# Unheard Voices

## Understanding the challenges faced by Black people living with HIV in primary care

Working together

ONE VOICE NETWORK

NATIONAL AIDS TRUST

# Contents

**Executive Summary**

**Forewords**
- **Professor Kevin Fenton**
- **Dr Aneesh Noonan**

**Recommendations**

**1. Introduction**
1.1. Background
1.2. Methodology
1.3. Limitations

**2. Discussions of findings**

**2.1. HIV stigma**
2.1.1. Understanding HIV stigma
2.1.2. Respondents' experiences of stigma
2.1.3. What can be done to challenge HIV stigma in primary care

**2.2. Booking issues**
2.2.1. Experiences with receptionists in GP surgeries
2.2.2. Waiting times and length of appointments

**2.3. Continuity of Care**
2.3.1. Patients' responses to triage systems
2.3.2. Benefits of a named GP system

**2.4. Confidentiality**
2.4.1. Patients' fear of having status shared without their consent
2.4.2. Confidentiality and its impact on medical mistrust
2.4.3. Structural changes needed to improve faith in confidentiality

**2.5. Cultural competency**
2.5.1. How culture impacts the quality of primary care services
2.5.2. Principles of cultural competency
2.5.3. How to deliver culturally competent care

**2.6. Accessibility of health information**
2.6.1. Language diversity within Black communities
2.6.2. Patients' experiences accessing translation services
2.6.3. Improving availability of language inclusive resources

**2.7. Care coordination**
2.7.1. Navigating comorbidities in primary care
2.7.2. Communication between primary and secondary care

**2.8. Lack of choice and agency in healthcare**
2.8.1. How often patients felt listened to by their GPs
2.8.2. Shared decision-making with patients

**2.9. Mental health and social well-being**
2.9.1. The mental health of people living with HIV
2.9.2. The relationship between culture and mental health
2.9.3. Referral to local welfare services
2.9.4. The impact of financial vulnerability on mental health

**3. Conclusion**

**About the Unheard Voices projects**

**Acknowledgments**

# Executive summary

## This report outlines the key challenges faced by Black people living with HIV in London when accessing primary care.

**Black people living with HIV continue to face distinct barriers to receiving adequate care. This is despite the advancements in HIV testing, treatment and care which have increased overall engagement. These barriers contribute to Black communities having:**

- Lower levels of engagement in care;
- poorer health outcomes, and
- higher rates of HIV-related morbidity and mortality.

As the UK Government works towards ending new HIV transmissions by 2030, implementing sustainable solutions that genuinely reflect the experiences and needs of all communities is essential.

**142**

**Black-heritage respondents living with HIV in London responses were analysed from our survey completed**

This report outlines the key challenges faced by Black people living with HIV in London when accessing primary care and explores opportunities for improving the quality of the care they receive. As HIV is a long-term health condition, there needs to be a positive relationship between people living with HIV and all healthcare providers to support continued engagement with care. Through analysing responses from our survey completed by 142 Black-heritage respondents living with HIV in London, we identify what must change to ensure greater satisfaction with primary care and improved engagement with GP surgeries.

The findings underline the need for culturally competent care, increased patient-provider trust, and further accessible resources to improve health literacy.

# Professor Kevin Fenton

Co-Chair of Fast-Track Cities London;
Regional Director for London, Office for Health Improvement and Disparities (OHID) and
Regional Director of Public Health, NHS London

**Our fight against HIV has delivered remarkable progress over recent decades, with advances in treatment and prevention transforming the lives of people living with HIV. However, persistent health inequalities—particularly for Black people living with HIV—highlight the urgent need to confront the broader social and structural determinants of health that continue to drive poor outcomes.**

We now know that social and structural determinants of health, including, poverty, structural racism and discrimination, healthcare access challenges, employment insecurity, lower educational attainment, and limited health literacy all play a critical role in shaping health outcomes. Left unaddressed, these systemic factors delay diagnosis, limit access to high-quality care, and undermine the goal of ending new HIV transmissions by 2030. Tackling these issues is essential not just for improving HIV outcomes but also for addressing the broader health inequalities that exist across the health and care system.

> **“Tackling these issues is essential not just for improving HIV outcomes but also for addressing the broader health inequalities that exist across the health and care system.”**

## The upcoming 2025 HIV Action Plan also offers a critical opportunity to strengthen current interventions and rethink our approach to prevention and care.

The inequities faced by Black people living with HIV reflect wider systemic challenges. While it may be tempting to focus on a single disease at a time, real progress will require us to understand and tackle the interconnected challenges that affect health outcomes across multiple conditions. Health inequalities are not isolated—they are deeply embedded in our systems and are influenced by overlapping social, cultural, and economic factors. Responding effectively means addressing the root causes of inequity and ensuring that interventions are holistic, integrative, and grounded in collaboration.

Working in true partnership with communities is essential to delivering intersectional care that meets the diverse needs of people living with HIV. This requires culturally competent leadership, a diverse and well-trained workforce, and co-designed, community-led interventions that are responsive to people's lived experiences. By integrating these principles into policy, research, and service delivery, we can create a more equitable system that provides accessible, high-quality care to all.

We must also acknowledge the significant financial pressures on the health and care system which may mitigate against the some of the deeper system transformation required to provide more equitable services. Despite these challenges, there are opportunities for change. The government's commitment to a new 10 Year Health Plan, and a commitment to drive system shifts from treatment to prevention, hospital to community, and analogue to digital opens the door for innovative approaches to tackling inequalities. These shifts align with the wider need to make primary care a key player in the fight against health disparities. Enhancing primary care services and ensuring that frontline staff have the skills and knowledge to provide holistic, joined-up care will help bridge gaps and improve outcomes for people living with HIV and beyond.

The upcoming 2025 HIV Action Plan also offers a critical opportunity to strengthen current interventions and rethink our approach to prevention and care. By applying the insights from this report, we can adapt our services, address health inequalities across the system, and move closer to creating an equitable healthcare system that truly serves all communities. To achieve this, we must focus on integration, collaboration, and continuous innovation—ensuring that no one is left behind.

# Dr Aneesha Noonan

National Primary Care Lead Hep C Elimination for NHS England; Medical Director for Specialised Commissioning, NHS London and Deputy Medical Director for Systems Improvement & Professional Standards, NHS London

**The release of this report comes at a pivotal moment, a moment in which it has become increasingly apparent that primary care cannot be separate from HIV care. Now more than ever, primary care must play a greater part in HIV care as a long-term condition. As specialists in holistic management of long-term conditions, the primary care sector is perfectly placed to address the health disparities faced by Black people living with HIV. By reframing HIV like this, primary care can take the necessary steps to improve quality of care for Black people living with HIV by addressing stigma, ensuring culturally competent care, and improving care coordination.**

Some of these barriers to integrating HIV into primary are already being addressed by projects such as London Fast Track Cities Initiative's (FTCI) HIV GP Champions. This pilot programme has delivered HIV awareness training in partnership with the HIV Confident Charter to over 1,000 people working in primary care. GPs have been working with HIV services to break down barriers to co-ordinated care and to develop solutions to strengthen confidentiality. In collaboration with VCSOs, they are ensuring primary care providers are aware of the full range of HIV treatment, mental health, and social support services available.

> **“...we have the ideas, the innovation and the voices of the community ready to influence change. Now it's time for our local and national Governments to implement that same change we're all envisioning.”**

# Black-led organisations have the insight into clinical experiences of Black communities that can help primary care improve patient experiences.

However, this is also a time marked by profound challenges within primary care, where access to services is increasingly strained and staff are already stretched thin. Support for the primary care workforce and investment in a better patient record system are the building blocks for achieving fully co-ordinated care. These changes can empower GPs to truly share coordinated care with HIV services and provide holistic person-centred care that will improve patient outcomes for Black people living with HIV. The FTCI pilot has demonstrated what is possible in London, but this is not enough. As HIV services become delegated to Integrated Care Boards, they should take every opportunity to introduce and scale up the GP Champions programme and projects that aim to dismantle healthcare stigma.

The data presented within this report paints a stark and sobering picture of the deep-rooted systemic issues that disproportionately and negatively impact Black people living with HIV. For Black communities, the incidence of new diagnoses is higher, delays in access to treatment persist, and the wider health and social consequences are more severe. These disparities are fuelled by systemic racism, cultural barriers, and the continued presence of HIV-related stigma in our healthcare system. Unless we unpack these problems, Black people living with HIV will continue to struggle with HIV treatment and care.

To make sure no one is left behind, the recommendations from this report should be implemented across London and the rest of England so quality of primary care for Black people living with HIV is never a postcode lottery. Because of the historical disappointment Black communities have faced when accessing healthcare, there is no better time than now to proactively engage primary care on the needs of Black people living with HIV in a way that prioritises person-centred care.

Black-led organisations have the insight into clinical experiences of Black communities that can help primary care improve patient experiences. If primary care and the voluntary sector are given opportunities to work collaboratively, together they can develop safe surgeries that Black people feel confident attending for all their health needs. Without this joint approach to systemic change, Black people living with HIV will continue to face barriers to accessing quality care through their GP, which will only worsen health inequalities.

GPs need training on HIV care, stigma reduction, and cultural competency, all of which should be embedded into the GP Curriculum. Investing in education on HIV for primary care is critical if we want to see fewer new diagnoses and a better quality of life for all people living with HIV. The message is clear: we have the ideas, the innovation and the voices of the community ready to influence change. Now it’s time for our local and national Governments to implement that same change we’re all envisioning.

# Recommendations

## For GPs

- Ensure there is transparency when sharing a patient's HIV status with other healthcare professionals through clear and continued communication with patients.
- Establish regular communication pathways between GPs and HIV clinicians to coordinate care.
- Further develop an understanding of the cultural norms of their patients' communities.
- Start a mindful dialogue on lifestyle factors, cultural norms and significant life events including career, family, and financial stability which impact treatment adherence and health management.
- Establish transparency with patients over all aspects of healthcare including data confidentiality (in line with NHS guidance on patient confidentiality and information sharing on STIs and HIV) and treatment options.

## For Primary Care Networks and GP surgeries

- Signpost complaints procedures to patients and when necessary and outline options for patients to move GP surgeries, making sure they are supported by staff through the entire process.
- Provide resources and wider training to clinical and non-clinical staff to combat HIV stigma within GP practices.
- Review policies on triaging systems to allow people living with HIV to request a named GP contact if they do not mind the waiting time.
- Conduct regular audits of patient interactions to assess adherence to confidentiality and discrimination policies.

## For Royal College of General Practitioners and General Medical Council

- Develop modules, resources and workshops that focus on understanding the cultural nuances and socioeconomic factors impacting Black people living with HIV.
- Review the standards for medical education and training to include understanding HIV stigma and the principles of culturally competent care.

## For local authorities and Integrated Care Boards

- Increase research into the needs of the diverse local communities impacted by HIV including regular in-person and online opportunities for local community members to feedback on how their experiences could be improved.
- Work closely with local support services (housing, immigration, domestic violence, and HIV-specific services) to review and introduce best practice for effective referral protocols.
- Ensure continuation of the Fast Track Cities London HIV GP Champions programme and other projects aiming to reduce HIV stigma and improve quality of life.
- Create and signpost opportunities to improve the digital literacy of vulnerable and older community members.
- Collaborate with local communities and voluntary sector organisations to develop standards, guidance and resources on culturally competent care, focusing on lifestyle and cultural norms and how this impacts healthcare.

## For NHS

- NHS Improvement should conduct research into the barriers of recruitment and retention for primary care staff from ethnic minority backgrounds and develop recommendations to address identified challenges.
- Develop guidance such as toolkits and best practice forums to improve care coordination between primary and secondary care.

## For National Government

- Increase the Public Health Grant and NHS funding to ensure strategies, resources and projects are tailored to the needs of Black people living with HIV.
- Upgrade patient record software and technology to improve care coordination and streamline communication between different healthcare providers.
- Outline actions in NHS 10-Year Health Plan to reduce waiting times for appointments, increase length of appointments, improve access to translation services and hire more GPs

## For all stakeholders

- All local authorities, NHS trusts and GP surgeries should register with the HIV Confident charter mark. All NHS trusts should ensure both clinical and non-clinical staff complete the HIV e-learning module.

# Introduction

**48%**

**of new HIV diagnoses in England were accounted for by Black African communities in 2023.**

## 1.1. Health Inequalities in HIV

As the deadline for the Government's commitment to reach zero new HIV transmissions by 2030 gets closer, responding to health inequalities must be a central focus. To achieve this, it is imperative that Government, commissioners, healthcare providers, and community-based organisations work together to strengthen HIV care for everyone.

Black communities are still disproportionately impacted by HIV despite them making up only 4.2% of the population of England and Wales.

In 2023, Black African communities accounted for 48% of new HIV diagnoses in England, while people of White or White other backgrounds accounted for 21%.[1] Additionally, from 2022 to 2023, there was a 31% and 17% increase in the rates of new HIV diagnoses in Black Caribbean and Black African populations, respectively.[2]

# Black communities are still disproportionately impacted by HIV despite them making up only 4.2% of the population of England and Wales.

Differences in health outcomes extends to treatment initiation and adherence: Black African heterosexual people are more likely to not receive antiretroviral treatment than White heterosexual people.[3]

People living with HIV are not a monolith; their lived experience is varied and their experience of living with HIV intersects with other aspects of their identity. Black people living with HIV have specific needs that require tailored intervention. Although people living with HIV will access their HIV treatment through secondary care, long term health management requires support from primary staff such as General Practitioners (GPs) and general practice nurses.

This report explores the concerns and experiences of Black people living with HIV in primary care. The findings and recommendations were informed by the insight of people with lived experience to ensure the report covered multiple barriers and perspectives.

## 1.2. Methodology

National AIDS Trust and One Voice Network jointly developed a 49-question survey (including sub-questions and demographic questions) to further explore what problems Black people living with HIV face when they access primary care and what they think of the quality of care they receive. It was disseminated through an online form and printed versions available via some HIV support services in London. 142 responses were analysed to put together this report.

Throughout the report, there are quotes from respondents to highlight, in their own words, their experiences accessing primary care.

The project team presented the findings to a focus group recruited from the respondents and Black-led voluntary sector organisations. During the focus group, key themes were examined and focus group participants were involved in shaping the recommendations. Following the initial draft of the recommendations, the Fast Track Cities London HIV GP Champions and their Oversight group were consulted on the findings and the recommendations to get their insight on the barriers GPs face when trying deliver quality care to patients living with HIV.

The survey received responses from a range of people across different ages, ethnic backgrounds, gender, sexual orientations, religions and socioeconomic positions.

**Chart 1. Percentage of respondents by gender**

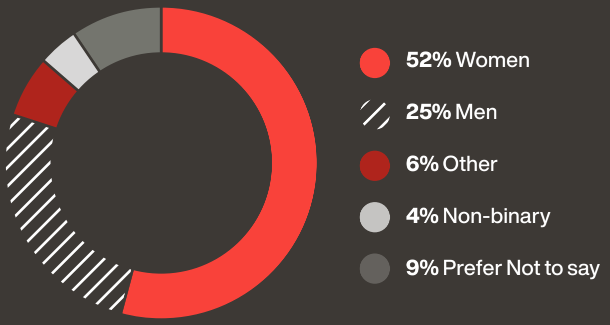
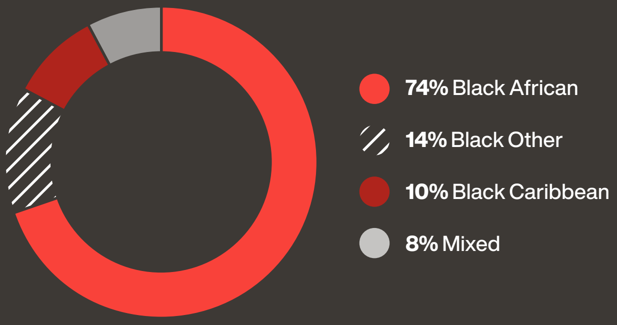


**Chart 2. Percentage of respondents by ethnicity**



## Throughout the report, there are quotes from respondents to highlight, in their own words, their experiences accessing primary care.

**Chart 3.** **Percentage of respondents by age**

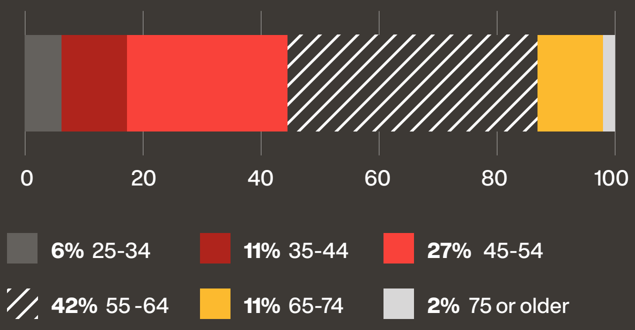


**Chart 5.** **Percentage of respondents by sexual orientation**

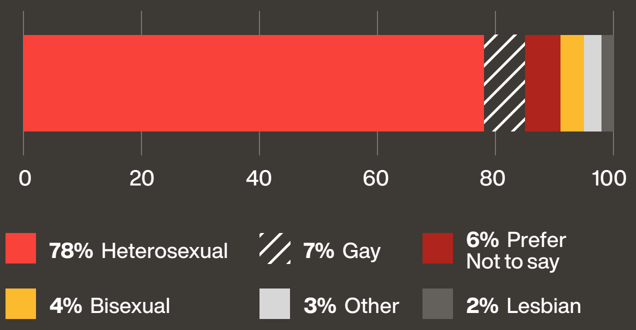


**Chart 4.** **Percentage of respondents by religion**

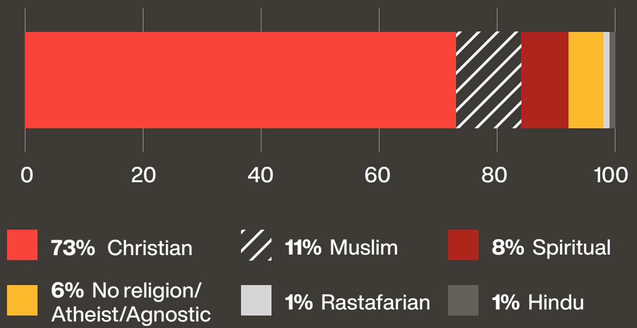
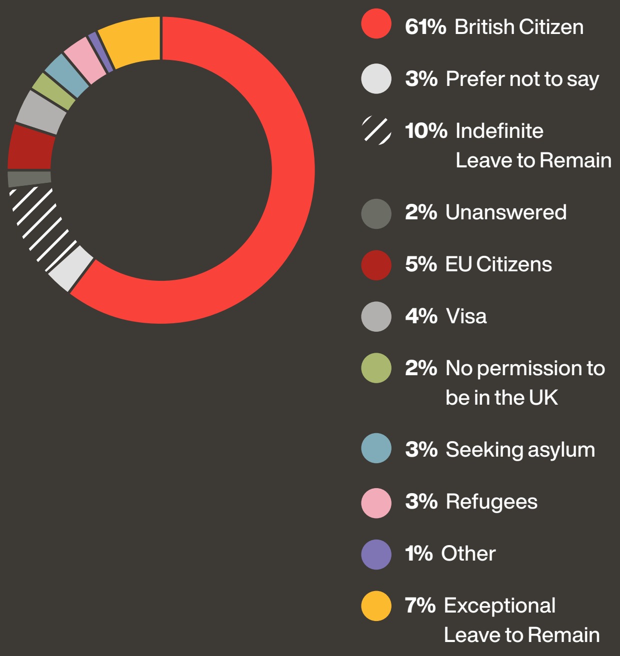


**Chart 6.** **Respondents by immigration status**

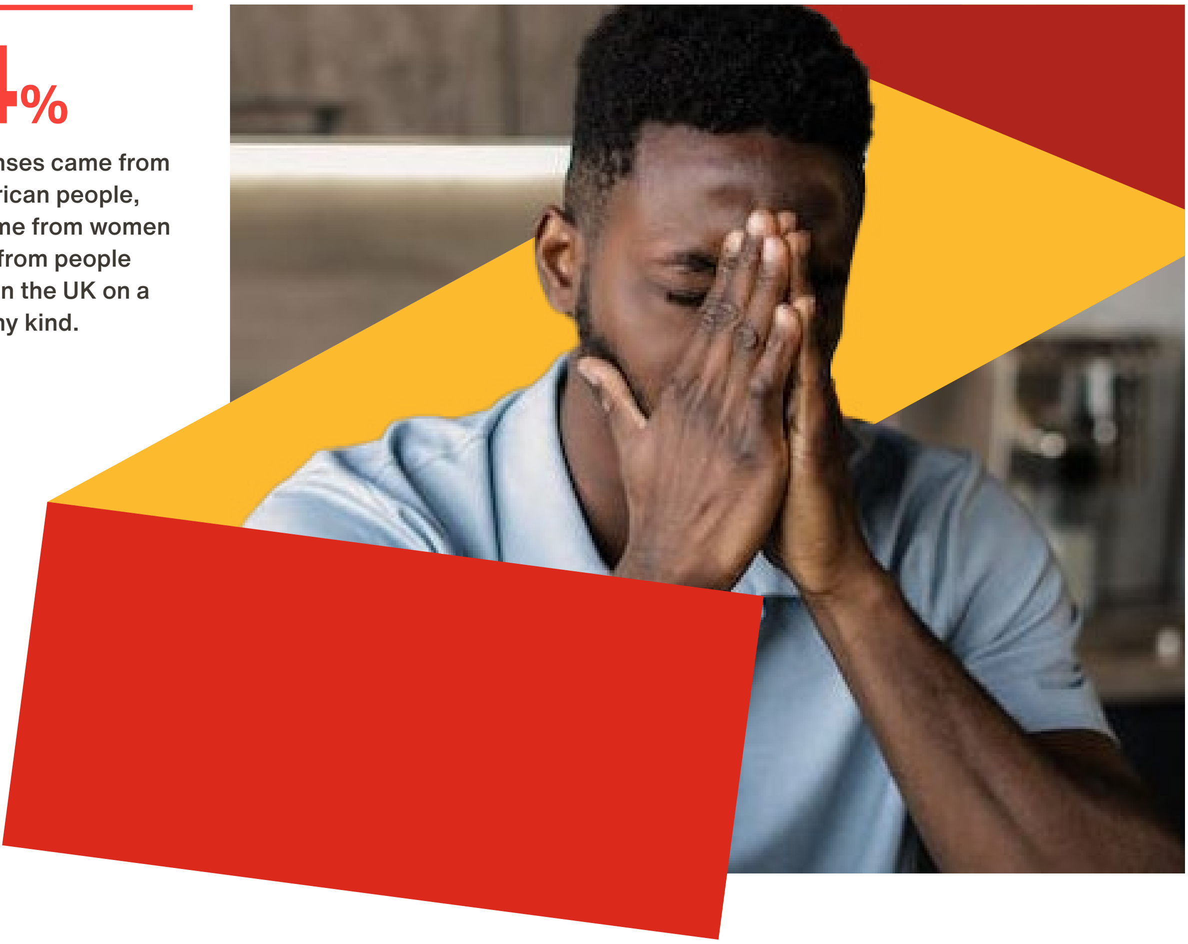


**31% & 17%**

increase in the rates of the new HIV diagnosis in Black Caribbean and Black African populations from 2022-2023.

**74%**

**of responses came from Black African people, 52% came from women and 4% from people who are in the UK on a visa of any kind.**



## 1.3. Limitations

All respondents to this survey were based in London and accessed GP services in London. While this report should be used to initiate wider conversation on the role of primary care in reducing health inequalities in HIV in the UK, the findings only reflect the experiences of Black people living with HIV who accessed GP services in London. This research does not assume the experiences and needs of Black people living with HIV in London are the same as in other regions within the UK.

Because of response burden, the quantitative questions were more likely to be completed than the qualitative ones. This means there were fewer answers that expanded on some of the points highlighted when answering the quantitative questions.

Some demographic groups were more likely to respond than others. For example, 74% of responses came from Black African people, 52% came from women and 4% from people who are in the UK on a visa of any kind. It is not certain that the representation within the sample size reflects the demographic representation in the overall population.

# Discussion of findings

## Stigma

### 2.1.1. Understanding HIV stigma

HIV stigma is the negative attitudes and beliefs held and perpetuated about people living with HIV. These beliefs can be held by the public, healthcare professionals and people living with HIV themselves. Stigma drives the epidemic because it stops people talking about HIV, getting tested and accessing treatment.

Stigma, when internalised by people living with HIV, can make them feel ostracised from loved ones and their community, resulting low self-esteem and mental ill health when not addressed. The fear of being treated differently and facing discrimination can then become a factor in life decisions as people seek to avoid these negative interactions.

When this stigma comes from healthcare professionals who are meant to support a person's health management, it can discourage people from interacting with GPs. The presence of stigma can easily lead to people living with HIV feeling uncomfortable and unable to trust their GP, nurse or primary care staff. When primary care staff are associated with that behaviour, this weakens people's incentive to attend appointments and engage with GPs.

In some cases, people feel more comfortable going to their HIV clinic about non-HIV related issues but this puts a strain on clinics' resources and time so is not recommended. Furthermore, access to primary care is essential to health management as they are best placed to support people with their non-HIV related needs. Healthcare professionals must be more mindful of their actions because perpetuating stigma can make it harder for people to adhere to treatment.

> **“I was asked by my GP how does someone like you get HIV. At the time I had no words I was just in shock at the question.”**

## 2.1.2. Respondents’ experiences of stigma

20% of respondents reported receiving judgemental or inappropriate comments or questions and 35% were concerned about being treated differently by GP staff. Stigma can be expressed in multiple ways by both clinical and non-clinical staff:

- Perpetuating stereotypes about HIV (e.g. making an assumption of promiscuity or assumptions around sexuality)
- Asking uncomfortable, unnecessary questions
- Taking unnecessary precautions
- Making comments that clearly insinuate the member of staff is passing judgement

> **“[My] GP was rude to me when she found out that I was pregnant, she said ‘who told you to get pregnant when you have HIV?”**

> **“One of the doctors at my practice would put gloves on and open the window before she would examine me.”**

All of these actions can be detrimental to the mental and physical health of people living with HIV. This is reflected in the responses, with nearly a fifth of all respondents (19%) saying that at one point they avoided going to the GP for fear of being treated differently due to their HIV status. Black people living with HIV are particularly vulnerable as HIV stigma is often compounded by other intersecting forms of discrimination. Black communities can face racialised stigma where they experience judgement based on their culture and their HIV status, igniting a fear of being negatively stereotyped.

28% of respondents felt they were discriminated against based on an aspect of their identity. Within this cohort, the most common response (40%) was that people were discriminated on the basis of their disability or health condition, suggesting either experiences of HIV stigma or ableism.

## 2.1.3. What can be done to challenge HIV stigma in primary care

Stigma can be challenged by providing educational tools to normalise the experiences of people living with HIV and to unlearn myths about how HIV is transmitted. Clinical and non-clinical staff should be provided with training to understand HIV, the impact of stigma on people’s healthcare experience and practise necessary adaptations to their bedside manner. When healthcare staff have internalised beliefs about people living with HIV, misinformation should be combated by engaging with accurate information and active commitment to changing their behaviours. If primary care staff asks questions or make comments that cast moral judgement on a patient, they risk isolating them and discouraging further engagement with care. It is the responsibility of healthcare professionals to remedy this behaviour, but they must be supported with resources.

HIV awareness training modules need to be meaningfully integrated into the curriculum for medical students to identify and avoid stigmatising behaviour as early as possible. There should also be opportunities to cover how stigma impacts all aspects of HIV and sexual health work in the GP training curriculum. However, commitment to addressing HIV stigma, discrimination and misinformation must be agreed upon across all staff, not just GPs. This would include HIV stigma being addressed by leadership within Primary Care Networks and the NHS, nurses, pharmacists, healthcare assistants, social prescribers, receptionists and other relevant staff.

# Case Study 1

## Fast Track Cities London HIV GP Champions

Fast Track Cities London introduced the first pan-London HIV GP Champions programme as a pilot. The successful programme brings together GPs across London invested in improving the quality of care for people living with HIV and access to testing in primary care settings.

The GP champions have made significant contributions to improving HIV awareness and tackling stigma in primary care which in turn is improving the health and wellbeing of people living with HIV. They have conducted talks and promoted HIV stigma resources to other GP colleagues and within Primary Care networks across London. Their understanding of the nuanced constraints of GPs makes the GP champions best placed to engage with their peers on these topics in a way that recognises their capacity.

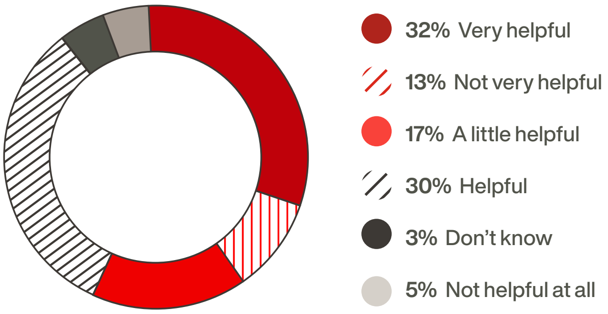
Various pilot projects and initiatives that address stigma within healthcare settings already exist but require additional funding to be properly scaled up into primary care network, GP surgeries and local authorities. Reducing HIV stigma through an intersectional lens should be a strategic aim for all ICBs; and actions on working with GP surgeries and Primary Care Networks to unlearn HIV stigma should be incorporated in all wider sexual health and HIV strategies.

# Booking Issues

## 2.2.1. Experiences with receptionists in GP surgeries

The survey included questions exploring all barriers to positive experiences within primary care for Black people living with HIV.

**Chart 7. Percentage of respondents by how helpful they found receptionists of their GP surgery**



Overall people were pleased with their experiences with receptionists: 61% claimed their receptionists were usually 'very helpful' or 'helpful'.

**"Why do I have to tell receptionist my illness when she or he is not a doctor? I feel it's humiliating to tell someone who is not a doctor my sickness."**

However, respondents who did face challenges with booking systems fed back that they often felt that receptionists were rude or treated them differently to other patients. In some instances, people preferred to not have their HIV status shared with the receptionists. In these cases, it may be useful for receptionists to try asking other questions that do not require people sharing their status but can still help ascertain how long is needed for an appointment and who to direct patients to.

**"There isn't enough time to talk to my GP, 10 minutes isn't enough. With illnesses [such as] HIV [...] there is much to talk about but not enough time. We are asked to double book appointments and then you can't!"**

Although receptionists are considered quite helpful, the length of waiting times disappointed patients. People said that they could not get emergency appointments even when they did share their status. One woman said that she often had to go to Accident and Emergency services to be seen in a shorter time frame, despite the fact she was not experiencing an emergency at the time.

## 2.2.2. Waiting times and length of appointments

There is an urgent need for government intervention to introduce real changes to reduce waiting times and increase the amount of time people can have for appointment. Ten-minute appointments leave patients dissatisfied and could be preventing people living with HIV from receiving adequate care and advice as there is limited time to unpack complex needs. GP surgeries are already finding it difficult to manage their current workloads generally, especially in areas with higher levels of deprivation. To manage their capacity and deliver impactful person-centred care, GPs and primary care networks must be supported by investment from the Government and NHS; this must include increasing the workforce to distribute labour across more healthcare professionals.

Older respondents conveyed how they struggled to use their surgery's website or the NHS app to make appointments. ICBs should be mindful that some older people living with HIV needs help with digital literacy as booking systems and websites change. Local communities could benefit from workshops to help patients to navigate websites for GP surgeries and online resources. If these workshops could be held in local libraries or community centres, this would help overcome barriers for people who cannot afford or access laptops and computers. People living with HIV who experience digital poverty should not risk being left behind as the NHS increasingly relies on apps, websites and digital resources.

# Continuity of care

**"No longer getting the same GP so the confidence of being given adequate care are now very low."**

Continuity of care was important for respondents as seeing the same GP helped to slowly establish a positive relationship. For some people living with HIV, it relieves them of the burden of having to explain their healthcare needs, treatment history or information about HIV to someone new every appointment. If a patient has a different GP every time, there is an increased risk of encountering GPs who behave in a stigmatising fashion, which caused concern amongst many of the patients we surveyed.

## 2.3.1. Patients' responses to triage systems

GP surgeries differ in how they divide patients and appointments, so uniformity in booking systems may not be possible.

Triaging systems are the most common alternative to having a named GP and are used to assign patients to a healthcare professional within their surgery who can see them as soon as possible. Some respondents had successfully requested a named GP despite their surgery practicing a triaging system. Although perhaps not a sustainable option for all surgeries, where possible, allowing patients the option of a named GP would improve quality of care and willingness to engage with primary care for Black people living with HIV. As of 2024, the Government has already announced plans to transition towards named GPs for people with high need so it is imperative that people living with HIV are considered as high need.

In some areas, triaging has increased in scale across entire primary care networks so a person may be assigned to a different surgery, not just a different GP. Some GPs expressed concerns that triaging at this level reduces the likelihood of regular engagement with patients, preventing GPs from improving the quality of the support they provide.

## 2.3.2. Benefits of a named GP system

**"[I had a] different GP each time who didn't understand my conditions or how they interact. After complaining, I was assigned a named GP and have an appointment every 6 weeks to catch up. I also get priority phone calls from named GP if I book an emergency appointment."**

If wanting to see the same GP limits availability of appointments, this should be communicated so patients understand the benefits and disadvantages of both options. To enable all surgeries to implement a named GP system without increasing wait times, the Government should prioritise hiring more GPs and general practice nurses. The pressure on GPs to see the same patients, when thousands of people are registered with them, can be lessened if there is an increase in GP recruitment and retention. This would align with the commitments from the current Government's 2024 manifesto to incentivise GPs to see the same patients and train more GPs.

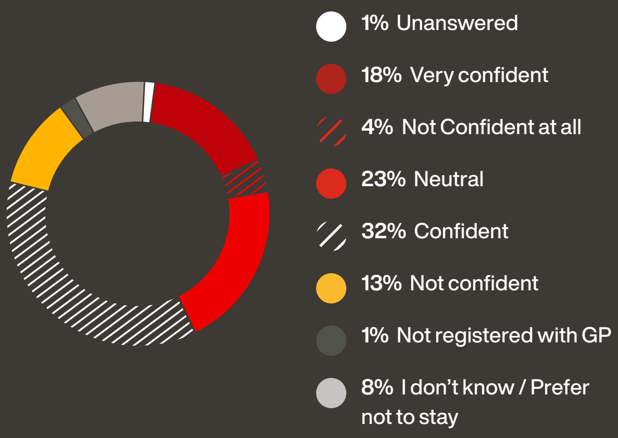
As of 2024, the Government has already announced plans to transition towards named GPs for people with high need so it is imperative that people living with HIV are considered as high need.

# Confidentiality

## 2.4.1. Patients’ fear of having status shared without their consent

For many people living with HIV, maintaining privacy about their HIV status allows them to exert control over their lives. HIV stigma and the fear of discrimination may be the driving force behind the choice to not share HIV status. Managing who knows about your status can make people feel like they can navigate their lives without fear of being treated differently.

**Chart 8. Percentage of respondents by how confident they are in their GP surgery’s handling of their information confidentially**



Nearly a third of respondents were ‘confident’ that their GP surgery could handle their information confidentially (32%) – the next most common response was ‘neutral’ (23%). People who had their HIV status shared without their consent previously were more likely to respond that they were ‘neutral’ or ‘not confident’ of their GP surgery’s ability to handle their information confidentially.

16% of respondents confirmed that information on their HIV status had been shared without their consent, and this negatively impacted their perception of GP surgeries. Not having control over how their information is used can create feelings of discomfort especially when they had experienced stigma from healthcare professionals in the past.

## 2.4.2. Confidentiality and its impact on medical mistrust

In conversation, GPs highlighted how they wanted to balance allowing people the levels of confidentiality they desired with also having to prioritise the health outcomes of their patients. GPs want to provide the best support and ensure all health-related needs are met but that is made difficult if they can’t share patient details.

However, sharing a person’s HIV status without at least notifying them, even if it is for the patient’s wellbeing, weakens their trust in the GP surgery and reduces their sense of security. Complicated feelings of shame can be attached to living with HIV and lack of communication might lead to feelings of powerlessness.

It is right that GPs prioritise patient safety and wellbeing, but this should include communicating confidentiality standards to patients, to build and maintain trust. NHS Transformation Directorate is a useful resource that provides guidance on primary care staff’s duty to share information for care purposes and the common law instances where explicit consent is needed before a patient’s HIV related information can be shared.[4]

The focus group reiterated how important it was to be told about confidentiality expectations so as not to feel powerless or passive when receiving news about their own healthcare. Training for clinical and non-clinical staff including receptionists should cover the significance of confidentiality with consideration of HIV stigma.

> "They informed me that they had had training in HIV and that they would always liaise with my treatment provider. They assured me [of] confidentiality, and they haven't let me down."

### 2.4.3. Structural changes needed to improve faith in confidentiality

The online triage system of booking can mean multiple people may have access to information about the reasons for an appointment and other HIV-related information. Additionally, where people book appointments over the phone, having to explain their status to receptionists can also bring on feelings of shame due to stigma. People living with HIV may have to share their status when making an appointment to ensure they can speak with the best placed staff member. However, introducing multiple options for booking that focus on discretion would be the most effective way of catering to different preferences.

For transparency, all booking formats should inform patients that their data may be shared with staff for triaging purposes. Receptionists should also undertake training to develop their knowledge of HIV stigma, helping them to identify, and correct, their own behaviour when it is potentially stigmatising.

## Case Study 2

### HIV Confident

**HIV Confident is a HIV charter mark collaboration between National AIDS Trust and Positively UK.[5] It addresses stigma in a range of settings such as healthcare and employment to ensure that people living with HIV can work for those organisations or access their services with confidence.**

**HIV Confident has conducted a survey identifying gaps in knowledge within clinical and non-clinical staff across three NHS Trusts and three GP Practices in London and one NHS Trust in the North of England. The findings show a lack of knowledge and confidence around HIV and that stigmatising and unlawful discrimination is occurring. The charter mark programme includes an eLearning package, alongside a policy review process, which is being shown to address many of the concerns identified by the survey. Organisations achieving HIV Confident recognition make a commitment to provide clear reporting routes for any stigma that does occur as well as commitment to acting in response to those reports.**

# Cultural competency

Delivering culturally competent care is fundamental to every aspect of support for Black people living with HIV. Culturally competent healthcare recognises that a patient's ethnic, cultural and religious background impacts every part of their life including health management. Relevant aspects of culture include diet, dietary restrictions, languages, cultural attitudes, taboos, traditions and holidays amongst others.

## 2.5.1. How culture impacts the quality of primary care services

14% of respondents felt they had at some point been discriminated against because of their race, culture or ethnicity when they accessed primary care. Focus group participants flagged the importance of understanding the differences in healthcare systems in the UK compared to a person's country of origin. One person stated that healthcare staff should note, where possible, smaller behaviours such attitudes and approaches to eye contact. In some cases, reflecting someone's body language may make them feel more comfortable.

Black communities can often be treated as a monolith, and the differences between cultures and experiences within the UK can be erased when this happens. This is exemplified by how often Black African and Black Caribbean people are homogenised. Culturally competent care requires a person to realise that racism and racist structures may impact both these groups but not in the same way. Their cultural attitudes to topics such as sexual and mental health may be different which means a GP should tailor the support offered.

When asked if they are confident that their GPs understood their cultural and religious background and how it affects their needs, 36% of people surveyed felt 'neutral' and more than one fifth said they were 'confident' (22%) in their GP's understanding. 18% responded they were 'not confident 'and 6% claimed to be 'not confident at all'.

When discussing the findings with the focus group, it was suggested the data might suggest that many people do not actually have any experience of their culture being factored into healthcare so feel neutral towards this model of care.

Confidence in understanding of cultural norms varied across demographics. Amongst Christian respondents almost half (48%) said they were said they were 'confident' or 'very confident' their religious beliefs were understood. Most Muslim people who responded (57%) said they felt 'neutral', with only 28% claiming they were confident.

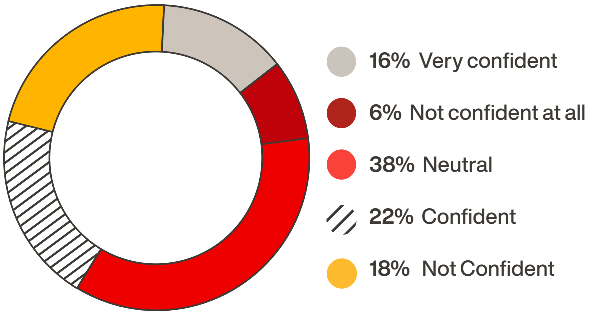
People who identified as Mixed – White and Black British were the only demographic where everyone responded that they were 'confident' or 'very confident' in the GP's understanding of their cultural background. Black African people (41%) were more likely to claim they were 'confident' they felt their GP understood their culture than Black Caribbean people (23%), but both groups were still more likely to say they felt 'neutral' about this.

**14%**

**of respondents felt they had at some point been discriminated against because of their race, culture or ethnicity when they accessed primary care.**

# Confidence in understanding of cultural norms varied across demographics.

**Chart 9. Percentage of respondents by how confident they are their GP understands their cultural and religious background and how impacts their needs**

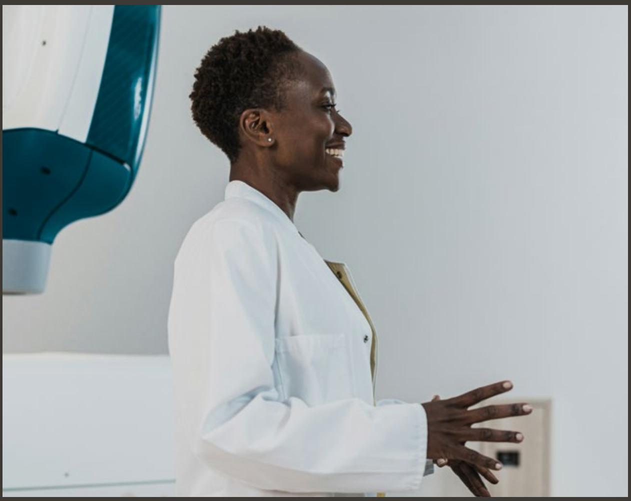


For example, Muslim communities make up 6% of the UK population but 15% of London's overall population. Islam is a minority culture and religion in the UK; the understanding of religious and social practices is not as widespread as it could be. However, religion can have a significant impact on lifestyle choices. Therefore, healthcare professionals should ask themselves how the lifestyle changes and treatments they suggest will fit around a patient's religious commitments. When working with Muslim patients living with HIV, healthcare professionals must take account of factors such as fasting and dietary habits.

**To achieve and embed cultural competency in healthcare, there needs to be structural, cultural and individual commitments.**

## 2.5.2. Principles of cultural competency

An effective approach to culturally competent care is to understand the specific needs of the local community and the cultures represented within it. To achieve and embed cultural competency in healthcare, there needs to be structural, cultural and individual commitments which must be supported by resource allocation, leadership, policy reviews and continuous learning. Some underlying principles that GP surgeries, primary care networks, ICBs, local authorities, NHS and the Government should consider when starting to develop protocols and processes for culturally competent care are:



### Flexibility

By creating and signposting options to tailor care to the needs of different communities, stakeholders adopt a person-centred care approach, aligning the care with the lifestyles of Black people living with HIV. By providing options for different types of support, treatment and advice, this acknowledges the diverse needs of Black and ethnic minority communities. This may require stakeholders to examine their biases, adjust their beliefs and adapt approaches to policy, healthcare provision and research that reflect the lived experience of Black people living with HIV.

### Acceptance

It is necessary for healthcare professionals, commissioners and other Government and NHS stakeholders to recognise that there is a dominant culture in the UK that is considered the default experience. By recognising the multiple ways treatment and care reflects this attitude towards culture, they can then develop a more intersectional approach to counteract this. All stakeholders should also work to avoid placing judgement on different cultures or proceeding as if the dominant culture in the UK is superior. This will only risk further ostracising patients and communities by antagonising them.

### Valuing lived experience

Black people living with HIV or any underserved groups need to be treated as the experts on their lives and their cultures. At a structural level, this means Black people living with HIV and Black -led voluntary sector organisations should be regularly consulted on how to improve access, knowledge and quality of primary care. Local authorities, ICBs and Governmental bodies should use lived experience and cultural knowledge to shape their strategies to overcome health inequalities.

For individual healthcare staff, this may include letting patients lead conversations on difficult issues to gauge tone and preferred terms, asking about various aspects of their lives to understand how their health fits into their life and intently listening to their cultural experiences. By validating and giving weight to their lived experience, it demonstrates a willingness to personalise care to suit the needs of Black people living with HIV and improve their experiences when accessing care.

## Accountability

Recognising the ways in which the actions of institutions and individual staff have caused harm, it enables stakeholders and healthcare professionals to reflect and improve their approaches to culturally competent care. There must be structures to monitor progress towards cultural competency at a local and national level.

For healthcare staff, this can look like accepting fault and apologising to patients to built trust and ensure they know you have accepted you need to improve. There must also be structures in place for continued feedback and co-development of resources, programmes and strategies with Black people living with HIV, community leaders and voluntary sector organisations.

## Proactivity

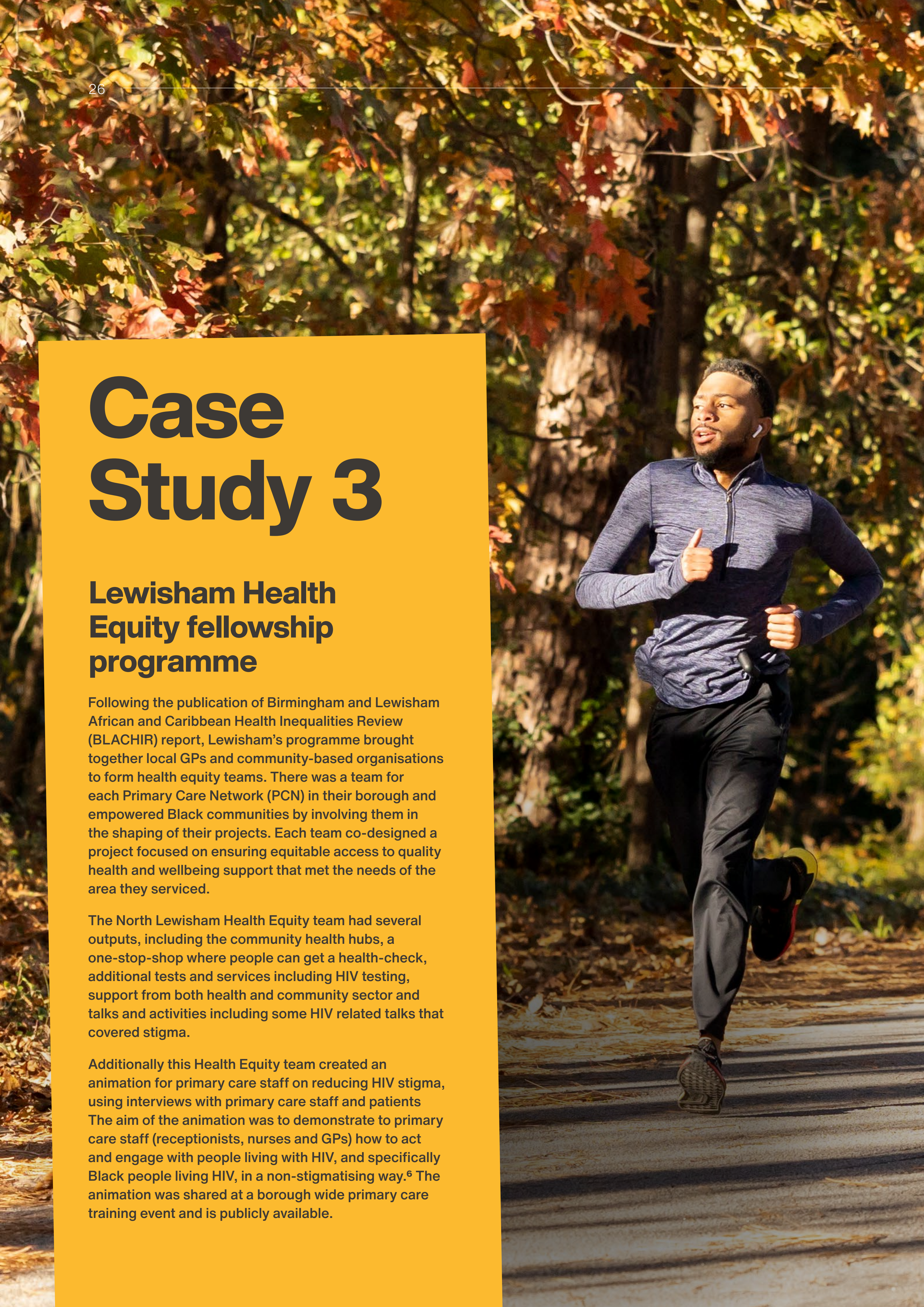
Culturally competent care should mean not expecting ethnic minority groups to constantly have to explain or educate others about their culture, without compensation. Primary care networks, surgeries, local authorities, ICBs and Government departments should embed continuous learning on cultural knowledge into their work and should adapt their healthcare approaches to account for what they learn.

## Sharing knowledge

In the process of learning and growing, knowledge should be shared and discussed with colleagues to facilitate further learning. This means larger structural barriers can be addressed, best practice can be shared, and ongoing trends can be identified and explored. This should include involvement of and collaboration with Black people living with HIV and Black voluntary sector organisations to continue centring their experiences.

## 2.5.3 How to deliver culturally competent care

GPs and GP surgeries need to be supported to deliver this quality of care. It requires access to training and knowledge building around accounting for cultural differences in care. Embedding cultural competency into protocol, training and policy will create accountability so that staff and patients understand what type of care should be expected. ICBs, the NHS and local authorities should work on toolkits and produce minimum standard guideline to show GPs how they can start practising cultural competency.



# Case Study 3

## Lewisham Health Equity fellowship programme

Following the publication of Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR) report, Lewisham's programme brought together local GPs and community-based organisations to form health equity teams. There was a team for each Primary Care Network (PCN) in their borough and empowered Black communities by involving them in the shaping of their projects. Each team co-designed a project focused on ensuring equitable access to quality health and wellbeing support that met the needs of the area they serviced.

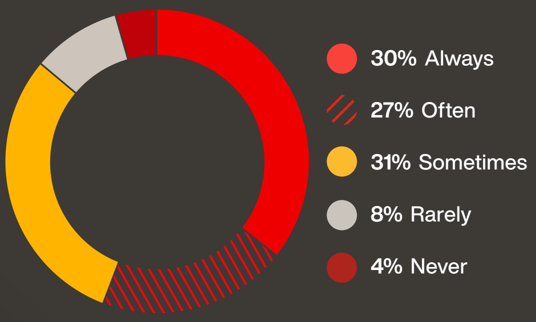
The North Lewisham Health Equity team had several outputs, including the community health hubs, a one-stop-shop where people can get a health-check, additional tests and services including HIV testing, support from both health and community sector and talks and activities including some HIV related talks that covered stigma.

Additionally this Health Equity team created an animation for primary care staff on reducing HIV stigma, using interviews with primary care staff and patients The aim of the animation was to demonstrate to primary care staff (receptionists, nurses and GPs) how to act and engage with people living with HIV, and specifically Black people living HIV, in a non-stigmatising way.[6] The animation was shared at a borough wide primary care training event and is publicly available.

# Accessibility of health information

**Respondents ‘sometimes’ (31%) or ‘always’ (30%) understood the health information they receive from their GP. Focus group participants suggested some issues with healthcare**

**Chart 10. Percentage of respondents by how often they understand health information from their GP**

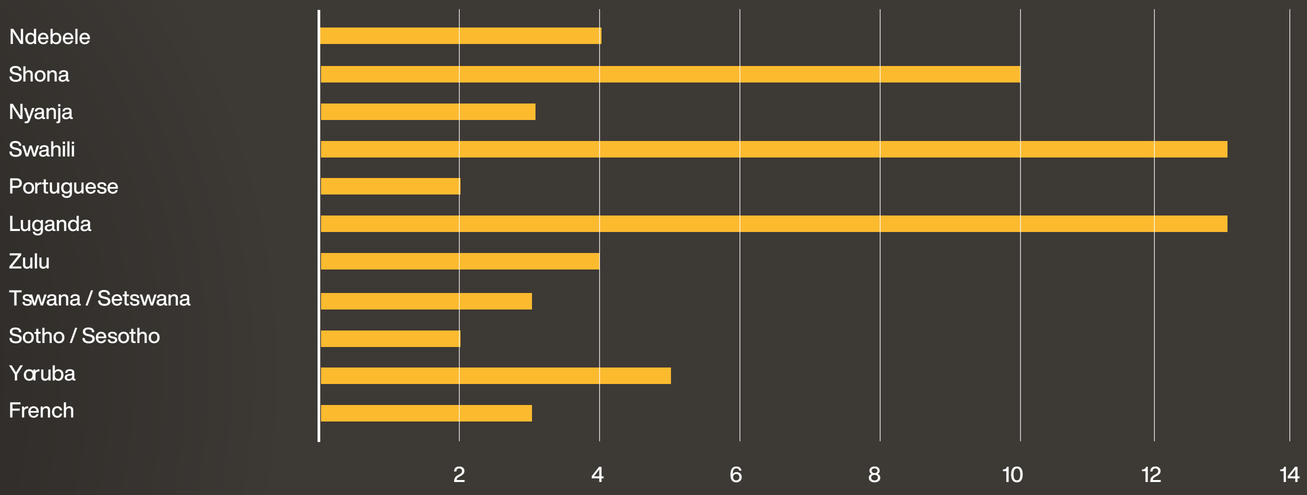


## 2.6.1. Language diversity within Black communities

The data shows language inclusivity significantly influenced people’s ability to understand the health information they received. 80% of respondents had a native language or languages they spoke outside of English. The most common languages spoken were Luganda and Swahili – some people spoke multiple languages other than English.

Proficiency in languages outside of English does not automatically suggest that a person cannot understand English sufficiently to understand health advice or information. Respondents who spoke a language outside of English were more likely to respond that they ‘always’ understood their GP when they had discussions about health than those who only spoke English, with rates of 35% and 11% respectively. However, the only respondents who said they ‘never’ understood information they received from their GP all spoke a language other than English and this group also included a higher percentage of people that respond they ‘rarely’ understood their GP.

**Graph 1. Number of languages spoken by respondents [7]**

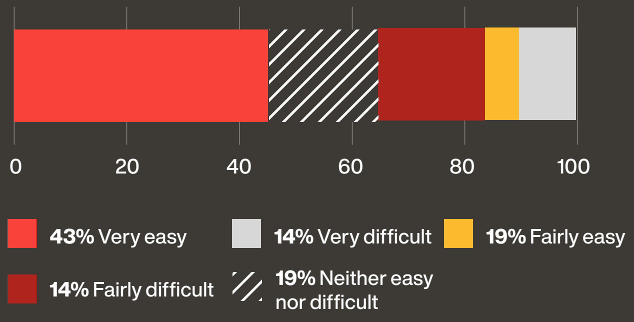


**ICBs are responsible for the hiring of translators, and they collect data on the language needs of the constituencies they are responsible for.**

## 2.6.2. Patients' experiences accessing translation services

Despite the diversity of languages spoken by respondents and reported barriers to understanding GPs, 81% did not know how to access translator supported services or that they were entitled to this support. Of those people who accessed these services, 43% said they were very easy to use which suggests that awareness of translation services is a key barrier. However, 19% claimed accessing translation services was 'fairly difficult' and 14% said it was 'very difficult'.

**Chart 11. Percentage of respondents who successfully access translation services by difficulty of accessing**



Providing the option of having a translator or translated resources allows people to make the decision that will be easiest and most comfortable for them. Information comprehension is important to build trust with a GP and as mentioned, creates a comfortable safe space to facilitate useful conversation. Where people are unaware or have recently moved to the UK and are not familiar with the NHS, it is essential to ensure that they understand that they are entitled to an interpreter and clarify the service is free.

Some GPs shared that they had to rely on phone translators, on which many of the languages reported by respondents were not available. Often GPs had to rely on a patient's understanding of French or Arabic because languages such as Lingala, Igbo, Wolof and Fula were not readily available. Where the latter languages were available, they needed to be booked in advance of the appointment, which was not possible for emergency appointments.

## 2.6.3. Improving availability of language inclusive resources

Focus group participants and representatives from Black-led HIV support services pointed out that many people do not necessarily read in the languages that they speak. ICBs are responsible for the hiring of translators, and they collect data on the language needs of the constituencies they are responsible for. Local authorities and ICBs should create actionable plans to develop and integrate both aural and written resources to respond to the pressures GPs face.

GPs, nurses, receptionists and other non-clinical and clinical staff should proactively signpost interpretation services where they infer there is a need. These services could be flagged when people register with a GP.

Most GP surgeries' registration forms have a section regarding translation services, but it is still worth receptionists reiterating the availability of these services – both at registration and while handling calls. In some cases, the language used on the forms may need to be more explicit and simplified rather than just referring to translation services as an 'accessibility need'.

# Care Coordination

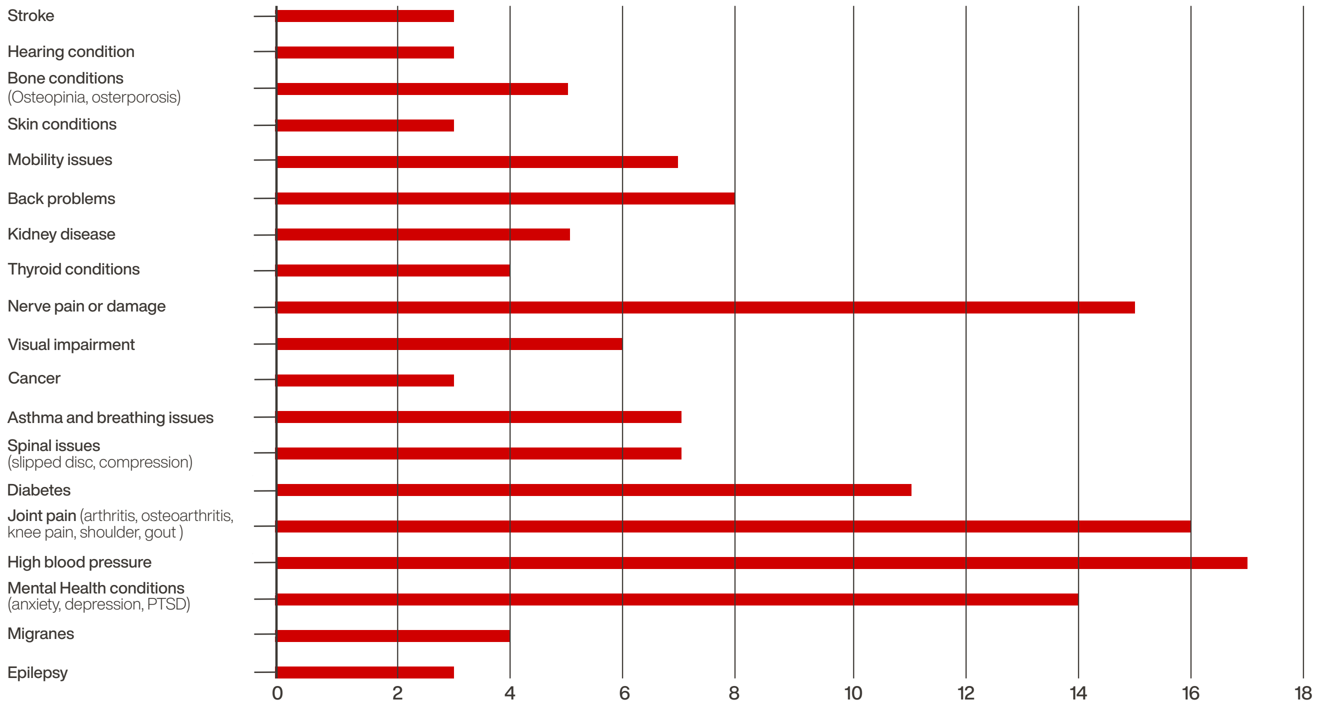
## 2.7.1. Navigating comorbidities in primary care

**“When I visited the GP sometimes, I am having two different sicknesses they just attend to one only.”**

People living with HIV can often have complex needs (e.g. comorbidities, socioeconomic support needs) and therefore, need a support system where there is streamlined communication between services and healthcare providers. Enhanced care coordination prevents delay in arranging emergency appointments and allows for consistency in health management without overlap between healthcare providers. It also ensures that responsibilities over certain aspects of care are agreed in cases where people are going between primary and secondary care.

58% of respondents confirmed they had another condition or disability outside of HIV. 30% of respondents reported having two or more conditions outside of HIV they had to manage. For a few people, they felt that their HIV was used as an excuse for the GP to say a particular issue was the responsibility of their HIV consultant. Overall, many respondents struggled to get attention for both their HIV and the other conditions they wished to discuss. They felt there was little consideration about how one condition impacted the others.

**Graph 2: Rates of additional conditions reported by survey respondents more than 3 times.** [8]



**“People living with HIV have to do a yearly cervical smear and my GP refused to do it for me. I had to go back and forth between my GP and HIV clinic.”**

### 2.7.2. Communication between primary and secondary care

**“... Sometimes I feel I get tossed between GP and consultant because I have two medical conditions and sometime the GP blame it on HIV and consultant blame on diabetes. No one wants to take responsibility to get to the bottom of the issue/problem.”**

In the consultation with GPs, it was mentioned that there is often a misunderstanding about the roles and responsibilities between GPs and secondary care. A part of role of GPs is knowing when to connect patients to secondary care for specific conditions. A source of frustration from some respondents was the lack of clarity over when to go their GP and when to go their HIV clinician.

Efficient communication between primary and secondary care providers is necessary so that HIV clinicians can advise and educate on the impacts of HIV if the GP needs to develop their knowledge. It also allows HIV clinicians to understand the responsibilities of a GP, and explain this to patients. GPs are often the point of entry to care, but the pressure on primary services can be reduced if patients understand the circumstances in which they should go to secondary care services directly.

To improve care coordination and delivery of wraparound care, current NHS software needs to be updated to facilitate communication. This technology should prioritise removing barriers such as difficulties accessing letters from secondary care clinicians, which was highlighted in some of the responses as a factor in delaying care.

In light of the Health Secretary’s commitments for the Data Bill and the 10 Year Health Plan, the Government should prioritise technology for the NHS that will enable better coordination between care providers. HIV clinicians will find it easier to contact GPs about necessary screenings and what tests have already undertaken. To ensure safe drug interaction between antiretroviral treatment and other medications, detailed notes must be communicated to all care providers including pharmacists, to avoid antagonistic effects on HIV or other medication.

**“I once given the medication that I was not supposed to take while I’m taking HIV medication.”**

ICBs should invest in care coordinators and peer navigator positions. Having a designated person to organise and triage care can alleviate the pressure on primary and secondary care to handle this.

# Lack of choice and agency in healthcare

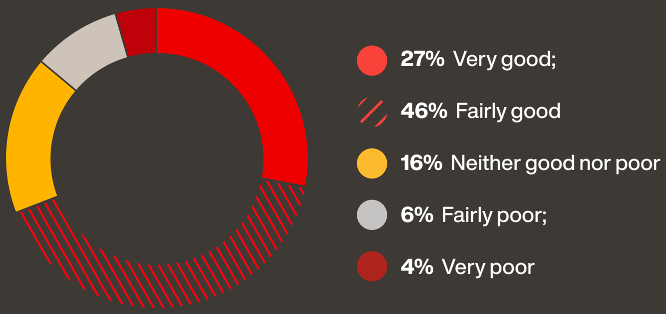
## 2.8.1. How often patients felt listened to by their GPs

When asked how good their GP was at listening to them, 46% felt their GPs were ‘fairly good’ and 18% said they were ‘neither good nor bad’. As only 10% of respondents claimed they felt GP’s listening skills were ‘fairly poor’ or ‘very poor’, this would suggest that most respondents are satisfied with the interactions and levels of communication they have with GPs.

However, a common theme in the responses was that some people’s requests for specific treatments and medication were refused, with little to no explanation. This was even the case when treatment or medication was suggested by their HIV clinician or another healthcare professional. 13% of respondents had confirmed they had been refused medical procedure or medication.

Focus group participants agreed with the sentiment that they did not always feel involved in healthcare decisions. Additionally, 20% of respondents agreed with the statement that they were not being listened to by their GPs. Respondents expressed their frustration over lack of explanation of healthcare decisions and concerns not always being taken seriously. People felt removed from decisions around referrals, suggestions about lifestyle changes, supplements and medications, and treatment options.

**Chart 12.** **Percentage of respondents by how good their GP is at listening to them**

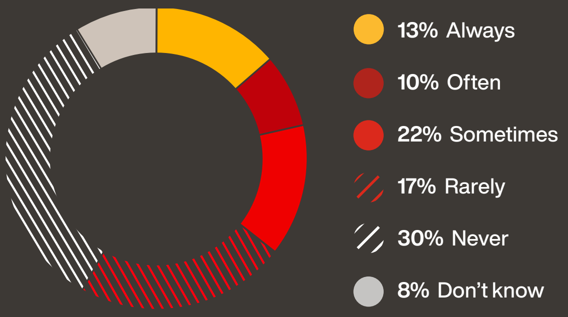


**“When [I] asked for a referral for prostate cancer test, this was ignored and I am still waiting and hoping.”**

### 2.8.2. Shared decision-making with patients

Most people responded that their GP ‘never’ (30%), ‘sometimes’ (22%) or ‘rarely’ (17%) asked their opinions about their medical care or treatment.

**Chart 13. Percentage of respondents by how often their GP has asked for their opinion or beliefs around medical treatment or care**



Some people shared that their relationship with their GP worsened after experiences where their GP had not consulted them about their concerns about treatment. There was a clear need for people to feel like they had control over their healthcare and how it fit into their lives.

**“Most of the time I have to fight to be heard.”**

**“When I first started becoming ill in 2014 I went to my [GP] ... his diagnosis was that I was depressed and he put me on anti-depressants. He also ordered lots of blood tests but never discussed the results with me. When the results came it was from the receptionists who didn’t know what they meant.”**

The dissatisfaction over the lack of discussion of treatment options were linked to feelings of medical mistrust within the Black community. People expressed a desire for joint ownership over these decisions where possible or at least to have a thorough conversation about side effects, concerns and risks.

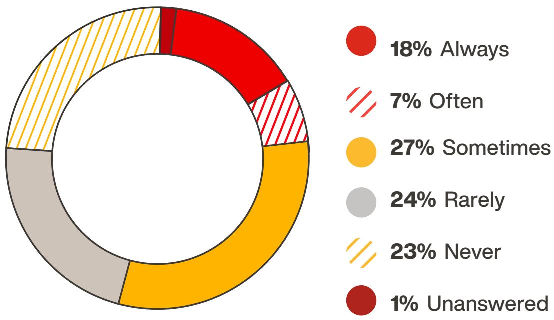
Where it is relevant, GPs, nurses and healthcare staff should take time to answer all questions and not be quick to dismiss concerns. Transparency as to why a GP thinks a person should not have a certain treatment empowers patients by validating their need to understand this decision. A GP then suggesting an alternative course of action after rejecting the requested treatment or procedure can help people feel that their concerns are being taken seriously.

# Mental health and social wellbeing

## 2.9.1. The mental health of people living with HIV

**"My GP doesn't always ask about my wellbeing and mental health. My HIV consultant shares my information with my GP but they don't always ask about my wellbeing."**

**Chart 14. Percentage of respondents by how often they are asked by their GPs about their mental health and social wellbeing**



Without good mental health, physical health often cannot be prioritised. Poor mental health can make it difficult to find energy, focus and motivation to adhere to treatment and practise recommended lifestyle changes – it can impact diet, exercise and the ability to attend Always Often Sometimes Rarely Never Don't know appointments. Struggles with mental health can be harder for people to identify, especially if people have not had conversations about it previously, or they have incorrect or stereotypical assumptions around the types of behaviour associated with mental ill health. People living with HIV are significantly more likely to show symptoms of anxiety and depression according to Positive Voices survey 2022.[9]

Most respondents shared that their GP 'sometimes' (28%), 'rarely' (24%) or 'never' (23%) ask about their mental health and social wellbeing in appointments. By not discussing mental health and social wellbeing, GPs might not understand the practical, mental and emotional barriers to the physical and mental health advice they are providing. To effectively tailor support to meet patient needs, clinical staff should assess how major life events, daily stresses, changes in aspects of a person's lifestyle impact a patient's health.

Although only 10% of respondents identified themselves as having a diagnosed mental health condition, this does not mean that poor mental health is not prevalent within communities of Black people living with HIV. The PRIME study found that Black Caribbean and Black African women were more likely to feel socially isolated or experience psychological distress, and Black African women were the least likely to be diagnosed with depression, illustrating the cultural and structural barriers to formal diagnosis.[10]

# The need for proactive engagement around mental and social wellbeing is especially relevant for Black people living with HIV.

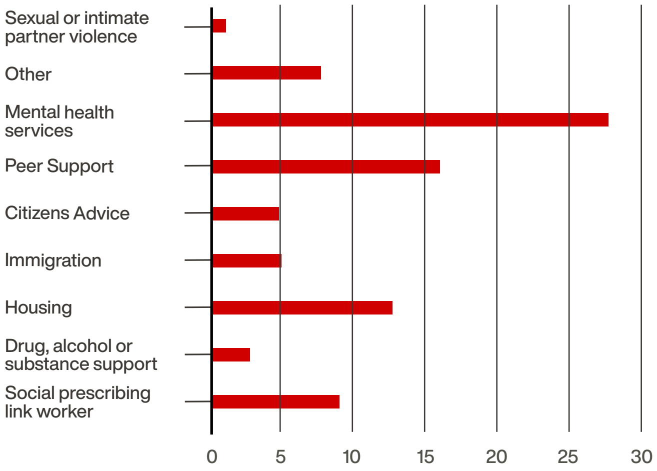
## 2.9.2. The relationship between culture and mental health

As the focus group discussed, conversations about symptoms and personal lives can help break down concepts like mental health. This is useful as mental health can be considered a taboo discussion for some, or people may not be aware that they are experiencing poor mental health, as it has never been explained to them. When people understand that lack of interest and joy in most things, sleep disturbances and low self-esteem are symptoms of depression, this may help them to realise that they might be experiencing depression, if showing these symptoms. If GPs and nurses start to facilitate these conversations, they can further unpack the extent of a patient's needs, and so offer effective advice and practical next steps.

The need for proactive engagement around mental and social wellbeing is especially relevant for Black people living with HIV. The distinct experiences of Black people living with HIV, with their intersecting identities, create challenges and barriers to a good quality of life that may be exclusive to them. For example, Black people living with HIV and other minority ethnic groups can face intra-community stigma. This type of stigma occurs where a person belonging to a minority group that they rely on for support and understanding fears being treated differently by people in this group when they are diagnosed with HIV. Black people living with HIV risk losing those closest to them who understand their lived experience as a Black person in a dominant culture that is white, because of stigma. This can exacerbate poor mental health unless conversations on mental health are initiated early on in primary care.

## 2.9.3. Referrals to local welfare and support services

**Chart 16.** Percentage of respondents who were referred to additional services by which services they were referred to



45% of respondents reported being referred to services that cater to socioeconomic or mental health related needs but 30% were not referred even though they would have been interested in this support. 15% said they did not need the services, and the remaining respondents did not answer. Three quarters of respondents were accessing or felt they needed to access services that addressed issues in their life outside of their physical health. These findings align with the increasing demand on GPs to address complex needs associated with the social determinants of health.

Those who reported that their GP 'rarely' or 'never' asks about their mental and social wellbeing were less likely to be referred than people who said their GP always or often asked. Mental health services (18%), peer support (11%) and housing services (6%) were the most accessed services, despite not all respondents who were referred having a formal mental health diagnosis.

**74%**

**of Black African people living with HIV were likely to report they did not have enough money to meet basic needs.**

## 2.9.4. The impact of financial vulnerability on mental health

The 2022 Positive Voices report revealed that 74.4% of Black African people living with HIV were likely to report they did not have enough money to meet basic needs, significantly more than other people living with HIV.11 This data shows why clinical staff should enquire about lifestyle and socioeconomic factors as financial difficulties and stress aggravate physical and mental health conditions. These structural issues also force people living with HIV to have to make difficult decisions on how they spend their money, which impacts the food, supplements, aids and support they can afford.

While all people living with HIV should be referred to welfare services as needed, primary care staff should understand that Black and ethnic minority people living with HIV can be disproportionately vulnerable. Therefore, they should be proactive in sensitively initiating conversations around a patient's personal circumstances. These conversations should take into account that conversations around personal finances or other issues such sexual orientation may be considered taboo in the culture, so patients may be slow to share this information. A named GP system would allow healthcare professionals to build a rapport with patients and enable them to become more comfortable being open about some of their barriers to healthcare.

Survey responses also reported referrals to nutritionists, citizens advice, intimate partner violence services, substance support services, immigration services and social prescribing. Clinical staff should proactively seek to identify psychosocial and practical barriers to health management and begin a dialogue on what support patients need to overcome them. Primary care networks and local authorities should collaborate to identify which practices would strengthen referral pathways to welfare services and identify barriers to positive patient outcomes.

# Conclusion

## Comprehensive support and a commitment to change are needed to achieve a more inclusive and effective primary care system.

As of 2023, 38,477 people are receiving HIV care in London and 14,587 of those people are from Black communities.[12] Many of those people will be already registered with a GP surgery and for those who aren't, accessing primary care services would greatly benefit their physical and mental health.

At this pivotal time in the HIV response and given continued efforts to integrate HIV care, primary care must be equipped to handle the physical and mental health needs of people living with HIV, especially Black people living with HIV. Black communities impacted by HIV should receive healthcare advice that is tailored to the specific barriers that impact their quality of life. To achieve this, GPs, nurses and healthcare providers first must understand that the concerns, lifestyles and experiences of HIV Black communities are distinct and shaped by cultural attitudes.

**38,477 people are receiving HIV care in London**

**14,587**

**of those people are from Black communities**

Primary care staff can effectively work with Black patients living with HIV by making changes at an individual level and revising their approaches to engagement with patients. If they are not already doing so, GPs, nurses and clinical staff should be factoring the impact of culture, stigma and lifestyle into the care that they provide Black people living with HIV. It is vital that primary care services provide holistic, patient-led support and foster an environment where Black people living with HIV can feel safe discussing their health.

However, GP surgeries and primary care networks are subject to the constraints outside of their control such as their patient caseload, workforce numbers and budget restraints. Local authorities, UK Government, Integrated Care Boards and the NHS must acknowledge their role in supporting the delivery of culturally competent non-stigmatising healthcare. This should include improving communication between primary and secondary care, facilitating learning on cultural competency and funding projects that aim to reduce HIV stigma.

Investing in these programmes that address challenges around stigma, cultural competency and care coordination will prevent ill-health, support retention in care and help realise the target of ending new HIV transmissions by 2030. Moreover, these investments are cost effective as supporting the treatment adherence and health management of people living with HIV is necessary to end further HIV transmissions.

The intersections of living with a long-term health condition and being Black in the UK often means Black people living with HIV often have parts of their experience left unacknowledged. By prioritising these recommendations, Black people living with HIV can have equitable access to healthcare and have a better quality of life. Comprehensive support and a commitment to change are needed to achieve a more inclusive and effective primary care system.

## About the Unheard Voices Project

**Unheard Voices is a partnership between One Voice Network, a collective of 15 Black-led community health organisations, and National AIDS Trust, the UK's HIV rights charity.**

The project aims to end structural inequalities by ensuring Black communities living with or at risk of HIV can hold decision-makers to account, influence actions, and become part of the decision-making process. Unheard Voices recognises there needs to be a health and support system which offers equitable standards of care for Black communities and ensures they do not disproportionately experience impact of HIV or HIV related stigma and discrimination.

All aspects of this project focus on platforming the lived experiences of Black people and insight from Black led organisations. By prioritising the meaningful involvement of Black people living with HIV in research and policy, stakeholders such as GPs, Integrated Care Boards (ICBs) and Government departments can develop effective tailored responses to the needs of Black communities impacted by HIV.

## Acknowledgements

National AIDS Trust and the One Voice Network would like to thank **City Bridge Foundation** for kindly supporting this publication and wider project.

Thank you to the focus group participants for your contribution.

We would also like to thank the **London HIV GP Champions** and the **Fast Track London GP Champion Oversight group** for their contributions.

## Members of the One Voice Network:

- **Addington Afro-Ethnic Health Promotion Group** (AAEGRO)
- **Africa Advocacy Foundation** (AAF)
- **African Equality Foundation**
- **African Health Policy Network** (AHPN)
- **African Institute for Social Development** (AISD)
- **Catholics for AIDS Prevention & Support**
- **Embrace UK**
- **French African Welfare Association** (FAWA)
- **House of Rainbow**
- **Organisation of HIV Positive African Men** (OPAM)
- **NAZ Project**
- **Red Ribbon Living Well**
- **4M Network My Health, My Choice, My Child, My Life**.

# Footnotes

[1] **UK Health Security Agency (2024), New diagnoses, AIDS, deaths and people in care in England: data tables. Available at:** https://www.gov.uk/government/statistics/hiv-annual-data-tables

[2] **Ibid**

[3] **UK Health Security Agency (2024), New diagnoses, AIDS, deaths and people in care by key population: data tablesUK Health Security Agency (2024) Positive Voices 2022: survey report. Available at:** https://www.gov.uk/government/statistics/hiv-annual-data-tables

[4] **HIV and Sexually Transmitted Infections (STIs) (2024)** Available at: https://transform.england.nhs.uk/information-governance/guidance/hiv-and-sexually-transmitted-infections-stis/

[5] **More information about HIV Confident can be found on their website** Available at: www.hivconfident.org.uk

[6] **'Stigma Free Experience - Health Equity Partnership' YouTube, uploaded by Geroff Animations, September 5th 2024** Available at: https://www.youtube.com/watch?v=pDGEubtD-8E

[7] **27 languages were reported through the survey. The graph shows all languages that were reported by more than 3 people. Other languages spoken by respondents were Russian, Dutch, Runyakole, Patois, Igbo, Xhosa, Lozi, Bemba, Tonga, Amharic, Lingala, Kikongo, Hausa, Mendee, Creole, German and Kasem.**

[8] **Other conditions and health issues not included were blood disorders (such as haemophilia), tremors, high cholesterol, gastrointestinal conditions (such as irritable bowel syndrome), hernias, incontinence and neurodevelopmental conditions.**

[9] **UK Health Security Agency (2024), Positive Voices 2022: survey report** Available at: (https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report)

[10] **Solomon D, Tariq S, Alldis J, Burns F, Gilson R, Sabin C, Sherr L, Pettit F, Dhairyawan R. Ethnic inequalities in mental health and socioeconomic status among older women living with HIV: results from the PRIME Study. Sex Transm Infect. 2022 Mar**

[11] **Ibid**

[12] **UK Health Security Agency (2024), New diagnoses, AIDS, deaths and people in care England data tables** Available at: https://www.gov.uk/government/statistics/hiv-annual-data-tables

**National AIDS Trust** is a Registered Charity No. 297977
and a Company Limited by Guarantee No. 2175938,
(registered in England and Wales)

Registered Office: Unit 3.9 The Green House,
244-254 Cambridge Heath Road, London, E2 9DA

Unit 3.9
The Green House
244-254 Cambridge Heath Road
London
E2 9DA

**T:** +44 020 7814 6767
**E:** info@nat.org.uk

**nat.org.uk**
**onevoicenet.org**