ethnic people living with HIV.
25. 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. This data should also include ethnicity to better understand the HIV epidemic using an intersectional approach
26. Research looking at issues affecting Black, Asian and Minority Ethnic People Living With HIV should be led where possible by researchers from Black, Asian and Minority Ethnic communities, and funded and supported adequately.

Introduction

We recognise that people from Black, Asian and Minority Ethnic communities (BAME) are not one homogenous group, and the experiences of individuals cannot be grouped together as one. For the purpose of this report, we use the term Black, Asian and Ethnic Minority communities, but we acknowledge the problematic nature of the acronym and that it does not take into account the intersectional identities of Black, Asian and minority ethnic people.

The Covid-19 pandemic has amplified and exacerbated longstanding social, economic, health and structural inequalities Black, Asian and Minority Ethnic communities have faced for decades, with a disproportionate rate of deaths from Covid-19 in Black, Asian and Minority Ethnic communities as found in studies by the Institute of Fiscal Studies[1]; Public Health England[2]; and the Office of National Statistics[3]. This is on a background of ethnic inequalities in outcomes in many areas of health[4].

A recent report by Public Health England concluded: "The unequal impact of Covid-19 on Black, Asian and Minority Ethnic communities may be explained by a number of factors ranging from social and economic inequalities, racism, discrimination and stigma, occupational risk, inequalities in the prevalence of conditions that increase the severity of disease including obesity, diabetes, hypertension and asthma." The report further went on to say that 'historic racism and poorer experiences of healthcare or at work' meant individuals in Black, Asian and Minority Ethnic groups were less likely to seek care when they needed it.

Black, Asian and Minority Ethnic communities were disproportionately impacted by HIV prior to Covid-19. Of the 4,139 new HIV diagnoses in the UK in 2019[5], 45% were among Black, Asian and Minority Ethnic communities[6], and 26% were among Black ethnicities[7] despite making up only 3.0% of UK population in the last census.

Although new diagnoses are falling[8], over the past five years, the most marked decline in new diagnoses when stratified by ethnicity is in people who are White, with a decline of 47%[9]. Black African ethnicities have seen less of a drop, with a 37% decline in the past five years in new diagnoses in people who were Black African. Late diagnosis is an issue in the UK. The proportion diagnosed late remains high among Black African ethnicities, at 47% compared with 39% for White ethnicities[10].

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[1] https://www.ifs.org.uk/inequality/chapter/are-some-ethnic-groups-more-vulnerable-to-covid-19-than-others/

[2] PHE Beyond the data; Understanding the impact of COVID-19 on BAME groups 2020

[3] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronavirusrelateddeathsbyethnicgroupenglandandwales/2march2020to10april2020

[4] Raleigh V, Holmes J (2021). The health of people from ethnic minority groups in England [online]. The King's Fund website. Available at: www.kingsfund.org.uk/publications/healthpeople-ethnic-minority-groups-england (accessed on 17 September 2021)

[5] Trends in HIV testing, new diagnoses and people receiving HIV-related care in the UK: data to end Dec 2019 – PHE (2020), p.9

[6] (of those where ethnicity is known). National HIV surveillance data tables , UK 2019– PHE (2020), table 1a

[7] (of those where ethnicity is known). National HIV surveillance data tables, UK 2019– PHE (2020), table 1a

[8] Trends in HIV testing, new diagnoses and people receiving HIV-related care in the UK: data to end Dec 2019 – PHE (2020), p.3

[9] HIV report 2020 slideset, slide 12. Available: https://www.gov.uk/government/statistics/hiv-annual-data-tables

[10] National HIV surveillance data tables , UK 2019– PHE (2020), table 1b

We know that 44% of people accessing HIV care in the UK are from Black, Asian and Minority Ethnic backgrounds[11], despite making up only 13% of the UK population in the last census. Of those women accessing HIV care, 79% are from Black, Asian and Minority Ethnic backgrounds[12].

While Black Africans have the highest HIV prevalence, other Black, Asian and Minority Ethnic communities are also disproportionately affected by HIV. For example, South Asian gay and bisexual men testing at NAZ had the highest levels of reporting sex without a condom on a regular basis (47%), with only 9% having heard of PEP.

It is widely believed that the inequalities in Black, Asian and Minority Ethnic sexual health and HIV must be scrutinised under a wide lens; there are so many interconnected factors, such as housing, poverty and education that impact sexual health, that the responsibility for sexual health outcomes cannot rely solely or even mainly on sexual health services and charities. Any HIV action plan should aim to shine a spotlight on the need for joined-up thinking required to tackle this range of impacts, as well as recommendations of how to get to 80% by 2025.

We know from our experience with Covid-19 that data is key in targeting testing, prevention, and messaging. This report will look at how well the UK is doing in capturing the data we need to ensure we end new transmissions of HIV by 2030 and for those living with HIV to have a better quality of life.

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[11] (of those where ethnicity is known). National HIV surveillance data tables , UK 2019– PHE (2020), table 4

[12] (of those where ethnicity is known). National HIV surveillance data tables , UK 2019– PHE (2020), table 4

In recent years there has been a steady decline in funding across the HIV prevention and care sector. For example in England we have seen the Local Authority public health funding (which finances most sexual health services) decreased by 23% between 2015/16 - 2020/21[13].

A consequence of these cuts is that the work with Black, Asian and Minority Ethnic communities has been brutally impacted, as highlighted in an NAT report[14]:

"In England, there has been a noticeable squeeze in health promotion funding for bespoke services targeting men who have sex with men (MSM) or BME groups. For example, between 2015/16 and 2016/17, funding for BME targeted health promotion contracts dropped by more than 50% in London."

This decline in funding has not been isolated to Local Authorities; we have witnessed a reduction in funding from Trusts and Foundations as well. In 2012 there were approximately 40 Black, Asian and Minority Ethnic-led HIV and sexual health agencies; today there are 11[15].

We have seen levels of investment in public health have been steadily reducing for years, with public health allocations playing a role in aggravating inequalities, entrenching poverty and poor health. It was recently found in England that £1 in every £7 cut from public health services comes from the 10 most deprived areas, compared with £1 in every £46 in the 10 least deprived[16]. NAT's research into HIV funding for local authorities also highlights that it is not aligned with prevalence[17]. Simply put - money does not follow need.

Not least in the context of the Black Lives Matter movement, and the disproportionate impact of COVID-19 on BAME communities, this report will set out to identify the barriers and what actions are needed to overcome them, to ensure that the Black, Asian and Minority Ethnic communities can access HIV testing, prevention and care.

"The person that had HIV I knew, they did say they were kind of embarrassed and they were discriminated against when they went to get the support... it's such a taboo in Asian Culture[18]."

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[13] PHE: Response to APPG Health and social care enquiry https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/

[14] UK Investment in HIV prevention-2015/16 and 16/17; Examining UK expenditure on Primary HIV prevention and HIV Testing. NAT (2017)

[15] NAZ Submission

[16] Institute for Public Policy Research, How Public Health Cuts Hit the Poorest Worst https://www.ippr.org/news-and-media/press-releases/poorest-areas-hit-hardest-by-public-health-cuts-finds-ippr-think-tank

[17] NAT, UK investment in HIV prevention 2015/16 and 2016/17: Examining UK expenditure on primary HIV prevention and HIV testing https://www.nat.org.uk/sites/default/files/publications/NAT_PREVENTION%20REPORT_V2.pdf

[18] South Asian Participant – NAT https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf

Report Format

Area 1: **HIV Testing**

Area 2: **HIV Prevention**

Area 3: **HIV Care**

Area 4: **Data, policy, meaningful involvement and co-production**

"You hear now and again that HIV is undetectable, and I think it then becomes a matter of trusting that the drugs work and that the person is taking them. If there's not a lot of information out there, a lot of people might see a relationship with someone with AIDS as a gamble. Does that put them at risk?[19]"

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[19] Black Participant – NAT https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf

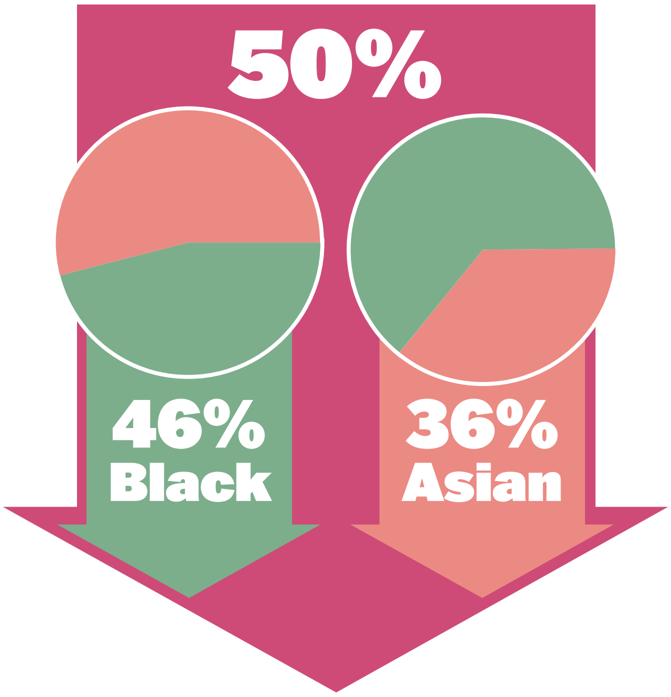
Stats[20,21]

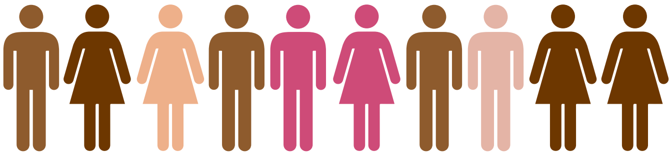
New Diagnosis: UK in 2019

Total number of cases in 2019 - **4139**

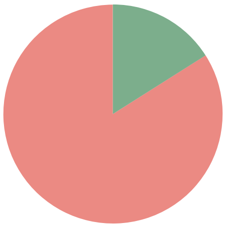
Ethnicity	Male	Female	Total
White	1660	305	1965
Black African	316	446	762
Black Caribbean	49	34	83
Black other	45	33	78
Asian	201	52	253
Other/mixed	301	82	383
Unknown	428	187	615

Between 2014 and 2019 there was a 50% decrease in number of new diagnoses amongst the White population and a 46% decrease amongst new diagnosis amongst individuals of a Black ethnicity. In comparison, the decrease was only 36% amongst Asians.



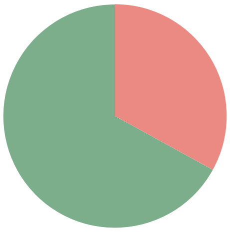


2 in 10 respondents were able to identify the main, or potential routes of HIV transmission, without also identifying any incorrect routes.



just 16% of the general population were aware HIV treatment stops HIV from being transmitted. If a person is on effective treatment, they cannot pass HIV on and can expect to lead a long and healthy life.

only a quarter of the general public knew there is medication available to prevent someone from acquiring HIV (PrEP).



🟥 **67% of people believe that people with HIV will always go on to develop AIDS**

🟥 21% of Black people believe this

🟥 30% of Asian People believe this

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[20] Public Health England Data 2019

[21] NAT report on Knowledge and Perception of HIV

Figure 1: Number of attendees tested for HIV and positivity among GBM and Black African heterosexual attendees at specialist SHS: England, 2015 to 2019

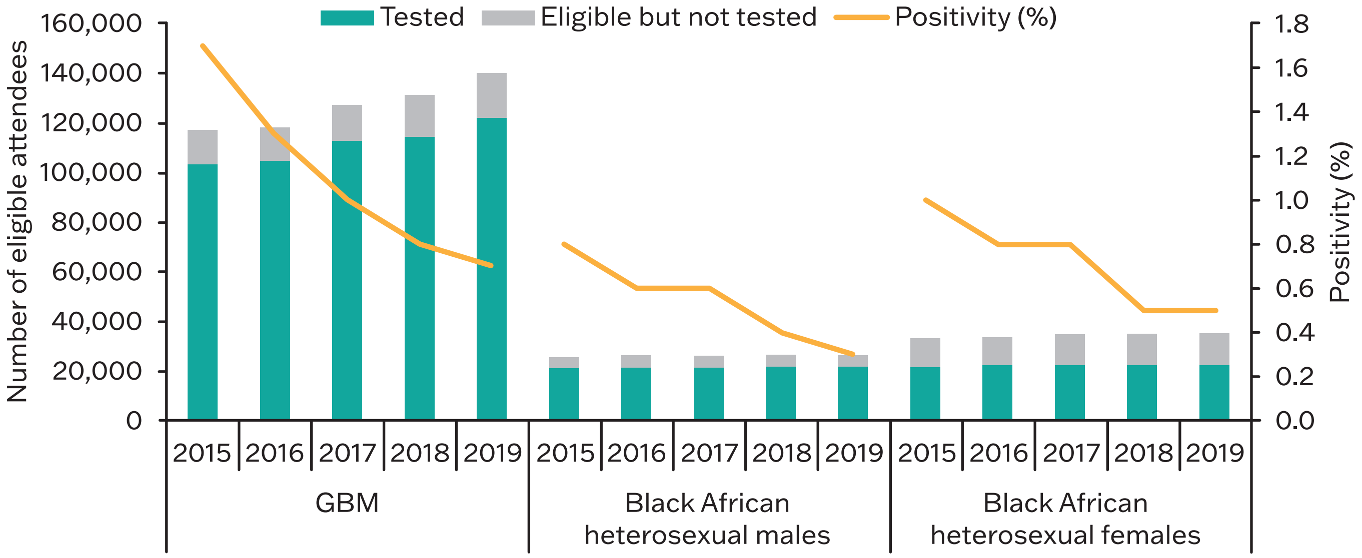


Figure 2: Missed opportunities among people not tested for HIV at specialist SHS by ethnicity and sexual orientation: England, 2019

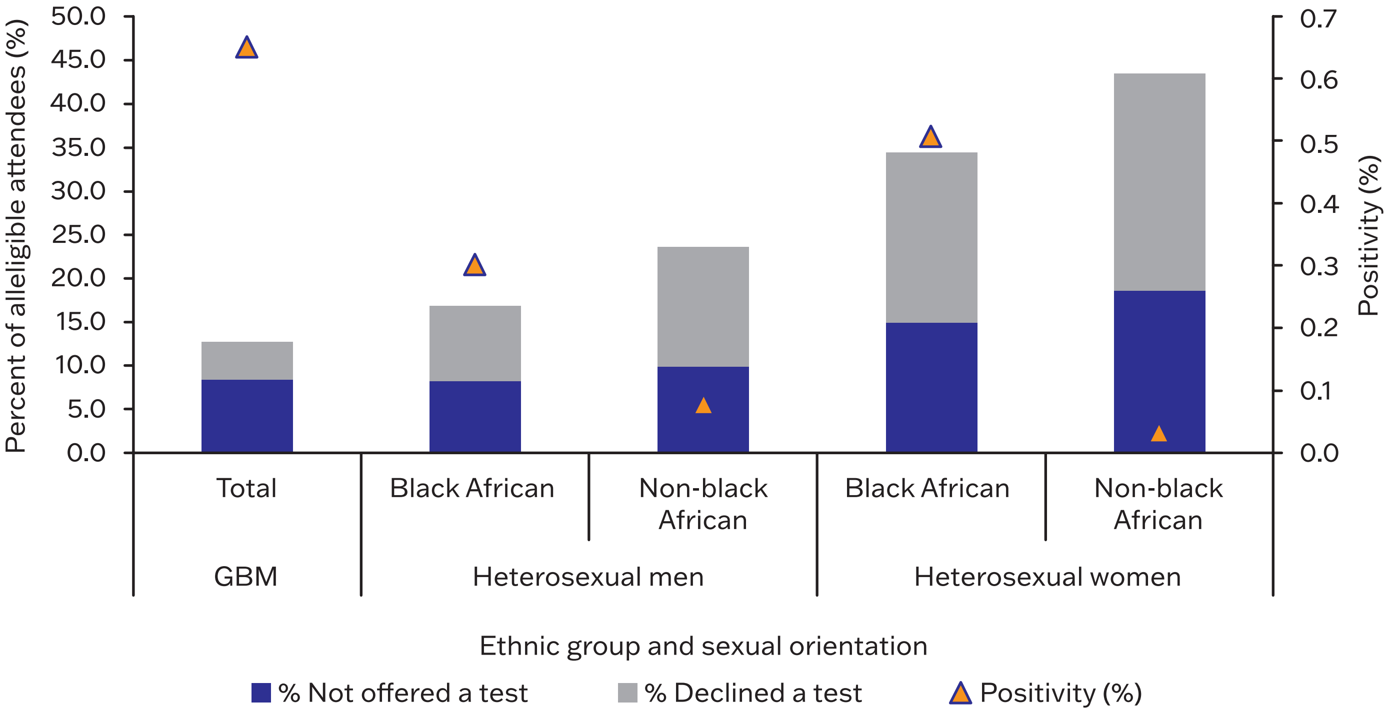
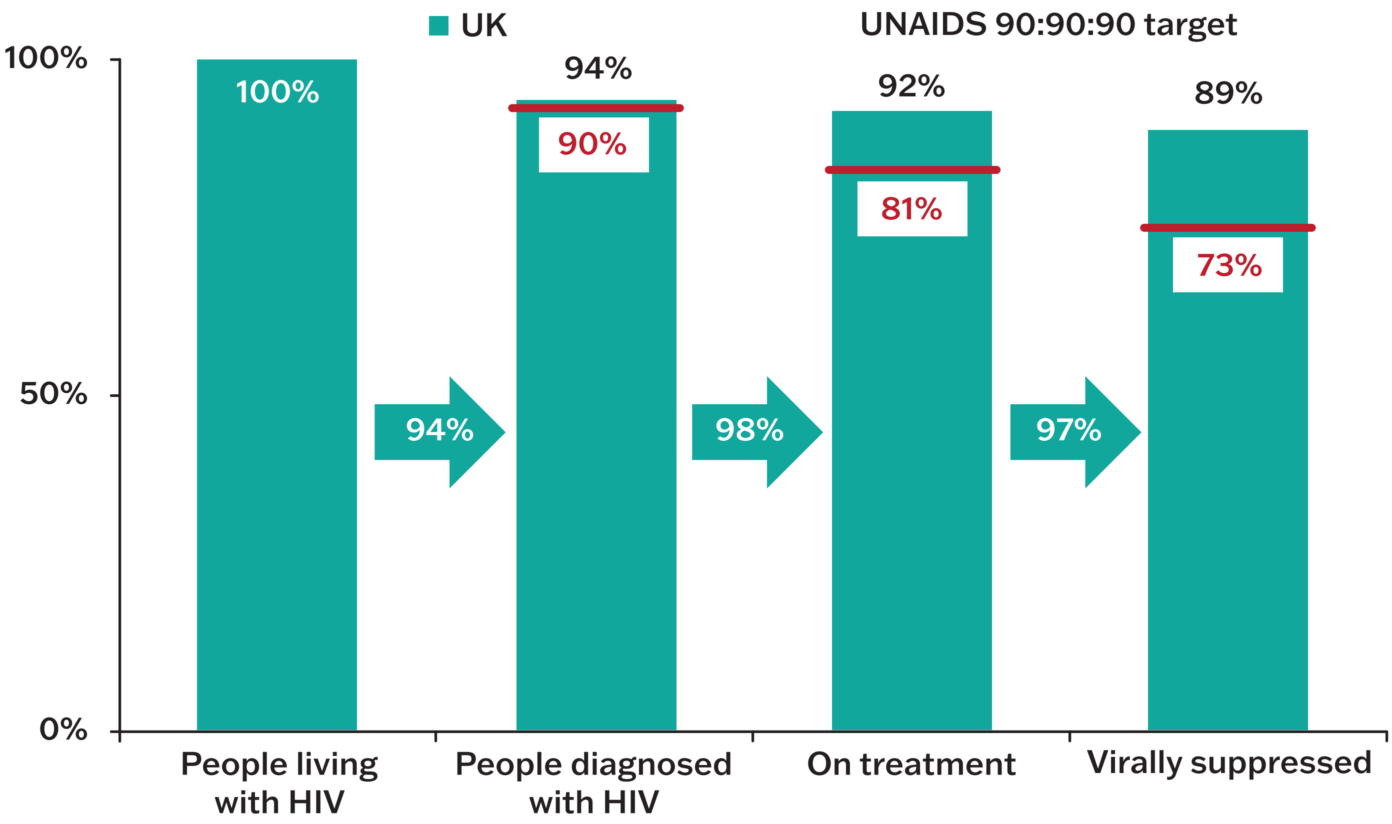
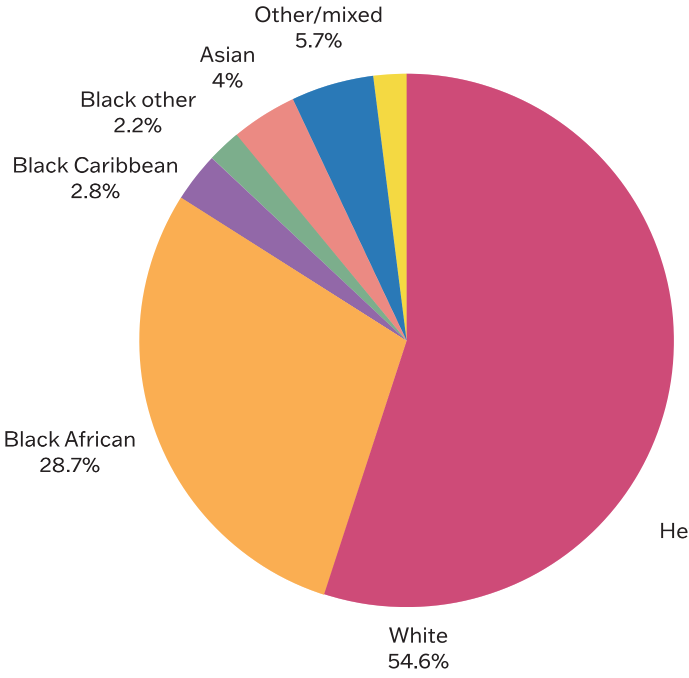


Figure 3: Continuum of HIV care in the UK, 2019



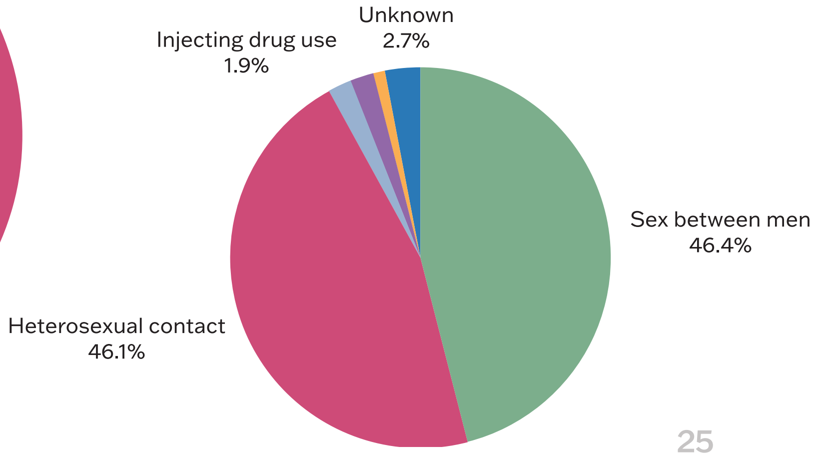
Ethnicity

- Over half of people receiving HIV specialist care in the UK in 2019 were white (53,621 - 54.6%), and just over a quarter were Black African (28,525 - 28.7%)
- 5,581 (5.7%) of people receiving HIV care were of ‘Other/mixed’ ethnicity, 3,902 (4%) were Asian, 2,780 (2.8%) were Black Caribbean and 2,153 (2.2%) were Black other.



Mode of transmission

- The majority (91,216 - 92.6%) of people accessing HIV care in 2019 acquired HIV through sexual transmission.
- The proportion of people accessing HIV care in 2019 who acquired HIV transmission through heterosexual sex (45,445 - 46.1%) is very similar to the proportion of people who acquired HIV through sex between men (45,771 - 46.4%).
- Much smaller proportions of people accessing HIV care in 2019 acquired HIV through injecting drug use (1,872 - 1.9%) or vertical transmission (1,941 - 2.0%). Vertical transmission occurs when HIV is passed from mother to baby, either in the womb, during birth or via breastfeeding.
- The mode of transmission has not been determined for 3,523 (3.6%) people accessing HIV care in 2019.



Area 1: HIV Testing

"You only hear about HIV in the media when someone has come out with it… when someone high profile dies of it…[22]"

In the evidence we have received from organisations such as NAZ, One Voice Network, The Love Tank and others, views or perceptions around HIV testing range widely in different Black, Asian and Minority Ethnic communities. Some cultures and faith groups see it as taboo; talking about sex is always uncomfortable and they think that HIV is only associated with sex.

As we found in our "Increasing and normalising HIV testing across the UK" report, improving testing uptake within Black, Asian and Minority Ethnic communities is a multifaceted task. Trust, shame, stigma and socio-economic inequality all need to be tackled. This report will focus on how these barriers affect uptake in testing and how we can do better.

When considering Black, Asian and Minority Ethnic groups in HIV testing, there is a real need to recognise the breadth of diversity within the most at-risk populations and see beyond that.

There are known barriers that these communities continue to face in accessing health services in general. These include structural and systemic barriers which can lead to already marginalised communities feeling unwelcome, judged, or alienated. There is a wealth of evidence of the stigma faced by communities and the barriers this can pose to the uptake of HIV testing

Evidence presented to this inquiry suggests that communities need to be further disaggregated in the approach to encourage HIV testing. For example, the experiences and needs of engagement for West Africans are different from those of East Africans. Furthermore, we see a rising prevalence amongst South Asian men who have sex with men, and their needs are different to those of Black African and Black Caribbean men who have sex with men[23].

The 2020 BHIVA/BASHH/BIA national HIV testing guidelines advocate HIV testing in a variety of settings, including:

- Community pharmacies
- Primary and secondary care.

And a range of testing options, including

- Community-based,
- Self-sampling and
- Home-testing.

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[22] Black Participant – NAT https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf

[23] One Voice Network Submission

BHIVA, like all the organisations, in its evidence calls for free access to a full range of testing options, a broader choice of community testing settings, and appropriately tailored promotion according to target population preferences and needs. Along with other HIV organisations, BHIVA has argued that the stigma surrounding HIV creates a barrier to people accessing testing, and so increasing accessibility and testing options would help to get more people tested.

Addressing fears about testing, including stigma and confidentiality, is crucial. As we argued in our “Increasing and normalising HIV testing across the UK” report, normalising testing via opt-out strategies can help and reduces the risk of populations who already experience stigma feeling ‘targeted’.

HIV testing also has an important role in reconnecting people to care who are already aware of their diagnosis. Elton John AIDS Foundation in its work in Southwark, Lewisham and Lambeth to normalise testing, found of the 47 people reconnected to care after HIV testing through their Social Impact Bond, 24 were from Black African, Black Caribbean, and Black Other communities, and a further 2 from Asian communities, with 21 of these people having CD4 counts of less than 350[24].

While Sexual Health Service (SHS) and specialist testing are an essential part of HIV testing in the UK, there is evidence to suggest that Black ethnic populations may tend to avoid interacting with SHS services[25]. This may contribute to SHS services being less likely to offer them an HIV test, and why they are most likely to decline it. However, further work is needed to have a better understanding of why this is.

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[26]. 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. 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.

Since 2011, NICE has recommended that all sexual health clinics offer and recommend an HIV test to everyone who attends for testing or treatment[27]. Guidelines by BASHH, BHIVA, and BIA also recommend opt-out testing at sexual health services, and recommend ‘for many clinical settings, opt-out testing

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[24] EJAF Submission

[25] EJAF Submission

[26] 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

[27] HIV testing: increasing uptake among people who may have undiagnosed HIV, NICE, 2016

is the most effective method to increase testing coverage.'[28] BASHH, BHIVA, and BIA define opt-out testing as follows: "Opt-out testing means that attendees are informed that they will be automatically tested unless they actively decline."

Migrants

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[29]. NAT and others suggest that 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.

What Works and Doesn't Work

The UK has a range of other HIV testing opportunities outside of sexual health clinics, and the introduction of home-testing brought about by a change in legislation does provide people with 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. Terrence Higgins Trust suggests that people who use their services have stated that some service users from Black, Asian and Minority Ethnic Communities would prefer to see HIV testing made available within other support settings, for example, women's health groups[30].

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[28] BHIVA/BASHH/BIA Adult HIV Testing guidelines 2020, BHIVA, 2020

[29] HIV and migration report, National AIDS Trust, June 2021

[30] Terrence Higgins Trust submission

Data from Terrence Higgins Trust's "It Starts With Me" self-assessment HIV test tool found testing outside of sexual health clinics was popular among Black, Asian and Minority Ethnic Communities[31]. Terrence Higgins Trust in its evidence advised there was good uptake among users from a Black, Asian and Minority Ethnic 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[32].

It was clear from the evidence we received, that focusing on where these ommunities work, live and socialise, makes engaging with them to take up HIV and sexual health services effective.

The One Voice Network argued that community-based point-of-care testing which includes STIs has many advantages – it is quick, easy and has near instant results. Including syphilis testing alongside HIV testing offers more opportunity to address broader needs.

A key benefit is that any individuals with a reactive test result can be referred immediately to a sexual health clinic. Utilising a pathway system, those who showed reactive test results reported that the service design worked well for them[33].

The Elton John AIDS Foundation Zero HIV Social Impact Bond (SIB) has provided much information about the reach of HIV testing and re-engagement interventions to south London Black, Asian and Minority Ethnic communities. The SIB three-year programme funds opt-out HIV testing in hospital Emergency Departments (EDs), GPs practices, and targeted testing by community groups in Lambeth, Southwark and Lewisham to increase new HIV diagnoses and engagement into care[34].

The Elton John AIDS Foundation told the inquiry that the SIB HIV testing nterventions have so far reached 36 men and 35 women from Black African, Black Caribbean and Black Other groups. Comparing this with the ratio of new diagnoses from the same groups from Public Health England 2019 data, 44% men to 56% women, and they suggest that the benefits of these testing interventions are both required and broadly experienced across both male and female genders Whilst recognising that the SIB numbers are much smaller, EJAF suggests that HIV testing, especially Emergency Department HIV testing, is very effective in reaching Black African, Black Caribbean, Black Other groups who have not and will not come into contact with any other testing intervention and have potentially been living with HIV for many years undiagnosed, severely increasing the number of late diagnoses.

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[31] Which test? It Starts With Me
[32] Terrence Higgins Trust submission
[33] One Voice Network submission
[34] EJAF submission

CASE STUDY

An ongoing pilot to examine how GP services in South Cardiff might recommend HIV self-testing to all adult patients by text message illustrates some difficulties: of the six GP surgeries originally interested in the pilot, all but one withdrew from the initial phase, citing issues such as fear of patients being offended and fear of patients from ethnic minority communities not understanding or not wanting to discuss the issues with their families. However, the one surgery which sent out the text found that it was highly acceptable, with no or low levels of support needed by most patients – and it has already been successful in getting people at higher risk tested, including identifying someone in need of treatment. This pilot is ongoing and subject to formal evaluation from Cardiff University.

Wales HIV Testing Week was created by Fast Track Cardiff and Vale as part of European Testing Week initially and follows its timing. Fast Track Cardiff and Vale has found that people respond much better to the campaign if it has a Welsh title. Fast Track Cardiff and Vale told us that imagery and messaging for this campaign deliberately, and for the first time in Wales, included Black, Asian and Minority Ethnic people and this, along with the ability for health boards and NGOs to co-badge the materials, substantially increased the take-up and reach of the last campaign in May 2021.

They also told us that, similarly, social media imagery supporting the recent South Cardiff testing pilot included targeted imagery which mirrored local interests, such as a black youth boxing. Images from these campaigns are attached to this evidence. Other than this, Fast Track Cardiff and Vale are not aware of any testing or other HIV messaging of any kind aimed at Black, Asian and Minority Ethnic communities in Wales. However, this mirrors a general lack of such messaging in Wales for over a decade other than imported English materials via THT.

It is important to understand that there are nuances between different ethnic groups – African, Caribbean, South Asian, East Asian, South East Asian, Middle Eastern, Arab, etc. – and clumping them into one set of messaging ignores different forms of stigma and challenges.

Some organisations run specific sexual health services for specific groups – for example Metro Charity who offers specific services for Latino men, NAZ likewise for GBTQ+ black men, as well as Black Beetle Health and LGBT Foundation's spaces for QTIPOC (queer, trans, and intersex or Black, Asian and Minority Ethnic people). Partnership work allows individual organisations to reach more people in their communities by working together.

Many community services work on an outreach model, using community figures such as barbers, faith leaders, and influencers to support health promotion messaging. Distrust of medical services and staff may decrease with increased familiarity, the outreach model should be used more widely, including by clinical services. We cannot expect individuals to have the confidence, trust, and means to access services; we must make an effort to meet them where they already are.

NAZ and the Love Tank suggested that the needs of Black, Asian and Minority Ethnic women and Black, Asian and Minority Ethnic LGBTQ communities are currently not being met in the way that would optimise engagement and continuation of care. For example, Trans Black, Asian and Minority Ethnic people often face more challenges when accessing healthcare services and elevated rates of discrimination. They suggest that there has been little research into the experiences of Trans Black, Asian and Minority Ethnic people accessing HIV testing services and their experiences in the UK. From the research that does exist, Black, Asian and Minority Ethnic transgender people face higher rates of discrimination than the White transgender community, experiencing multiple marginalisations when attempting to access healthcare settings, including being refused treatment, being misgendered and being blamed for their health condition[35].

Messaging

Many of the organisations that work with the Black, Asian and Minority Ethnic communities suggested that the messaging around HIV testing in Black, Asian and Minority Ethnic communities tends to centre around the White narrative, including imagery and language which does not resonate with Black, Asian and Minority Ethnic communities as they are unable to see themselves represented within them. This is in part due to the scale of campaigns for Black, Asian and Minority Ethnic communities, which tend to be smaller, limiting their impact.

NAZ, SAHAR, BHA and CHIVA argued that campaigns underestimate the role of stigma and discrimination within Black, Asian and Minority Ethnic communities. They argued that it is a theme that underpins many aspects of HIV prevention and treatment. It was also noted that they are not targeted at the diversity and different intersections of the Black, Asian and Minority Ethnic community. There is currently a one-size-fits-all approach.

CASE STUDY

Sholay Love was a NAZ run campaign specifically promoting HIV awareness among the South Asian community. The campaign allowed NAZ to disseminate information about HIV to a wider audience - by accessing families at home through national radio and TV rather than traditional 'known premises' of mainstream media.

We have heard that there are several things that can be learnt from the engagement of the Gay community, such as the convenience and consistency of testing and campaigns. Testing facilities in saunas, clubs and public sex environments allow people to test in an atmosphere that is comfortable to them. The diversity in testing facilities for the Gay community has given people confidence and encouraged people to know their status. We could argue that the COVID response in having a wide range of testing facilities and opportunities was one lesson that the authorities learnt from the engagement of Gay men in the HIV response.

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[35] The Race Equality Foundation, Barriers to health faced by transgender and non-binary black and minority ethnic people, 2016. Accessible via: http://raceequalityfoundation.org.uk/wp-content/uploads/2018/02/Better-Health-41-Trans-NB-final.pdf

The Love Tank and NAZ strongly suggest that the engagement of Queer Men of Colour has shown that putting the protagonist at the centre of the narrative, and highlighting their story, has enabled them to speak their own truth and share experiences with other members of the community. It enables people to have open and honest conversations about HIV testing and prevention, to encourage more people to know their status and understand the different prevention methods available.

Summary:

In our latest report on “Increasing and normalising HIV testing across the UK”, our key recommendation is to ensure opt-out testing when patients register for a GP, present at A&E or when the NHS takes blood samples across all kinds of healthcare settings. This would give us an opportunity we cannot miss to diagnose every case of HIV, stop preventable transmissions, and bring back into treatment those who have been diagnosed but then lost to the system. This would also help tackle the stigma, misinformation and other barriers the Black, Asian and Minority Ethnic communities face when it comes to accessing HIV testing.

HIV Stigma and shame surrounding sexual health is a factor in how people access clinical facility-based services. Experiences of community organisations show that targeted community-based testing should be encouraged and facilitated – pop-up testing in barber shops, community sporting events, churches, shopping centres, click and collect and more. Support provided following a reactive test and linkage to care is also crucial and the associated costs should be adequately covered. It is crucial that statutory services promote and otherwise support community-based testing nationally and in their respective local authorities.

There is a need for safer Black, Asian and Minority Ethnic community-based women and LGBTQ spaces that foster open and honest conversations about HIV testing to empower these groups around HIV prevention and care.

Interventions need to take account of the different identities that exist, and tailor and target interventions to specific groups with appropriate campaigns, working with communities and supporting organisations who work with these groups who can deliver community-based programmes and testing.

As we heard during this inquiry and as the HIV Commission reported, one of the major barriers is funding, both in terms of clarifying responsibility and accountability, and in terms of making the necessary investment available. If the four governments are serious about eliminating HIV by 2030, they will ensure that opt-out testing in healthcare settings is made available.

Recommendations

1. More tailored and targeted HIV interventions are needed to reach out to Black, Asian and Minority Ethnic communities.
2. Opt-out testing should be implemented across the UK when patients register with a GP, present at A&E or when the NHS takes blood samples across all healthcare settings.
3. All four nations should review their policies and ensure clinical departments are consistently testing for HIV in patients presenting with indicator conditions.
4. Services delivering HIV self-testing to Black, Asian and Minority Ethnic communities in the UK should be provided to support these groups. Where possible, they should be led by BAME organisations and funded appropriately.
5. The four Departments for Health and Social Care along with the HIV voluntary sector need to engage with community-based organisations and faith groups that work within target communities to enable the facilitation of community testing.
6. Interventions need to take account of the different identities that exist within the Black, Asian and Minority Ethnic communities and interventions need to be tailored and targeted to those specific communities.
7. The four governments should investigate the possibility of implementing a Click and Collect system outside of healthcare settings for people to access home test kits.
8. The NHS in England, Northern Ireland, Scotland and 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).
9. Long-term and sustainable funding should be made available by governments to support Black, Asian and Minority Ethnic community HIV testing initiatives.
10. Where appropriate and where 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.
11. Healthcare settings which have current opt-out HIV testing guidelines 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 any gaps.
12. All parts of the UK should have free, at-home, self-sampling HIV testing available all year round, which should also include options to Click and Collect at pick-up points.

Area: 2: HIV Prevention

"I've never heard of this (PrEP) before. I don't know what the situation is right now, but years ago I saw it was not treatable[36]."

You can only get HIV by coming into contact with specific bodily fluids of someone living with the virus (e.g. blood, vaginal fluids, semen, breastmilk). No single prevention method or approach can stop the HIV epidemic on its own.

We know that HIV can be transmitted during unprotected sex, through breastfeeding, sharing injecting equipment and through contaminated blood transfusions. The latest research carried out by National AIDS Trust and Fast Track Cities London, found that only 2 in 10 people could identify the two main ways that HIV can be transmitted[37].

The use of condoms during sex, or taking PrEP consistently, will protect you from HIV infection through sex. Taking HIV treatment if you are a new or expectant mother, and avoiding shared injecting equipment if you use drugs, will also protect you and those around you from HIV.

For the past five years it has been widely accepted that if a person living with HIV is on effective treatment it can lower the viral load of that person to such low levels that they are undetectable in a blood test. This means that they cannot pass on HIV through sex.

PrEP

PrEP (pre-exposure prophylaxis) is medicine people can take to prevent getting HIV. PrEP reduces the risk of getting HIV from sex by about 99% when taken as prescribed. Although there is less information about how effective PrEP is among people who inject drugs, we do know that PrEP reduces the risk of getting HIV by at least 74% when taken as prescribed. PrEP is much less effective when it is not taken as prescribed.

There are currently three ways that PrEP can be accessed in England, Wales, and Scotland:

- Free from NHS sexual health clinics
- 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).

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[36] South Asian Participant – NAT https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf

[37] https://www.nat.org.uk/publication/hiv-public-knowledge-and-attitudes

In the oral evidence we received from the Love Tank, NAZ and One Voice network, they advised that there are low levels of awareness about PrEP in the Black, Asian and Minority Ethnic communities, particularly with women, suggesting existing campaigns are not particularly effective.

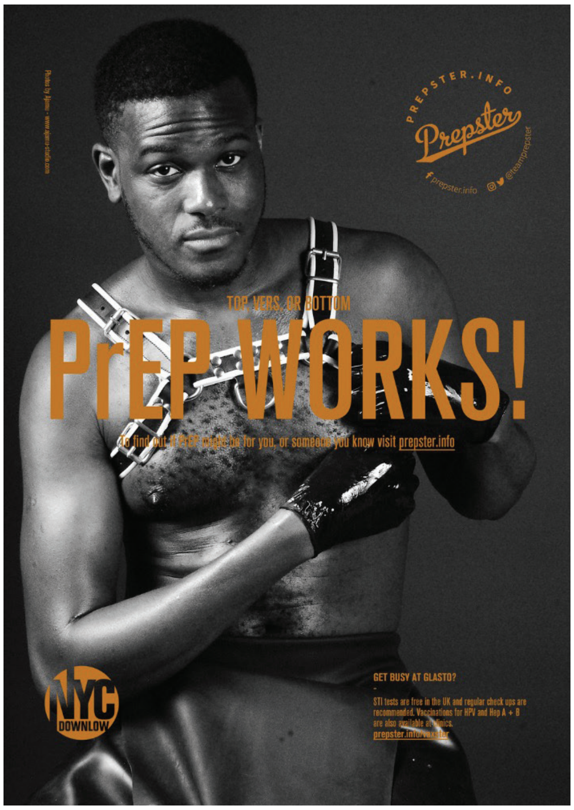
In England between 2017 and 2020, PrEP was only available through an Impact Trial. Data of those who enrolled on the Impact trial showed there were[38]:

- 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 Black, Asian and Minority Ethnic Communities were similarly low in comparison with White trans people[39]:

- 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[40]. It was argued by THT and others in their submissions that the reason for 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, it has been argued by THT, has resulted in PrEP uptake among this population, which has been highlighted as one of the reasons for the reduction 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 is no data for Wales for the breakdown of who is accessing PrEP.



To find out if PrEP might be for you, or someone you know visit prepster.info

STI tests are free in the UK and regular check ups are recommended. Vaccinations for HPV and Hep A + B are also available at clinics.
prepster.info/vaxster

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[38] 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

[39] 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

[40] Implementation of PrEP in Scotland, Health Protection Scotland, 2019

Barriers in Accessing PrEP

The evidence that was given to the inquiry by all of the organisations states that stigma, shame, and cultural taboos play a role in many aspects of HIV prevention. Stigma exists in several settings including self-testing, community and organisational testing and remains a prominent barrier to testing on a multi-dimensional level. On an individual level it stops people from going to get tested/ accepting a test through fear of a positive diagnosis. On a community level there is fear of rejection and the link to other discriminations, ie homophobia, transphobia. Organisational stigma exists in clinical settings where there is a lack of knowledge on indicator conditions and structural racism - for example, the belief that HIV only affects certain ethnic groups. Challenging stigma and discrimination within Black, Asian and Minority Ethnic communities is an important aspect of increasing uptake of services and encouraging people to know their status.

Barriers for community access include[41]:

- Lack of information about PrEP, including on where and how to access PrEP;
- Lack of institutional and regulatory support for the roll-out of PrEP programmes;
- Some Black, Asian and Minority Ethnic communities people are too stigmatised to even try PrEP – there are negative perceptions within communities which may make individuals reluctant to try PrEP.
- A lack of perception that they may be at risk of acquiring HIV, so PrEP is not needed.

Increasing uptake can be achieved through[42]:

- Providing more targeted information about PrEP;
- Making PrEP more easily available, not restricted to sexual health services. People also need to know where they can get PrEP;
- Reducing stigma within Black, Asian and Minority Ethnic communities would lead to more people being willing to use PrEP.

It is felt amongst the HIV sector that there is not enough being done to tackle stigma and misinformation, especially given history of medical racism.

It was argued by One Voice Network, The Love Tank, BHA, NAZ and SAHAR that PrEP has been seen as a ‘gay lifestyle drug’ by the press and associated with promiscuity. During the Impact trial, PrEP was offered to three groups: men who have sex with men and trans women who have sex with men, those with a HIV positive partner with a detectable viral load, and those who are otherwise clinically assessed as at high risk of HIV acquisition. This means that in order to access PrEP via the trial, individuals likely needed to identify their own risk. While many men who have sex with men may recognise their own sexual activity in this way, for communities who have had less exposure to messaging about HIV transmission, it is unlikely they would label themselves as ‘at high risk’.

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[41] One Voice Network submission

[42] One Voice Network submission

The journey to routine commissioning on the NHS in England has been complex, making PrEP hard to access for many. There has been limited public messaging from clinical services stating that they're now offering PrEP, so individuals may not be aware. As PrEP is provided in Level 3 sexual health services, the only way to get an NHS prescription is by attending a Sexual Health clinic. Those who are reluctant to do so because of fear of discrimination and racism would need to purchase PrEP online, which comes with its own set of barriers, including financial. Even then, PrEP users should be accessing HIV and STI screening and renal function monitoring, which is available in sexual health services. In Scotland and Wales, PrEP has been available through the NHS since 2017.

It is unanimously agreed amongst the HIV sector who provided evidence to this inquiry that PrEP prescribing and monitoring should be shared more widely across the healthcare system, to encourage those who cannot or will not attend sexual health services – community and clinical services could work in partnership, and GPs could support with prescribing and monitoring.

Treatment as Prevention (TASP)

The discovery that people living with HIV who have an undetectable viral load cannot pass HIV on through sexual transmission was a breakthrough moment in the HIV epidemic. Undetectable = Untransmittable is a powerful message that can not only empower people living with HIV, but also provide the evidence that underpins HIV treatment as an important HIV prevention tool in its own right. However, the HIV Commission found that engagement with and understanding of the U=U message may vary by demographic group, so greater effort and resources may be required to reach all communities equitably.

Scientifically, HIV treatment is as effective in Black, Asian and Minority Ethnic communities as in any other. According to Public Health England (2020), in the UK, a similar proportion of Black, Asian and Minority Ethnic PLWHIV and receiving treatment are virally suppressed (95% or higher). This means that 95% of Black, Asian and Minority Ethnic people cannot pass the virus on. The claim that TASP does not work well for Black, Asian and Minority Ethnic communities must therefore be refuted[43].

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[43] https://www.hivcommission.org.uk

Black, Asian and Minority Ethnic PLWHIV may experience compounded issues linked to non-HIV related factors like migration, socio-economic, cultural or personal factors which provide serious challenges for them to become linked nto care or take/adhere to treatment. It is important to provide holistic and wraparound services for highly marginalised individuals to minimise the factors that are acting as barriers for them to stay linked in to care and take medication.

Re-engagement of people living with HIV who know their status but are not on treatment is vital to support Treatment as Prevention efforts. One large-scale longitudinal study found 28.1% of people who entered HIV care were lost to care within 10 years[44]. Unfortunately, robust surveillance data on these lost-to-care populations does not currently exist. In its most recent surveillance report, PHE concluded that "further improvements can be maximised through focusing attention among those lost from care."[45]

The Elton John AIDS Foundation SIB re-engagement activities in Lambeth, Southwark and Lewisham have focused needed attention on those who have discontinued their HIV care. The SIB data as explained by EJAF has highlighted important demographic differences in this population, similar to the trends found in the SIB's new diagnoses[46]. They found that the focus on re-engagement reaches proportionately more Black African, Black Caribbean, Black Other. EJAF argue that investment in re-engagement would be especially beneficial for Black, Asian and Minority Ethnic communities. Many of these people are also engaging at a late stage of their HIV progression, so re-engagement is essential to improve their health outcomes and minimise risk of mortality.

Messaging

CASE STUDY

A coalition-led campaign, led by Africa Advocacy Foundation and other Black, Asian and Minority Ethnic organisation partners, delivered the first-of-its-kind national PrEP campaign for Black, Asian and Minority Ethnic communities called PrEP and Prejudice (www.prepandprejudice.org.uk). This is a perfect example of the first ever black community led campaign on PrEP that was a great success, despite the previous and ongoing healthcare failures to engage black communities in PrEP as recently evidenced by PrEP Impact Trial.

It was widely argued by organisations that existing campaigns and messaging are not reaching Black, Asian and Minority Ethnic communities in the numbers that they should be. The lack of representation in the imagery and language means that many Black, Asian and Minority Ethnic communities feel alienated from the outset of the campaign[47]. A campaign led by the Sophia Forum focusing on women was provided as an example on using different voices to reach a diverse audience by providing engaging content about HIV prevention[48].

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[44] Jose, S., Delpech, V., Howarth, A., Burns, F., Hill, T., Porter, K., Sabin, C. A., & UK CHIC Study Steering Committee (2018). A continuum of HIV care describing mortality and loss to follow-up: a longitudinal cohort study. The lancet. HIV, 5(6), e301–e308. https://doi.org/10.1016/S2352-3018(18)30048-1

[45] Public Health England. 2020. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. Health Protection Report. Vol. 14 No. 20.

[46] EJAF subnmission

[47] NAZ submission

[48] NAZ submission

During the oral evidence sessions and in the written evidence we received, it was widely felt that it is important that HIV programmes, including prevention-focused work, take a community-owned approach that is not tokenistic. For example, Metro argued that it is important that national HIV campaigns sufficiently address the needs of, and engage Black, Asian and Minority Ethnic communities. Positive East suggested that often national and regional campaigns show black and brown faces in their materials, but have not been developed by Black, Asian and Minority Ethnic communities. NAZ, The Love Tank and One Voice Network suggested that the messaging is often snappy, but speaks more to White British people than other communities, and is often designed by media companies with more history of creating campaigns serving white audiences.

However, it is recognised by organisations who submitted evidence to the inquiry that the "The Me/Him/Us" campaign was a popular and successful initiative.
This campaign featured people from the black community. The HIV Prevention England campaigns (It Starts With Me and National HIV Testing Week) have also been moving in the right direction, though more needs to be done to show more diversity. They felt that it is important to recognise absence and tokenism such as this when it occurs, and develop approaches that are firmly rooted in and designed by Black, Asian and Minority Ethnic communities. Any messaging, approach and promotion (including online/offline approaches and locations) must be appropriate to the different Black, Asian and Minority Ethnic communities.

It was felt that a community-owned approach exceeds HIV campaigns and includes a wide variety of elements, such as employing Black, Asian and Minority Ethnic staff allowing Black, Asian and Minority Ethnic communities to advocate on their own behalf and providing necessary training and capacity building. NAM aidsmap amongst others suggests that it is also important that the burden of engagement does not fall just on Black, Asian and Minority Ethnic communities or on Black, Asian and Minority Ethnic community organisations as they saw with the PrEP IMPACT trial.

Dr Will Nutland from PrEPster, at the latest International AIDS Society conference, argued that emphasising how PrEP users are an integral part of HIV prevention should be embedded in PrEP practice, policy, and research.
He discussed the importance of engaging PrEP users to proudly talk about PrEP use and offer/deliver PrEP in convenient/ appropriate settings, as well as the need for PrEP open access, user control, and conversations surrounding additional benefits of PrEP use (eg sexual enjoyment).

CASE STUDY

Case Study MobPrESH (Mobilising for PrEP and Sexual Health) was established to recognise that women have been far less involved in such activities. The programme was founded to train and support peer mobilisers for PrEP across three UK cities. MobPrESH prioritised recruitment of those most affected by the epidemic, specifically Black and other women of colour (trans and cisgender), migrants, and sex workers. The qualitative evaluation of the project found mobilisers "were highly enthusiastic about MobPrESH and many felt that their knowledge and confidence had grown considerably through their participation".
The report also highlighted recruitment barriers created by funding restrictions limiting the ways in which peer mobilisers could be compensated and the impact of short-term funding cycles on sustained activities.

As a freelance writer, Rianna Raymond-Williams writes extensively about ineffective PrEP messaging and how that leaves Black women vulnerable and less informed about their prevention options. "As a Black woman who is both a service user and a service provider, I understand that when some Black women are offered an HIV test by providers, they may feel they are being targeted," said Raymond-Williams. "Or that assumptions are being made about their body and sexual behaviour, rather than seeing an HIV test as part of the full sexual and reproductive health service offered alongside managing or treating [yeast infections], accessing contraception, and getting sexual health advice."[49]

We were told by Fast Track Cardiff and Vale that there is currently no health promotion campaigning on HIV for any population other than that done by them via social media, which is targeted at Cardiff and Vale. There has been no national prevention or testing campaign for well over a decade. Fast Track Cardiff and Vale argues that if there are no prevention or support services funded or provided for any people with or at risk of HIV, there will be none targeted at the Black, Asian and Minority Ethnic community populations.

Summary:

All four governments should actively consider different settings in which PrEP could be made available outside sexual health clinics as part of their HIV Action Plan. The current model of PrEP delivery is not reaching all communities who could benefit from PrEP and, in particular, is failing Black, Asian and Minority Ethnic 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. THT in its submission showed 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.
We all have a responsibility to ensure that Black, Asian and Minority Ethnic voices are heard around HIV and we must design programmes that empower and build capacity among communities to speak up around HIV.

Any prevention campaign aimed at the Black, Asian and Minority Ethnic community must be co-designed and delivered by that community. This would ensure that the messaging and the approach is the right one for those it is aimed at.

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[49] https://www.thebodypro.com/article/prep-messaging-black-women-compassion-respect

Recommendations

1. A UK wide Campaign to educate the general population with equitable Black, Asian and Minority Ethnic representation on the benefits of PrEP needs to be formed and implemented.
2. PrEP should be made available in other parts of the NHS across the UK, including pharmacies and GP surgeries.
3. Funding should be made available by governments to support community outreach projects that work with Black, Asian and Minority Ethnic Communities to increase awareness of PrEP and HIV testing in a culturally appropriate way.
4. HIV prevention messaging should be embedded within wider community support settings, such as women's health groups or GP surgeries, and in other non-health settings where people from Black, Asian and Minority Ethnic communities may visit regularly, such as faith organisations and barber shops.
5. Governments, the NHS, Public Health bodies and the HIV sector need to explore all methods of communication with Black, Asian and Minority Ethnic communities, by working with them to understand what is most effective. This communication should include health promotion to ensure Black, Asian and Minority Ethnic communities have the knowledge to empower themselves to better look after their sexual health.
6. The four governments should deliver access to free infant formula milk for mothers living with HIV and their babies.

Area 3: HIV Care

"Everything you hear about HIV is negative. Until they change the narrative, that's not going to change. Older generations have a certain viewpoint on it, younger generations don't really know about it, and then there's the rest of us in the middle. It's a shame, but it's down to ignorance isn't it[50]."

Every organisation that submitted evidence stated that structural racism plays a significant role in the disparities in HIV outcomes, highlighted in the research of Dr Dhairyawan and colleagues[51]. A number of organisations advised that a number of people have shared experiences of racism in healthcare settings that discourages them from sharing their concerns with healthcare professionals, with concerns that they would not be believed, or any action would be taken.

As we have seen with COVID, socio economic status is frequently linked to structural racism. People from African communities with HIV are frequently more highly qualified than white British people, but much more likely to be in low paid work[52].

NAT stated in their "HIV and migration: Understanding the barriers faced by people born abroad living with HIV in the UK"[53] report that the asylum process can have a harrowing impact on people with HIV, with enforced destitution, dispersal to areas that disrupts healthcare, asylum accommodation that makes taking treatment difficult, detention to removal centres resulting in illness and sometimes illegal lack of access to their medication.

One Voice Network advised that people from the Black, Asian and Minority Ethnic communities often face problems in accessing effective primary and secondary care, and are sometimes unaware that HIV treatment is free regardless of immigration status.

In Positively UK's submission they advised after consultation with the public that many from Black, Asian and Minority Ethnic communities face barriers to remote consultations, often due to lack of technology, cost of data and somewhere private for phone consultations. When planning services, barriers to remote consultations need to be considered with ways that may be addressed, such as providing data bundles to patients when appropriate and partnerships with community organisations that can provide a safe space for remote consultations. Many people from migrant communities experience language barriers and this needs to be addressed when providing information, ensuring it is clear, accurate and accessible, with translations available both in print and digitally. LGBT

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[50] https://www.huffingtonpost.co.uk/lisa-power/hiv-testing-week_b_2176718.html

[51] Dr Dhairywan submission

[52] Dr Dhairywan submission

[53] https://www.nat.org.uk/press-release/government-and-nhs-are-failing-migrants-uk-finds-national-aids-trust-research

Foundation argued that better translation services are needed to ensure that everyone feels comfortable in receiving care.

In the follow up of care, it is important for clinicians to discuss quality of life with their patients, beyond monitoring blood testing and the perception of an undetectable viral load as the only measurement of success. It was argued that health related quality of life assessment needs to be routine[54]. For the Black, Asian and Minority Ethnic communities, often experiencing intersecting disadvantage, taking care of their health can take a lower priority in coping with other challenges, such as immigration concerns, experiences of racism and often for women being the primary care giver putting the needs of others in their families first and therefore neglecting their own health. Clinicians need to find the time to discuss these concerns and be able to signpost their patients to access further support. Peer support is of huge benefit to Black, Asian and Minority Ethnic people living with HIV, particularly as many feel unable to share their status with family and friends. Healthcare professionals need to prioritise ready referral to peer support, with ideally a peer support worker in each HIV clinic, available to speak with patients - particularly the newly diagnosed.

Accurate and accessible Information about co-morbidities affecting people living with HIV and how to effectively navigate the healthcare system to best look after their health has an empowering effect on the wellbeing on Black, Asian and Minority Ethnic people who are disproportionately affected by co-morbidities such as hypertension and diabetes.

COVID-19

empowering

WOMEN KNOW BEST:
What are the best practices in effective, high-quality HIV support for women in the UK?

We want change. We are positive.

POSITIVELY UK

Supported by AbbVie and BHIVA

Over half (51%) of Black, Asian and Minority Ethnic community participants reported that their access to HIV clinical services worsened during lockdown, whilst 38% found no change, and 9% reported an improvement. Barriers included reduced clinical services (45%) and difficulties booking appointments (31%)[55]. Participants also reported problems getting medications and repeat prescriptions (13%).
A minority (9%) found that access to HIV clinical services had improved during lockdown, largely as a result of the greater flexibility afforded by online service provision.

Whilst the majority (58%) of White British and White Other respondents reported that changes to access to clinical services during lockdown had no or little impact on their mental health and well-being, only 29% of Black, Asian and Minority Ethnic people reported no or little impact; nearly half (47%)stated that changes to services during lockdown had a great deal of impact on their mental health and wellbeing[56].

One-in five (21%) Black, Asian and Minority Ethnic community respondents stated that their medication adherence had worsened during COVID-19; 41% stated that they had 'too much going on', a third (29%) reported that this was due to mental health difficulties, and 6% said they had difficulty obtaining prescriptions.

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[54] NAM AIDSMAP submission
[55] Positively UK submission
[56] Positively UK submission

This contrasts with 7% of White British, Irish and White Other respondents who reported a decline in adherence over the same time period and Socio-economic challenges[57].

Positively UK say that when they asked respondents to rank the most pressing issues they were facing, Black, Asian and Minority Ethnic community participants identified immigration, money, racism, language and HIV-related stigma as key.

A useful comparison would be to understand how Black, Asian and Minority Ethnic communities have been impacted by the COVID-19 pandemic, information about which has been published by Public Health England[58] and The Guardian[59], as well as from a specific LGBTQ+ perspective in our own *Hidden Figures*[60] report.

Institutional racism can have a significant impact on HIV testing and care. Research by Dr Rageshri Dhairyawan and colleagues showed that Black, Asian and Minority Ethnic people with HIV in the UK face significant barriers to testing, taking treatment consistently and staying engaged with care, likely linked to structural racism and economic disadvantage. The impact of structural racism on health outcomes is felt across different disease areas in the UK, including COVID-19, and is apparent in HIV where the health inequities based on ethnicity are stark[61].

Existing studies have already been conducted that show the racial wealth gap in the UK. The Office of National Statistics[62], for example, noted that median income for Black African households in the UK was £34,000 between April 2016 and March 2018, compared to £314,000 for white British households. Websites such as Black Girl Finance also exist to provide evidence and support with regard to this gap. This is inevitably going to have an impact on services, such as financial access to transport, access to mobility-friendly transport for disabled Black, Asian and Minority Ethnic individuals, arranging childcare during appointments, health surcharges for Black, Asian and Minority Ethnic immigrants, etc. It will also likely push other health concerns lower down the priority list during the financial impact of job losses and reduced income in the aftermath of the COVID-19 pandemic.

Undetectable=Untransmittable

Undetectable=Untransmittable (U=U) is an empowering message which improves optimal sexual and mental health. However, hesitancy of U=U messaging among healthcare providers (HCP), particularly non HIV specialist HCPs, is a barrier to widespread adoption. Addressing provider concerns and improving the understanding of U=U among vulnerable populations is key to increasing adoption of U=U.

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[57] Positively UK submission

[58] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

[59] https://www.theguardian.com/society/2021/jan/28/health-inequalities-in-uk-are-major-factor-in-high-bame-covid-cases

[60] https://s3-eu-west-1.amazonaws.com/lgbt-website-media/Files/7a01b983-b54b-4dd3-84b2-0f2ecd72be52/Hidden%2520Figures-%2520The%2520Impact%2520of%2520the%2520Covid-19%2520Pandemic%2520on%2520LGBT%2520Communities.pdf

[61] Dr Rhageshri Dhairywan submission

[62] https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/articles/householdwealthbyethnicitygreatbritain/april2016tomarch2018

U=U has been adopted by 1,050 organisations in 102 countries. U=U improves the wellbeing of people with HIV and dismantles HIV stigma. Bruce Richman presented at the recent IAS conference recently published data from the 25-country 2019 Positive Perspectives Survey (n=2,389). Being informed of U=U by a Health Care Professional was significantly associated with higher odds of optimal sexual health, and self-reported HIV disclosure and viral suppression. Data from South Africa suggests that peer-delivered U=U messaging increased HIV testing uptake among men by 89% in a setting where testing coverage is lower among men than women. U=U messaging is empowering for transgender people whose access to HIV services is hindered by multi-level barriers, but few trans people are aware of U=U or the impact it can have on their lives.

U=U hesitancy persists among Health Care Providers despite robust evidence of effectiveness. Engaging them, understanding reasons for hesitancy, utilizing U=U champions including young people who can communicate inclusive and positive messaging, and scaling up Black, Asian and Minority Ethnic viral load testing are key to increasing adoption of U=U. Better understanding what works and for whom is needed.

Stigma

The perception of HIV is steeped in the 40-year legacy of the disease. A lack of awareness and education around HIV exacerbates stigma and existing perceptions of what it means to have HIV. Through the media and public discourse around the Channel 4 series “It’s a sin”, it became apparent that younger generations are not fully aware of what HIV is and if they are, they associate it with earlier generations when transmission rates were at their highest and it was seen as a condition that results in death. There is a need to tackle the root cause of this stigma through education.

Stigma reduction is a critical part of the journey to supporting Black, Asian and Minority Ethnic people living with HIV to live well. This can be assisted by encouraging members of Black, Asian and Minority Ethnic communities to gain a better understanding of HIV, including how HIV is transmitted, and the advantages of treatment so that they can understand that having HIV does not mean a death sentence, and that a person with HIV can live a near normal life. Through better understanding of HIV, the fear and stigma that may be prevalent within some Black, Asian and Minority Ethnic communities will reduce. An example of how this could be done could be through compulsory relationship and sex education, which includes content about HIV and HIV prevention.

It is felt amongst the HIV sector that encouraging people with HIV to openly talk about their condition will not only help promote a better understanding of HIV within the wider community, it will also drive self-confidence in positive people, and consequently lead to a reduction in self-stigmatisation.

NAZ in its submission set out that stigma within South Asian communities is largely down to knowledge gaps, but the impact of those gaps can be devastating to the individual who might be rejected by their family if they receive a positive diagnosis. They also advised that it often impacts on the individual’s ability to access both health and social services through the associated trauma, shame, and self-stigmatisation.

CAN'T PASS IT ON

People on effective HIV treatment CANNOT pass on the virus

FACT

www.tht.org.uk

Terrence Higgins Trust

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Photograph by Sam Egarr

One particular subgroup of Black, Asian and Minority Ethnic PLWHIV who are more likely to be affected by HIV stigma are asylum seekers and refugees, argues the One Voice Network and the Love Tank. According to the Africa Equality Foundation and NAT, PLWHIV who are asylum seekers may include their status in their immigration forms because existing conditions is a question asked on the forms, which is mandatory to answer. The Home Office should change this and make it optional to disclose HIV status. Currently, if their application is subsequently refused, many believe that it is because they have HIV, and that they are being discriminated against which causes many negative effects on the individual. Clarity around this is needed and communication norms should be changed to ensure that it is clear that HIV status does not impact on the immigration process.

NAT and the One Voice Network in their evidence suggest that there are inconsistent Home Office accommodation practices which lead to bad experiences for PLWHIV asylum seekers. In London Home Office accommodation for new arrivals, individuals share rooms and have no privacy. The inquiry was told of the work that the Africa Equality Foundation have done with clients where their HIV positive status has been disclosed against their wishes due to this lack of privacy. However, out of London, some accommodations are separate, not shared, which minimises inadvertent disclosures and is key to ensure private accommodation is universally accessible to avoid such breaches of privacy, confidentially and outing of people's HIV status.

We have heard from NAT from its recent research on Migration and HIV that Open court hearings for PLWHIV going through the asylum and immigration processes have also led to unwilling disclosures in court, causing great distress when individuals are already going through a very difficult process. People's HIV status should not be raised in open court without the express wishes of the person in question. If the HIV status has to be raised, it should be in closed court only and people should always be asked if they are happy with their status being discussed. More needs to be done to ensure that all actors involved in the immigration and court processes are sensitive and respect the privacy of this sensitive and personal data, and that there are mechanisms in place to ensure unwanted and public disclosures do not occur.

Summary:

Structural and institutional racism is a significant barrier to accessing HIV testing, treatment and care services. Often, people fear being judged when they go into healthcare settings. To address this concern, services need to be overtly non- judgemental, and clinic staff need to be supported and trained in issues of culture and diversity so they can serve Black, Asian and Minority Ethnic community clients with sensitivity and empathy. Stigma and shame surrounding sexual health is a clear factor in how people access clinical facility-based services Black and minority ethnic groups may need additional support to stay engaged in care and on treatment. Clinics should be proactive in signposting and referring patients to advice and community services for help with issues such as benefits, housing and immigration. Within the clinic, they should ensure they have access to interpreters and are informing migrants about their entitlement to NHS care.

Immigration status can also affect willingness to access HIV services. Many people from the Black, Asian and Minority Ethnic community have not yet regularised their stay in the UK. Those with HIV may not want to engage with services for fear that doing so might work against their right-to-stay applications. In other cases, they may have a lack of knowledge - Black, Asian and Minority Ethnic migrants may not know that it is important to have regular checks, not only when they feel ill. They may not have access to the appropriate advice and messaging. Studies have shown that Black African men and women tend not to access services unless feeling seriously ill. There may indeed be concerns, on their part, of over-burdening already stretched state resources, and this view tends to support ideologies of accessing services only in crisis.

Other barriers find members of the Black, Asian and Minority Ethnic community preoccupied with other 'more pressing' priorities such as immigration matters and financial hardships, evidencing the intersectional nature of health and social inequality. A further impact of poverty is that it can culturally position individuals, particularly men (but women also), into pressured situations as family 'breadwinners'. This individual focus predominantly or exclusively on working to gain income to escape poverty and support family, can supersede taking care of one's own health, and possibly thinking about HIV risk.

Clearly It is important to ensure that HIV services are available to all residents of the UK regardless of their immigration status; and that clear, accessible and effective mechanisms are put in place to ensure migrants know that HIV services are free, and they are entitled to it regardless of their migration status.

Services should not be 'one-size-fits-all'. Black, Asian and Minority Ethnic community service users should be meaningfully involved (including in decision-making processes) from the design through to the delivery phase of any service that is intended for them. It is also essential for research activities which are used to inform service design, to be developed with equity principles of better health outcomes for Black, Asian and Minority Ethnic people.

There is an increasing fear of ageing with HIV amongst Black GBM, a demographic that live most of their lives in hiding due to societal pressures to conform to the ideal of heteronormativity. There needs to be a champion of activities led by organisations designed to deliver this extraordinary support. That is, organisations of Black GBM living with HIV for Black GBM living with HIV. House of Rainbow (HoR) is proud to be able to provide a space to provide this support to this often-overlooked community. However, these approaches need to be upscaled and funded to continue to have impact and ensure no Black GBM living with HIV in the UK are suffering in silence.

Recommendations

1. Anti-stigma campaigns and interventions to increase understanding, dispel myths and change attitudes towards HIV and HIV testing are needed to engage with the under-served ethnic minority groups.
2. Campaigns should include information about U=U to reduce stigma in the wider community.
3. All government strategies to end new HIV cases by 2030 should have a focus ensuring Black, Asian and Minority Ethnic people living with HIV can enjoy fulfilling and healthy lives.
4. There should be zero tolerance towards stigma and discrimination within all healthcare settings for people living with HIV. Relevant healthcare inspection agencies should assess how services are working to better support all people living with HIV.
5. National HIV action plans should include targeted work to ensure migrants and asylum seekers living with HIV can, and know they can, access HIV care and treatment without fear or intimidation by policies from the Home Office.
6. Provide additional funding for organisations providing psychosocial support to Black, Asian and Minority Ethnic groups so that mental health disparities do not worsen.
7. Clinicians should discuss quality of life with their patients, beyond monitoring of blood testing and the perception of an undetectable viral load as the only measure of success.
8. Patients should be at the heart of co-production of their care to ensure meaningful involvement and trust. This must include patients from Black, Asian and Minority Ethnic backgrounds.
9. Al patients should have access to peer support which should include, where possible, peer support workers from a variety of ethnic backgrounds.
10. Black, Asian and Minority Ethnic people living with HIV must be better supported to engage in HIV care and take treatment regularly. Clinicians should assess the structural barriers that each individual may face, eg poverty, homelessness, insecure immigration status, food insecurity, domestic violence, and ensure that pathways exist to refer patients to, in order to address these unmet needs.
11. Services should make use of interpreters where possible, to ensure good communication with patients who may not have adequate knowledge of English.
12. Services should provide information about HIV care, testing and prevention in a variety of languages. Consideration should also be taken of how to communicate to patients with low literacy levels.

Area 4: Data, policy, meaningful involvement and co-production

"It would be very difficult if you had it in a Muslim community. You'd be an outcast and never accepted. It would be very difficult. People might think you have been up to bad things. It's a lack of knowledge, education and negative perceptions. It's judgemental[63]."

The inquiry was provided many examples that community-led organisations doing great work at grassroots level are not well supported financially to carry out the work due to biased commissioning practises. Consultations on sexual health strategies and commissioning intentions need to involve everyone, and the commissioning models need to reflect diversity of communities and organisations involved in frontline work. What is more, there needs to be recognition of the historic under resourcing of community-based organisations and the limited capacity and resources afforded to community members.

Community members may not determine the issues that are relevant to their personal experience; or maybe cannot afford to be involved. They may have other priorities, such as financial difficulties, unemployment and other family and life problems that may make it difficult to take part. For example, organisations or government services may wish to involve community members as campaign models or peer consultants; however if there is no allocated funding for these community members to be involved then they may not be privileged enough to afford to do it for free[64].

A Black, Asian and Minority Ethnic individual may have their identity rooted in the distinctiveness of ethnic origin. This may fuel an 'outsider' sense that may hold individuals back from participating fully in the formulation of HIV policy and planning development. Some individuals and communities may understandably distrust healthcare organisations due to previous negative experiences in healthcare and other government institutions. However, some Black, Asian and Minority Ethnic people were born and grew up in communities where respect for authorities meant existing traditions, protocols or methods were followed without question[65].

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[63] South Asian Participant – NAT https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf

[64] One Voice Network submission

[65] One Voice Network submission

Organisations such as NAZ, The Love Tank, BHA and One Voice Network suggested that there is a need to recognise that unconscious biases and discrimination towards Black communities and Black-led organisations working in HIV exist. Where inclusion does occur, it is tokenistic and only for appearance's sake. Decision-makers need to genuinely embrace partnerships that are committed to inclusion and meaningful involvement; not omit them altogether or only use them in a tokenistic way.

It was strongly emphasised in the evidence that it is important to encourage broad partnerships between different sized organisations and community groups to ensure reaching diverse audiences. Small organisations need to be funded adequately to a level commensurate to other partners – it is disingenuous to have big organisations hold all the funds and only provide participation vouchers for individuals linked through the small organisations.

Recruitment to clinical trials is also an issue. The Journal of Virus Eradication did a study a few years ago and found that licensing studies were 'overwhelmingly conducted in richer countries and white men were massively over-recruited'[66]. One Voice Network suggests that this means that important information about what impact the drug has on the bodies (of Black people) may be missed and potentially dangerous side effects go unnoticed (Pharmacokinetics). Phase III studies must recruit study populations that are more representative of the global HIV pandemic.

All of the evidence we received supported the need for training to empower Black, Asian and Minority Ethnic communities and arm them with the confidence to challenge, participate, and help influence HIV policy. This must be accompanied by a willingness by policy organisations to promote and include BAME communities in their work, acknowledging and addressing past barriers to participation.

In the UK, HIV care (including PrEP, testing, and treatment) is free, regardless of a person's immigration or income status. Despite this, there are significant barriers for migrants accessing healthcare in the UK, according to a recent National AIDS Trust report on HIV and migration. In 2019, 62% of all new HIV diagnoses were among migrants, and of this number, 33% were female.

Moreover, about 58% of all new diagnoses among migrants born in Africa were in women. Contrary to migration myths in public discourse, the report states that half of all migrants diagnosed with HIV in the UK in 2019 likely acquired HIV in the UK[67]. The report also named governmental policies introduced in 2012 - considered to have created a "hostile environment" for migrant populations - as significant barriers for accessing healthcare. Among the report recommendations, the National AIDS Trust calls for an end to data-sharing between the NHS and Home Office and a review of primary care registration models and practices to gain a better understanding of why migrants face difficulties accessing care.

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[66] One Voice Network submission

[67] NAT submission

Supporting people with HIV to live well

There is a need for greater funding and collaborative support for Black, Asian and Minority Ethnic organisations in the third sector and the sexual health sector. Funding cuts have severely reduced capacity and increased staff burnout, resulting in a loss of trust in third sector Black, Asian and Minority Ethnic providers to fulfil their obligations. Simultaneously, there has been an implicit expectation for Black, Asian and Minority Ethnic providers to do unpaid emotional and physical labour without any thought for remunerations. Respondents for trials, studies, interviews, focus groups, workshops, etc need to be properly compensated, and their accessibility needs fully taken into account in order for a model to be made sustainable.

A common issue is the assumption that Black, Asian and Minority Ethnic communities are "hard to reach" rather than recognising the structural inability to actually reach out to these communities. The most significant change in the system has been the increase in Black, Asian and Minority Ethnic service providers (including specific intersections like QTIPoC groups) in recent decades, so the most immediate step is to ensure that these groups are being empowered during data collection drives. There also needs to be reassurance against medical racism, misuse of data, and, whenever possible, appropriate remuneration.

Data Collection

We were told by Fast Track Cardiff and Vale that there is relatively little known about the needs of Black, Asian and Minority Ethnic people with HIV in Wales because, disgracefully, ethnicity data is not collected nationally; no services, either within specialist organisations or generalist ones, systematically target Black, Asian and Minority Ethnic people with or at heightened risk of HIV; there is minimal visibility of Black, Asian and Minority Ethnic people with HIV with the exception of one member of Fast Track Cardiff and Vale. There is, however, a diversity of Black, Asian and Minority Ethnic people here living with HIV[68].

The issue of data collection has been an acknowledged area of concern for the Welsh Government. Recently, the Welsh Government has committed to establishing "Equality Data Units", including a possible "Race Disparity Unit". Although this is still a work in progress and could be formalised later this year, it is an example of good practice on how to tackle the issue of lack of data concerning protected characteristics. Fast Track Cardiff and Vale hope that these efforts will include data collection exercises to make possible the analysis of local evidence, including regional and national data of Black, Asian and Minority Ethnic people and migrants living with, or at higher risk of, HIV.

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[68] FTC&V Submission

Fast Track Cardiff and Vale argue that there are high levels of stigma and misinformation to combat and there is an urgent need for a co-ordinated programme across Wales which includes targeted work with Black, Asian and Minority Ethnic communities and migrant services which talk about treatment saving lives, stopping transmission and keeping people well, alongside the usefulness of PrEP and the ease and confidentiality of testing services. They feel that community conversations are needed, which remove stigma from sexual health – and from sexuality and gender identity issues, which are often the source of reluctance to come forward.

To do this Fast Track Cardiff and Vale advised that Wales needs much better ethnicity data about who has HIV, alongside where and how it is being transmitted and what causes people to withdraw from Welsh services or fail to use them in the first place. To do this they argue that it needs financial assistance and commitment from Government to see this through, in order to reach no new diagnoses by 2030. If the status quo is kept, Fast Track Cardiff and Vale argue that it will not get us there, and failure to target Black, Asian and Minority Ethnic people, including both Black, Asian and Minority Ethnic men who have sex with men and heterosexuals, will leave an ever-increasing burden of disease with them.

It was argued by NAZ, Once Voice Network and others that there is a lack of comprehensive and consistent quality ethnicity data collection and recording in NHS and social care data collection systems, and there is a need for a good public health dashboard on inequalities in Black, Asian and Minority Ethnic women's health, and an understanding of how these issues are being met and managed across the country. Inaccurate recording of people's ethnicities means that data does not reflect the needs of Black, Asian and Minority Ethnic people accurately - as a result, identifying where interventions should be commissioned and services set up, can be difficult or misleading.

NAZ in its oral evidence session advised the inquiry that data collection at GPs is not successfully captured, which means that people from Black, Asian and Minority Ethnic communities who should be offered a HIV test are not, as their risk factors are not sufficiently identified[69]. This is despite evidence suggesting that GP surgeries are a setting where Black Africans are willing to take an HIV test[70]. As ethnicities are not being correctly reported those at risk are not offered HIV tests, resulting in missed opportunities for people to know their status and reduce the number of undiagnosed people living with HIV.

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[69] HIV Commission, How England will end new cases of HIV (2020), Accessible via: https://www.hivcommission.org.uk/wp- content/uploads/2020/12/HIV-Commission-Full-Report_online_final_pages.pdf

[70] National Aids Foundation, HIV and Black African Communities in the UK (2014) Accessible via: https://www.nat.org.uk/sites/default/files/publications/NAT-African-Communities-Report-June-2014-FINAL.pdf

It was argued that without disaggregation of data, Black, Asian and Minority Ethnic people will continue to be homogenised as one group, making interventions and targeting ineffective as they are not tailored to the specific needs of different communities. This results in the continuation of the disproportionate impact of HIV on Black, Asian and Minority Ethnic communities to a point where they have become more polarised towards the 2030 UNAIDS goals of net zero transmissions.

If data collection is not improved, the existing knowledge gaps for some practitioners and care providers across the healthcare system will continue to persist. This is compounded by a lack of training to enable them to better support and understand the specific and diverse needs of the Black, Asian and Minority Ethnic community. This is exacerbated by a lack of links to community providers working with Black, Asian and Minority Ethnic communities, and a lack of awareness of their role within these communities. This means that the contribution they could potentially make to the delivery of services is not happening.

Funding and sustainability

Funding is one of the most important factors when it comes to creating programmes that engage community members and provide HIV prevention and support services across Black, Asian and Minority Ethnic communities.

Issues around funding cuts have been previously raised by the All-Party Parliamentary Group (APPG) on Sexual and Reproductive Health. The APPG noted that past health reforms, namely the Health and Social Care Act of 2012, reorganised the NHS into NHS England, public health into PHE, and social care within local councils, but didn’t effectively map out clear lines of accountability. We previously suggested, in our “The HIV Puzzle: Piecing together HIV care since the Health and Social Care Act 2012” report, that HIV services were being increasingly fragmented as a direct result of the 2012 Act. We were also critical of the decommissioning of HIV services, which were often in urban areas with significant Black, Asian and Minority Ethnic populations and high rates of HIV infection. In order to ensure sustainable commissioning for HIV testing and prevention initiatives, we recommended that local authority public health grants be protected from further funding cuts, in line with the Government’s commitment to ring-fencing the NHS budget.

The inquiry was told by all the community-led organisations that funding cuts over the past few years have caused the following:

- A closure of grassroots community organisations, including HIV charities, with the resultant loss of help and support to members and service users.
- The loss of community workers who had built up critical skills and experience in delivering support services to Black, Asian and Minority Ethnic communities.
- 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.

- A loss of input on issues that affect the health and wellbeing of people from the Black, Asian and Minority Ethnic communities.
- The pandemic has made the situation worse as it has had a huge impact on resourcing Black, Asian and Minority Ethnic community-led organisation at all levels, local and national.

Organisations have argued that sustainable and long-term funding is required to ensure the evolving needs of Black, Asian and Minority Ethnic communities are met by the sector, as well as by mainstream health and social services, for the overall wellbeing of PLWHIV.

We were told by NAZ, The Love Tank, One Voice Network and George House Trust that currently, demand for services exceeds the level of support available. We were also told that many voluntary sector organisations are struggling to meet demand for appropriate cultural and linguistic services to support clinical outcomes. Capacity, sector retention and funding are all issues faced by the Black, Asian and Minority Ethnic HIV voluntary sector that impact on the ability to provide the support people need to continue their treatment plans.

It was strongly argued by organisations such as One Voice Network, NAZ, The Love Tank, NAM aidsmap that wrap-around support and advocacy is paramount to building relationships with those living with HIV. It is not just about making sure someone is on the correct medication, it is about supporting all aspects of their life, so that they are able to live their life to the fullest.

The inquiry was told that in 2012 there were approximately 40 Black, Asian and Minority Ethnic-led HIV and sexual health agencies across the UK; today there are 11[71]. There are currently no Black, Asian and Minority Ethnic-led HIV and sexual health agencies in Wales, Scotland or Northern Ireland.

In recent years there has been a steady decline in funding across the HIV prevention and care sector in England. The Local Authority public health funding in England (which finances most sexual health services) has decreased by 23% between 2015/16 - 2020/21. For example, between 2015/16 and 2016/17, funding for Black, Asian and Minority Ethnic targeted health promotion contracts dropped by more than 50% in London. This decline in funding has not been isolated to Local Authorities; we have witnessed a reduction in funding from Trusts and Foundations as well[72].

It was argued by NAZ and One Voice Network that future funding must be ring-fenced or restored to ensure Black, Asian and Minority Ethnic communities are receiving the prevention programmes and campaigns needed, and that capacity can be increased within organisations carrying out this vital work.

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[71] NAZ submission

[72] NAZ submission

Subsequently, the inquiry was told that funding cuts have a huge effect on not only the way Black, Asian and Minority Ethnic people access services but also the number of services available that are culturally, linguistically and faith tailored to their needs. Barriers for Black, Asian and Minority Ethnic communities when accessing appropriate services include cultural barriers, stigma, lack of trust, language, faith needs, racism, and homophobia. These barriers coupled with previous negative experiences all act as deterrents to accessing services.

In addition, sexual health services no longer exist in all health authorities. Continuous funding cuts have resulted in services being amalgamated and rationalised. Changes to the structure of sexual health service delivery have resulted in resource reductions nationally, servicing less people, although demand for services remains high.

Role of non-HIV organisations

Non-HIV organisations are crucial in engaging with Black, Asian and Minority Ethnic communities as they have the opportunity to reach individuals who would not typically engage with targeted interventions. It was agreed in all submissions that involving non-HIV organisations normalises discussions around HIV and sexual health as a whole.

There are distinct positive roles they can play, including[73]:

- Promoting a sense of belonging that can lead to Black, Asian and Minority Ethnic people sharing experiences and lessons, and finding solutions to challenges posed by HIV;
- Making it possible for Black, Asian and Minority Ethnic communities to create or strengthen social networks, which can imbue the confidence to access HIV services;
- Non-HIV organisations can provide a platform for the onward cascading of HIV information;
- One major role is informing and encouraging their service users to access mainstream services, including HIV/STI testing settings. In this aspect, churches and small business are playing key roles in informing and encouraging their congregation members and customers to take part in testing;
- Non-HIV organisations can also help to support and/or care for people living with or affected by HIV. Examples include mental health agencies, services for the elderly and Food Banks;
- Non-HIV agencies can provide social or legal services for people living with or affected by HIV.

In this sense it helps to de-stigmatise HIV by taking it out of the clinic and putting it into everyday life.

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[73] One Voice Network Submission

CASE STUDY

FAWA has been a member of several partnerships that have strengthened HIV intervention work. Key networks include the BME Forum in Inner Northwest London. Through the Forum, FAWA has been able to network with other community organisations, enabling them to pass on relevant information and advice to a wider audience. They have also worked with Health Watch. This is a forum bringing together agencies in West London. As a member of this forum, FAWA has delivered wellbeing work with men, women and young people who are living in West London. Through the group, they were able to recruit more men and women to engage in healthy lifestyle activities such as walks, cookery sessions, and health awareness workshops.

It was suggested by multiple organisations that using football and other sporting or cultural events to promote HIV prevention awareness can help reduce the spread of HIV in the Black, Asian and Minority Ethnic communities. Pre-Covid 19, many of these events were being staged around the country, especially in areas with big Black, Asian and Minority Ethnic communities. Organisers can partner with HIV organisations to make available leaflets, resources such as condoms, and even HIV testing.

Summary:

- Anti-stigma campaigns and interventions, to increase understanding, dispel myths and change attitudes towards HIV and HIV testing, are needed to engage with the different intersectionalities of Black, Asian and Minority Ethnic groups. Additionally, it is important to bring forward the multiple discrimination duty under Section 14 of the Equality Act 2010 to recognise that discrimination can take place based on one or more characteristics.
- Ensuring all clinicians have sufficient access to training resources and continuous professional development opportunities will enable them to better understand the testing considerations of Black, Asian and Minority Ethnic communities. There is also a significant need to improve links between GPs and existing community-based interventions that can then foster better co-delivery of services and gain greater community insight.
- Co-designing services with the communities that programmes are trying to reach, so that the different cultures, languages, and faiths are accounted for. Traditionally there has been a tendency for language, policy and guidelines to be skewed towards the white Gay and bisexual men audience, and this needs to be challenged.
- A factor impacting HIV service uptake in Black, Asian and Minority Ethnic communities is the presentation of health promotion literature. We heard that previous research identifies African men living with HIV reporting experiences of social isolation and exclusion. The feelings associated with these experiences tended to be magnified with potential disclosures of their HIV infection. Some have found difficulty with health promotion efforts designed to engage Black, Asian and Minority Ethnic communities' GBM. Clearly there is a need for tailored information for members of the Black, Asian and Minority Ethnic community as some current promotional materials were deemed culturally inappropriate by virtue of their content being highly eroticised.
- Raising awareness of risk and dismantling the perception of risk is paramount to increasing knowledge on HIV testing.

Recommendations

1. **Progress on addressing current inequalities that disproportionately impact these communities should be detailed in annual reporting.**
2. **All four governments should work with a large, diverse range of ethnic communities and organisations, using the principles of co-production and meaningful involvement, to create a consensus around more acceptable terminology to be used by the HIV sector and with communities directly.**
3. **Any HIV Action Plan developed in England, Northern Ireland, Scotland and Wales to end new cases of HIV by 2030, should have a specific focus on the needs of Black, Asian and Minority Ethnic communities in regard to testing, prevention and living well.**
4. **Funding should be made available to support increased and diversified HIV testing in all parts of the UK.**
5. **There should be a UK wide campaign to encourage everyone to know their HIV status with Black, Asian and Minority Ethnic community representation in its development and delivery.**
6. **All clinicians and frontline staff across health and social care should receive regular training so they are confident in having discussions about HIV, HIV prevention and HIV testing. This training should also focus on the barriers to HIV testing including stigma, racism, transphobia and wider discrimination.**
7. **Any HIV Action Plan adopted by any of the four governments must include the development of a strategy for recruitment of a diverse workforce, training, and retention of the HIV workforce, in clinical settings, local government and the voluntary sector.**
8. **Public Health Bodies in England, Northern Ireland, Scotland and Wales should produce more granular data linked to HIV, ethnicity, age, gender, and migration status so a greater understanding of intersectional issues impacting the many communities in the Black, Asian and Minority Ethnic community affected by HIV can be understood.**
9. **More research is needed to provide data on Black, Asian and Minority Ethnic communities so as to better understand their needs. Disaggregated data and research would inform targeting, identify gaps and address barriers to testing more effectively.**
10. **An audit of public sector data sources in all four nations should be conducted to establish where there are gaps in data collection and how data collection methods can be streamlined. This needs to be consistent across local authorities, Public Health Agencies and the NHS. Data needs to be disaggregated for BAME ethnicities in order to understand the needs of each group and where to target services.**
11. **The flexibility and granularity of data collection systems must be maximised to meet the changing face of HIV and tackle inequity, including reporting on all communities.**
12. **Public Health Bodies should produce more granular data linked to HIV, ethnicity, age, gender and migration status so greater understanding of intersectional issues impacting Black, Asian and Minority Ethnic Communities affected by HIV can be understood.**

13. **National data sets on gay and bisexual men should include a breakdown of ethnicity to better understand the HIV epidemic using an intersectional approach.**
14. **Public Health Wales and Public Health Scotland should publish national HIV data that includes statistics on ethnicity.**
15. **We recommend alignment with the ethnic groups published by the UK Government, which is used in census data.**
16. **Public Health England should produce further insight reports on the experiences of Black, Asian and Minority Ethnic women affected by HIV, with input from third sector organisations to inform its findings.**
17. **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 Black, Asian and Minority Ethnic Communities**
18. **HIV researchers should ensure that studies recruit a diverse proportion of BAME participants to ensure that the results are representative of the community of PLWHIV. Research should be designed in partnership with the HIV community including people from BAME communities.**
19. **The four governments should look at ways to support and expand the capacity of Black, Asian and Minority Ethnic voluntary sector organisations to help deliver the programmes and campaigns needed to meet the 2030 target.**
20. **Migrants' HIV status should not be raised in open court at all without the express wishes of the person in question.**
21. **The UK Government should end "no recourse to public funds" within the immigration system.**
22. **The NHS should stop sharing data with the Home Office.**
23. **Improve both the reporting and response to hate crime by establishing third party reporting centres and victim support programmes based in Black, Asian and Minority Ethnic community organisations.**
24. **The NHS in England, Northern Ireland, Scotland and Wales should ensure there is regular training and development for all frontline NHS staff to better support Black, Asian and Minority Ethnic people living with HIV.**
25. **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. This data should also include ethnicity to better understand the HIV epidemic using an intersectional approach**
26. **Research looking at issues affecting Black, Asian and Minority Ethnic People Living With HIV should be led where possible by researchers from Black, Asian and Minority Ethnic communities, and funded and supported adequately.**

Conclusion

The enduring impacts of colonialism and racism have long restricted the variety and quality of choices available to Black, Asian and Ethnic minority communities. We have seen that the four governments need to invest in understanding how colonial legacies and structural racism have impacted these communities in accessing sexual and reproductive health services. There needs to be a better understanding and awareness of how the intersections of race, class and gender impact their access to care.

One approach advocated by many of the organisations to improve the understanding and awareness of access to HIV prevention, testing and care is to collaborate with community-based organisations. It has been advocated that peer-led interventions have been shown to improve awareness of and access to PrEP; however, much of this has been evidenced among men who have sex with men.

The evidence we received overwhelmingly recommended that there should be shared decision-making in a collaborative process intended to develop a treatment plan that considers both the patient's preferences and the health provider's recommendations. This will ensure that health care workers get the training they need and recognise systemic and individual bias in medical settings.

From the organisations we have engaged with, we can say there are several ways in which Black, Asian and Minority Ethnic communities can be engaged.

First, offering HIV tests as part of a wider range of health checks is crucial since it can help engage those that might not ordinarily test for HIV. It can also normalise HIV testing by situating it within a wider discourse of looking after our health, which has broader appeal and can represent a 'hook' into testing.

Second, more community-owned and delivered testing is needed. This is a lesson we have learnt through years of work with gay men and the lessons we have learnt with the normalisation of the PCR test at home with Covid. Trust and uptake are increased when testing is designed and delivered by communities we are trying to reach. Testing programmes need to be more reflective of the communities they are seeking to engage. This can include race, ethnicity, age, language and religion, and should also include testing staff, volunteers and related resources.

Third, campaigns need to be culturally and linguistically appropriate and community co-created. A community-based approach to any campaign will mean it is owned by and created by those it is aimed at. This in turn will result in images and messages that are engaging and appropriate. This speaks to the need to trust community knowledge and the idea that 'we know best what we need'.

Fourth, there is a need to ensure there is the necessary data to know which communities are being engaged in testing, prevention, care - and why.
All organisations have argued that the sector needs granularity of data across the UK, collecting data on all communities, to inform HIV work.

Black, Asian and Minority Ethnic communities should be trusted and funded to take leadership on matters that directly impact their health. This is why we are calling for members of the Black, Asian and Minority Ethnic communities to be integral to any development and delivery of policy, programmes and campaigns, ensuring that these speak about them and to them.

We must not allow anyone to be left behind in the common endeavour of ending new transmissions of HIV by 2030, in combating stigma, and in ensuring quality of life for all Black, Asian and Minority Ethnic people living with HIV.

Annex 1

Sexual Health Provision in the UK

England

Sexual health services are commissioned at a local level to meet the needs of the local population, including provision of information, advice and support on a range of issues, such as sexually transmitted infections (STIs), contraception, relationships and unplanned pregnancy.

Local authorities commission comprehensive open access sexual health services (including free STI testing and treatment, notification of sexual partners of infected persons and free provision of contraception). Some specialised services for HIV are directly commissioned by clinical commissioning groups (CCGs) and at the national level by NHS England.

Wales

Public Health Wales (PHW) provides specialist public health resources at a national, regional and local level, including to Local Health Boards and to their respective Directors of Public Health. It provides centrally coordinated screening and health protection services for local health board populations, including the national STI and HIV postal testing service run through Frisky Wales.

Local Health Boards are responsible for all other testing service delivery and the health of the population in their areas, including local health promotion campaigns.

Scotland

Across Scotland, HIV testing is delivered in a range of settings including sexual health clinics, community-based services, via home test kits, and in other health care settings, eg GP Practices. However, specialist NHS sexual health services remain the primary location for HIV and sexual health testing.

Northern Ireland

Healthcare in Northern Ireland is regionally divided into five geographic areas, known as Health and Social Care Trusts.

Currently, sexual health and HIV services are available through three genitourinary medicine (GUM) clinics / sexual health clinics located in Belfast (the Belfast Trust), Downpatrick (the South Eastern Trust), and Derry/Londonderry (the Western Trust).

These Trusts operate under the guidance of the Department of Health (NI).

Organisations who gave Oral evidence

- African Advocacy Association
- BASHH
- Dr Rageshri Dhairyawan
- Fast Track Cities Cardiff
- George House Trust
- NAZ
- Positive East
- Public Health England
- Terrence Higgins Trust
- The Love Tank
- Waverley Care

Organisations who gave written evidence

- African Advocacy Association
- AIDS Healthcare Foundation UK
- Bakita Kasadha
- BHA for Equality
- British HIV Association (BHIVA)
- The British Association for Sexual Health and HIV (BASHH)
- Catholics for AIDS Prevention and Support (CAPS)
- Chase Ledin and Benjamin Weil
- The Children's HIV Association (CHIVA)
- Dr Rageshri Dhairyawan and Hajra Okhai
- Elton John AIDS Foundation (EJAF)
- Fast Track City Cardiff and the Vale of Glamorgan
- George House Trust
- Gilead
- HIV Stigma Survey Team
- LGBT Foundation
- Metro
- NAM aidsmap
- National AIDS Trust (NAT)
- NAZ
- One Voice Network
- Positive East
- Public Health England
- South Asian HIV Advisory Resource (SAHAR)
- Terrence Higgins Trust (THT)
- The Love Tank
- ViiV Healthcare
- Waverley Care

Members of the APPG inquiry Committee

- Stephen Doughty MP
- Florence Eshalomi MP
- Alison Thewliss MP
- Claire Hanna MP
- Baroness Barker
- Lord Black

Notes

I'M STOPPING HIV.

I'm on treatment.

People on effective HIV treatment can't pass on the virus

IT STARTS WITH ME

Terrence Higgins Trust

Find out all the ways to stop HIV

StartsWithMe.org.uk

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