

# Unheard Voices

Understanding the landscape of  
London HIV commissioning and  
community involvement of Black  
African and Caribbean communities

Working together

**ONE VOICE**  
NETWORK





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# Forewords

## **Winnie Byanyima** Executive Director, UNAIDS

Across the world, communities continue to be the frontline of progress in the HIV response. Communities' vital contributions include connecting people with person-centred public health services, building trust, innovating, and holding providers accountable. The advances we have seen in both the UK and the global HIV response are testament to the power of the communities most impacted by HIV.

For World AIDS Day last year, I was delighted to meet with community leaders in the UK's HIV response at a meeting convened by the National AIDS Trust and the One Voice Network, to learn more about their powerful work. Each of the personal stories of the inspirational change makers who gathered there demonstrated how effectively addressing inequalities depends on ensuring that people living with HIV and people most at risk of HIV are in the driving seat, guiding and leading the response.

Why? Because communities affected by HIV possess an incomparable wealth of knowledge that is invaluable in shaping effective and culturally appropriate services and bridging the gaps to ensure quality and equity of care. Whilst huge progress has been won, it remains the case that many communities still experience being held back. In my meetings with communities across the world I hear how myriad obstacles from funding shortages, policy and regulatory hurdles, and capacity constraints, to crackdowns on the human rights of marginalised communities and ongoing stigmatisation are obstructing the progress of HIV prevention and treatment services. It is clear that if these obstacles are removed, community-led organisations can add even greater impetus to the response.



The principles outlined in this report, and the stories shared, demonstrate powerfully UNAIDS' priorities for the HIV response. People living with HIV need to be involved at every stage – in designing as well as implementing HIV responses. This report shows effective ways to involve communities in the most meaningful ways which recognise their ownership of their own services. For example, it shows how when decision-makers structure commissioning processes around community members, all of society gains from improvements that reflect communities' ingenuity.

While celebrating the gains made in the HIV response, this report reminds us all of the hard work that still lies ahead for the world and for the UK. As the UK works to end HIV transmissions by 2030 and meet the holistic needs of people living with HIV, success will depend on the strongest collaboration, sufficient resourcing, and courageous commitment from leaders at all levels to ensure that interventions leave no one behind.

Community leadership is not an idealistic dream, it is the proven route to impact. The message of this report could be summed up in this call to action: for the HIV response to succeed, let communities lead.

## Florence Eshalomi MP

MP for Vauxhall and Co-Chair  
of All Party Parliamentary Group  
for HIV/AIDS

**The reduction in HIV transmission is a UK success story and the Government's HIV Action Plan aim to end transmissions by 2030 is an ambition to be lauded.**

However, progress on HIV has stalled, with the latest data showing stark and persistent inequalities in HIV – particularly for race and gender.

Emerging technologies and evidence-based interventions are not reaching every community equally. New HIV diagnoses in Black African communities have increased exponentially in the last year. Black communities living with HIV in the UK face barriers in realising their right to health. For example, recent data highlights 74% do not regularly have enough money to cover their basic needs.

I am proud to serve as the Member of Parliament for Vauxhall. My constituency has the highest HIV prevalence in England. I am also the Co-Chair of the All Party Parliamentary Groups (APPGs) on HIV & AIDS; and London. Through my work, I have seen both the inequalities that people living with HIV face and the transformational impact of London's voluntary and community sector organisations, particularly when they're resourced and supported by commissioners.

To ensure equitable access to HIV prevention, treatment and care, we must ensure that communities are at the forefront of the HIV response. Meaningful involvement fosters trust and partnerships between local authorities and Black communities. This can be key in increasing regular testing, early diagnosis, and effective management of HIV. At this pivotal point in the fight to end HIV transmissions, it is imperative that our strategies are responsive to the needs of underserved communities, which may be neglected by more general interventions.

The insight from this report reinforces the need to build structures for genuinely meaningful engagement with local communities into commissioning practices. As an MP and former councillor, I will always strive to listen and work with my constituents to create the change that reaches the most underserved communities. The commitment to meaningful involvement and ending inequalities should be built into Government and local authority strategies and decision-making processes.

To ensure we can end transmissions by 2030, targeted HIV services must be informed by the experiences of the people we aim to support. Investing in local authorities can unlock the research and innovation necessary to adequately reduce the health disparities that persist in London and the UK.

It has been three years since the APPG on HIV and AIDS released our report on the HIV-related needs of Black, Asian and Minority Ethnic communities, 'Nothing about us without us'. As rates of new HIV diagnosis exponentially increase in Black communities and obstacles to PrEP access remain, the need for urgent action from Government and local authorities remain.

The health inequalities Black people in the UK face will not be resolved without them in the room. Ending all new HIV transmissions in the UK by 2030 requires a comprehensive and inclusive approach. It is possible to achieve this – but only if we meaningfully work with communities and ensure no one is left behind.



# What is the Unheard Voices project?

Unheard Voices is a partnership between One Voice Network, a collective of 12 Black-led community organisations addressing health inequalities, and National AIDS Trust, the UK's HIV rights charity. The project aims to end structural inequalities by ensuring Black African and Caribbean communities living with or at risk of HIV can hold decision-makers to account, influence actions, and become part of decision-making.

Black African people are disproportionately affected by HIV. Even though Black African people make up only 2.4% of the UK population, they comprised 28% of new HIV diagnoses in 2022. In the same year, Black Caribbeans were one of a few groups who experienced a rise in late diagnosis rates, so their health outcomes are also at risk. Our goal is to see a health and support system which offers equitable standards of care for Black African and Caribbean communities and ensures they are not disproportionately impacted by HIV or HIV-related stigma and discrimination.

Photo credit:  
Fizzy Vortex Video Productions





**From left: Denis Onyango**, Africa Advocacy Foundation, **Kevin Fenton**, NHS London, **Winnie Byanyima**, UNAIDS, **Reverend Jide Macaulay**, House of Rainbow, **Oluwakemi Agunbiade**, National AIDS Trust

# Executive summary

## Who is this report for and what does it hope to achieve?

This report aims to support local commissioners to integrate Black African and Caribbean communities into their service development and commissioning practices. For both national and local HIV programmes and strategies to be effective, community members need to be involved in creating services by interacting with decision-makers. Through gathering data on London HIV programme commissioning, we now have a better understanding of the extent of community involvement in the development of these services.

This process also enabled us to have conversations with both local authorities and community organisations about their priorities. The insight gained from these discussions informed the recommendations.

Our further aim was to explore what co-production in sexual health commissioning can look like. All local authorities should strive to achieve the most meaningful co-production models, and this report highlights best practice and recommendations to facilitate reaching that goal.

# Key recommendations for best practice

Co-production and meaningful involvement of people living with HIV is achieved where the integrity and value of people's lived experience is recognised. This cannot be achieved if local authorities are not resourced to overcome barriers to engagement, for example through paid participation in co-production and community outreach.

## Recommendation 1

The Government must properly resource public health to realise savings across the system, including through increasing the public health grant to local authorities in real terms.

Commissioners need to meaningfully involve Black African and Caribbean community members in all aspects of service design, and this should be done in a manner which is culturally sensitive and respectful.

## Recommendation 2

Local authority commissioners should involve community representatives with lived experience at all stages of projects and initiatives, by:

**Adopting a full and comprehensive approach to community involvement by ensuring representation across different subgroups.**

Spaces should be allocated in co-production groups for Black community members of different faiths, ages, genders, sexual orientations and cultures to reflect the variation in attitudes.

**Establishing groups for lived experience representatives or having lived experience representatives in every decision-making group such as steering groups.** This can allow them to directly decide the direction of HIV programmes.

**Normalising continuous involvement.**

Local authorities should have community insight on every stage from the planning to implementation of services or programmes.

This will allow community members to have a say in project budgets, plans and objectives, and to influence the metrics used to measure success and key outcomes.

**Creating a culture that normalises co-production by using accountability structures.**

This could involve including sections on community involvement in policies, terms of reference and strategies, and training peer advisors to help achieve meaningful involvement. Tender specifications should also encourage contractors to outline how they will meaningfully involve people with lived experience from the local community.

**Creating opportunities for people living with HIV to review tender specifications.** There should also be an opportunity for those with lived experience to meet with service providers and score bids. This may facilitate continuous involvement.

## Recommendation 3

Local authorities should create an environment conducive to co-production by empowering community members and making the commissioning process accessible, by:

**Providing community members with clear contractual agreements that clarify remit of the role.** This will create transparency over the decision-making power and creates accountability by setting expectations that community members can hold about the role.

**Avoiding jargonistic language where it is unnecessary.** This adds to inaccessibility and hierarchal attitudes between commissioners and community members.

**Providing language inclusive support that meets the needs of community members.** This might require commissioners to collect data on the languages spoken in their local borough to have written or audiovisual resources that can support the inclusion of people who speak limited English. Different formats of resources would be best practice as it reaches those who may not read in their native language. Where face-to-face engagement is possible, a translator is ideal.

### **Ensuring skills development and leadership opportunities for community members.**

People with lived experience should be supported to lead or get involved with a variety of responsibilities such as contribute to programme design, strategy development, market engagement, research development, assessing tender bids and project planning. This helps to establish ownership over the services they access, improves their confidence and builds transferable skills.

### **Prioritising lived experience for employed peer advisors in the budget, or where community engagement roles are built into the commissioning structure.**

This should be reflected in job descriptions and person specifications for outreach or peer related roles in commissioning. Criteria should be reviewed to ensure more marginalised people are not disproportionately ruled out, especially where they could be trained.

**Developing training and resources for community members.** This can support education on commissioning practices and demystify the process, so they feel more confident when involved in decision-making.

## Recommendation 4

Local authorities should recognise the value of community insight and adequately reimburse community members, by:

**Remunerating community members for their time and involvement appropriately with financial support, training and/or qualifications.** Discussions should be had about what support or resources would benefit them most.

### **Wellbeing funds or wellbeing activities for community members involved in co-production should be built into commissioning processes and budgets to counteract fatigue from emotional labour.**

As we work to end health inequalities, grassroots organisations should be treated as stakeholders. Long term mutually beneficial relationships with Black-led community organisations are key to improving understanding of the needs of Black African and Caribbean communities.

## Recommendation 5

Commissioners should regularly engage in reciprocal early market engagement and open informal lines of communication with community organisations before the tender process, by:

**Adopting a targeted approach to reach and invite Black-led organisations to market warming events.** This can lead to discussions on how to best support the needs of marginalised groups such as Black African and Caribbean communities.

**Engaging in preliminary discussions with Black-led organisations to negotiate budgets, Key Performance Indicators (KPIs) and timelines when approaching them for funded work before they are signed off.** Early communication will allow for all parties to agree on achievable and realistic outputs, budgets and timelines.

**Adopting a trial-and-error approach.**

Sufficient funding can allow community-based organisations to test and develop innovative, culturally competent programmes of work. It also means they can expand work programmes that have been successful anecdotally and collaborate with commissioners to develop projects further figuring out formal measurements of impact and success.

**Treating tailored community organisations as stakeholders.** This may include proactive contact with these organisations when opportunities arise to bid for projects, where voices are needed for consultation and when new research is being released or developed.

## Recommendation 6

Local authorities should consider how they can support the upskilling of smaller voluntary sector organisations, by:

**Providing mentorship, training or workshops to strengthen the service provider market.** By upskilling the voluntary sector, commissioners reap the added benefits of consistently improving organisations that also have community expertise. These sessions could focus on areas such as bid applications and measuring impact amongst other areas of development.

**Creating more opportunities for partnership bids between multiple organisations in the procurement process to enable knowledge and expertise exchange.** Commissioners can aim to normalise and support more than one organisation successfully bidding for a contract. A multiple contractor model that requires larger organisations to partner with grassroots specialist organisations opens opportunities for the latter. It can also improve focus and reach on key populations.

# Introduction

## 1.1. HIV and Black communities

**An effective response to HIV needs to ensure Black communities are no longer underrepresented in the decision-making process that shapes their healthcare.**

Tackling the unique barriers Black African and Caribbean people living with HIV face is necessary to ensure HIV does not stand in the way of anyone's health, dignity, and equality. Services tailored for Black African and Caribbean communities are fundamental to ensuring that no one is left behind in the drive to end new cases of HIV in England by 2030.

Although Black communities make up 2.5% of the UK's population, Black African people accounted for 28.4% of new HIV diagnoses in 2022. This makes them the second most represented ethnic group in the statistics after White people including White other (33.4%).<sup>1</sup> There has been a significant drop in the proportion of people within the Black African community being diagnosed late 2 from 2021 to 2022 (46% to 32%) which shows progress in normalising testing. A decrease in late diagnosis means fewer Black African people are at risk of developing other conditions alongside HIV. However, there was an increase in late diagnosis in Black Caribbean communities within the same period (35% to 38%).<sup>3</sup> This suggests there needs to be further analysis into the needs of Caribbean communities with regards to sexual health messaging, prevention, and testing.

Further investigation into data highlights other worrying trends of disproportionate impact within subgroups. In 2022, just over half (50.1%) of people who acquired HIV through heterosexual contact were Black African compared to White communities (21.8%).<sup>4</sup> Black African women made up the majority (50.3%) of new diagnoses in women in the

UK followed by White women (18%).<sup>5</sup> This shows a need to pay particular attention to gender as a subcategory.

The HIV Commission, which informed the objectives of the HIV Action Plan for England, recommended that there should be national and local plans to address health inequalities.<sup>6</sup> With the knowledge that Black communities are a key population within the Action Plan, meaningful engagement with Black people living with HIV must be part of the development of these plans. For Black people living with HIV in the UK, their experience managing their HIV cannot be separated from their racial identity. So a person-centred approach must reflect this.

'Nothing about us without us' is an often-used phrase that calls for the involvement of all people living with HIV. However, it is especially pertinent to this conversation because the experience of being Black in the UK shapes the people's experiences of physical and mental health.

The Unheard Voices project strives to empower Black African and Caribbean communities through a culture of involvement and co-design where their voices are treated as integral. We know HIV services will only effectively meet the needs of Black communities when they are built to reflect the reality of their experience.

## 1.2. Methodology

This report is based on responses from London local authority commissioners to a 14 question survey that covered services, approaches to community involvement and barriers to involvement. The survey was built with the insight from both voluntary sector stakeholders and local authorities to reflect our desire to establish shared goals. The core project team was a mix of members from National AIDS Trust and One Voice Network.

The survey was intended to be filled out by London sexual health commissioners and 16 out of the 32 boroughs (and City of London) were accounted for in the responses.

The project group decided it was necessary to draft supplementary questions based on responses given by several commissioners

to extract more detail. This gave us an opportunity to develop a stronger understanding of processes and to highlight initiatives that are examples of best practice.

We wanted to engage with Black voluntary sector organisations, ensuring that discussions on best practice were led and informed by them. The next step was a series of roundtable discussion workshops with Black-led community organisations. These were semi-structured workshops with prompts and presentation of the findings. They were an opportunity for participants to share their experiences and shape the recommendations.

## 1.3. Limitations

As the project was funded to focus on London local authorities, this report does not assume that all the findings are applicable to health commissioners outside of London. Approaches to community involvement in HIV programme design outside of London will probably be different to those undertaken within London. Due to the differences in demographics and challenges, similar research should be pursued in both urban and rural areas outside of London to learn about their approaches to community involvement with key populations.

The aim was to have responses that were geographically diverse and represented the differences across boroughs. Inner London boroughs were overrepresented in the response data to our survey, making up nearly two-thirds of respondents (62.5%) even though less than half of London boroughs are Inner London (42%).

Boroughs with a higher prevalence of HIV in their local population tend to fall within Inner London so the data might lean towards representing the practices of the most impacted boroughs. Outer London boroughs were allocated less per person in Public Health grants in 2021.<sup>7</sup> This may also skew our findings towards boroughs with more resources. We did, however, still achieve obtaining a range of responses reflecting different areas with varying resources and differences in HIV prevalence.

Out of 33 London Boroughs contacted we received 14 responses to the consultation survey which covered 16 boroughs. Quantitative checkbox questions were responded to by all survey participants. However, not all respondents completed all qualitative questions. Response burden was probably exacerbated by the number of questions and the level of detail asked for.

## 1.4. What is co-production?

**Co-production is the practice of working and developing projects in partnership with people who use, or will potentially use, the services. This approach views service users, carers and people with lived experience as experts – considering them as equal to the commissioners who usually have the final say. To build services that accurately identify and address unmet needs of the population they are catering to, perspectives from the community need to be reflected throughout the service development.**

Genuine co-production of services needs to be adopted at structural, cultural and individual levels. While there are a range of definitions of co-production, these underlying principles are universal and fundamental to a co-production approach.

**Shared decision-making and equal power<sup>8</sup>:** The main feature of co-production is the fact that everyone involved, both commissioners and service users, have the same amount of power over final decisions. The hierarchy that exists usually does not enable members of the community to have as much control as commissioners. Service users have an equal vote rather than trying to influence the vote of commissioners.

**Valuing of all skills, strengths and expertise:** Meaningful involvement means recognising that lived experience is a form of expertise. Knowing what it is like to navigate life living with HIV is why service users should inform what services look like. Additionally, co-production takes this further by utilising all the strengths of everyone involved. Whether that is public speaking or finance management, the final output should reflect the knowledge and skills of everyone involved.

**Involvement at every stage:** To establish shared division of power, co-production involves service user representation at every point in the project. This distinguishes it from other forms of community involvement. The different perspectives of the service users and wider community inform the delivery, implementation and the decisions that shape the final version of the service.

**Reciprocity/mutuality<sup>9</sup>:** Receiving experience or remuneration in return for the contributions made to developing projects shows the value of people's contribution is recognised. On top of it, it incentivises the process by benefiting those who dedicate their time to improving the services. Reciprocity is about gaining something in general and this relates to another principle of mutuality where knowledge is shared.

A final concept that is crucial to co-production is diversity. Greater variety of opinions increase opportunities to learn from each other and ensures a wide range of barriers and needs are accounted for. Marginalised communities are most in need of representation in community engagement spaces.

The 1983 Denver Principles instructed that People with HIV/AIDS should ‘be involved at level of decision-making.’ More recently with the 2021 UN Political Declaration on HIV and AIDS, Member States committed, amongst other promises, to:

**‘ [...] work together through international cooperation, reinvigorated multilateralism and meaningful community engagement to urgently accelerate our national, regional and global collective actions towards comprehensive prevention, treatment, care and support.’<sup>10</sup>**

Undertaking co-production brings the HIV sector closer to that vision by empowering those who access these services every day to have their needs front and centre. Since the beginning, genuine involvement of people living with HIV has been built into the UK’s commitment to ending HIV transmissions and improving quality of life for people living with HIV. To reach the pivotal goal of zero new HIV transmissions by 2030, we must have systems where people with lived experience can hold decision-makers to account and be involved directly in service development.



# Types of services commissioned by local authorities

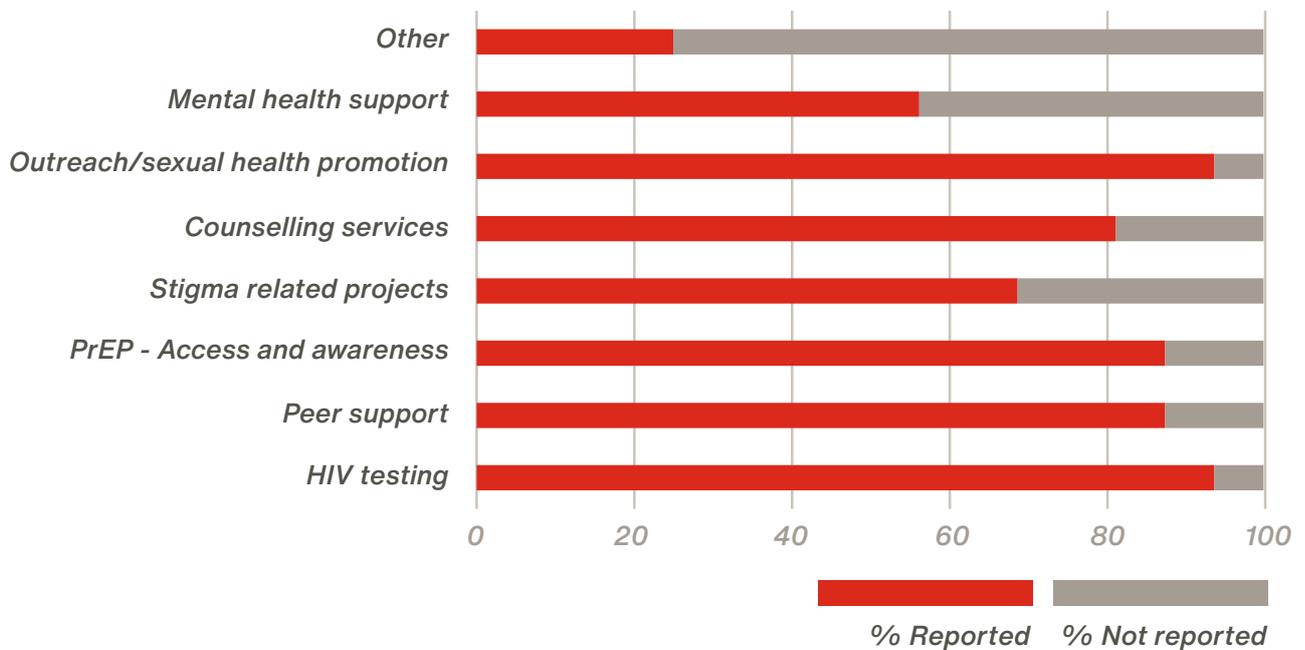
To identify their current service priorities, we wanted to understand what types of services local authorities commission.

Provision of testing for all STIs including HIV is a statutory duty shared by all local authorities which is reflected for the most part in the findings.<sup>11</sup> However, treatment and care for people living with HIV does not fall under the same duty and is overseen by the NHS. Also targeted prevention interventions

to address key populations are not explicitly required under legislation but it does refer to services being accessible to everyone. The first objective of England's HIV Action Plan is to ensure equitable access and uptake of HIV prevention programmes. The Action Plan also calls for targeted voluntary sector projects that reach high risk communities.

## 2.1. Services for general local population

**Graph 1.**  
Percentage of respondent boroughs by HIV services commissioned



## 2.1.1. Prevention

HIV testing is offered by most local authorities as was anticipated. 94% of boroughs confirmed offering HIV testing to their local community. One local authority respondent did not report commissioning testing or PrEP-related services but did state they were commissioning peer support and counselling. When asked in the survey if other agencies might commission services for their borough, the respondent did not state that testing was commissioned by another body such as integrated care boards (ICBs). This response probably reflects that HIV testing was available in sexual health services but not outside of those clinics. Moreover, all London local authorities currently contribute to the London HIV Prevention Programme so even where there is no borough-specific community testing, there is joint commissioning across London on testing and sexual health promotion.<sup>12</sup> Due to these provisions, testing is likely to be offered in all London boroughs and this response may be an outlier.

While we did not request information on testing methods, improving uptake of online self-testing kits was a recurring theme in qualitative responses. Diversity of testing methods could have a positive impact, particularly on Black African and Caribbean communities. Research has shown that testing options that reduce the need to attend specialist services can improve access to testing amongst Black African communities.<sup>13</sup> Alongside HIV testing, sexual health promotion and outreach was mentioned repeatedly with 94% reporting commissioning this service.

**Accurate information on HIV risk, HIV transmission and safer sex practices equips people with knowledge to make informed decisions around sexual health. Outreach resources and services**

**need to be developed with the goals to dispel false information and normalise behaviours such as regular testing. Importance of knowledge building was reflected in the responses around Key Performance Indicators (KPIs). Some of those answers touched on improving understanding of HIV transmission as a KPI. Condom distribution was also a popular practice amongst local authorities alongside information sharing.**

PrEP access and awareness followed as the second most commissioned service (88%). Investment in such prevention interventions has wider benefits. Improving access to preventative tools can also help manage the strain on health and support services that are already overwhelmed.

Treatment as Prevention (TasP) is also key to reducing HIV transmission and should not be left out of the conversation.<sup>14</sup> People living with HIV who are regularly taking antiretroviral treatment can reach a point where the HIV is undetectable in their blood. When they are virally suppressed, there is no risk of transmission through sex so diagnosing people and helping them to reach that level of viral suppression is essential to preventing HIV. Improving the quality and availability of HIV support services is also one of England's HIV Action Plan objectives and this can support treatment adherence by supporting good mental health and wellbeing. We should ensure that the psychosocial needs of people living with HIV should always be a principal consideration in service provision.

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they are virally suppressed, there is no risk of transmission through sex so diagnosing people and helping them to reach that level of viral suppression is essential to preventing HIV.

Improving the quality and availability of HIV support services is also one of England's HIV Action Plan objectives and this can support treatment adherence by supporting good mental health and wellbeing. We should ensure that the psychosocial needs of people living with HIV should always be a principal consideration in service provision.

## 2.1.2.

### Psychosocial, mental health and wellbeing

Peer support had the same rate of commissioning as PrEP initiation services (88%). Peer support strengthens the likelihood of retention in HIV care and increases likelihood of positive health outcomes.<sup>15</sup> Outcomes for people who have accessed peer support may include, increased self-worth, resilience and stress management as well as an overall improved sense of wellbeing.<sup>16</sup> People living with HIV have a greater risk of developing mental health conditions and are often subject of external and self-stigma.

**Peer support can create spaces for people living with HIV to manage those struggles by sharing experiences and developing a greater sense of community. Peer support should be tailored, accessible and available from the point of diagnosis to ensure people living with HIV experience good quality of life.**

Access to counselling was well represented across boroughs. Alongside other practical support such as peer support, counselling tends to be focused on providing coping skills and helping people manage more practical life challenges. People living with HIV often experience multiple disadvantages such as poverty or addiction, so commissioners should ensure that mental health and wellbeing staff have a concrete understanding of how HIV might intersect with these issues and its impact on their emotional wellbeing.

Mental health support and stigma-related projects were the least reported services at 56% and 69% respectively. The lack of commissioning of other types of mental health support might have been due to the prevalence of peer support and access to

counselling in boroughs. As the NHS is the main commissioner for mental health treatment, this may also explain why local authorities will more often provide lower level mental health and wellbeing support. It should be noted that peer support, counselling and other forms of mental health support serve different purposes and have different outcomes regarding a person's mental health especially where there is clinical diagnosis. So a range of referral pathways should be available to meet the specific needs of people living with HIV. In many cases, the provision of psychotherapies is left to general mental health providers instead so this might be why it is underrepresented in the findings.

## 2.1.3.

### Other services

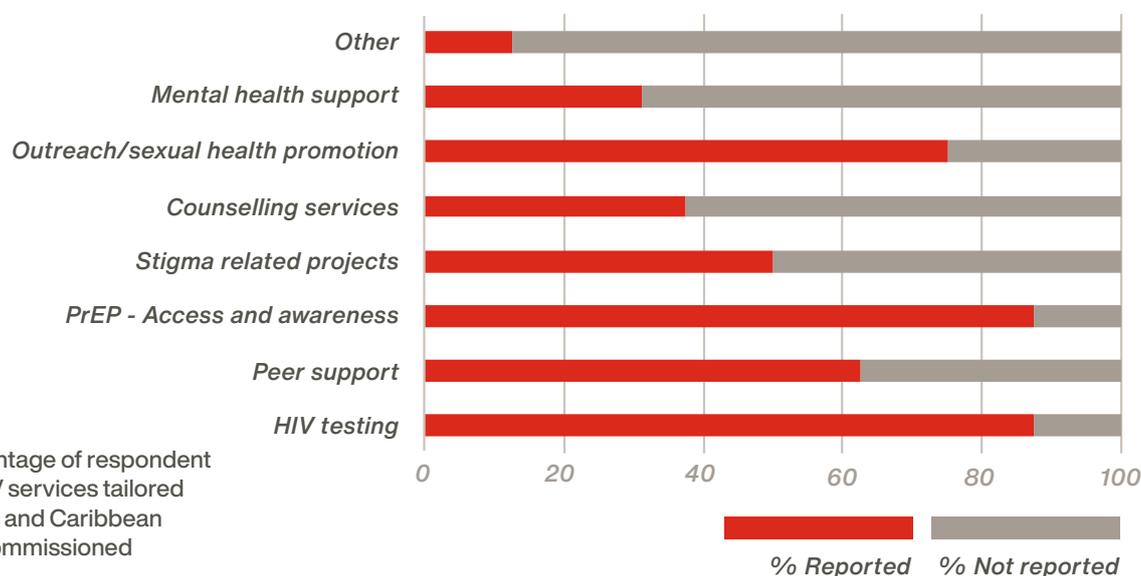
Other services respondents highlighted predominantly addressed targeting other (rather than specifically Black African or Black Caribbean) key populations who face disproportionate risk of HIV transmission. A commissioner mentioned their service having an HIV clinical nurse specialist in their council's drug intervention clinic.

Other examples of where local authorities are trying reach a specific group with unique needs include mentions of sex worker services and services tailored towards young people. Criminalisation of sex work in the UK has led to poorer health outcomes due to issues such as difficulties negotiating condom use and a lack of social support.<sup>17</sup> One local authority respondent shared how the sex work service merges provision of sexual health resources with more holistic support such as workshops on visa applications for migrant sex workers, support with budgets and peer mentoring. Strong referral links to sex work-friendly services including counselling was also a function of the service.

**This service exemplifies how local services can cater to the specific needs of marginalised groups. The development of the sex worker support service was a long journey; the commissioner shared how important it was to do in-depth mapping, build connections with stakeholders and engage with local sex workers who are such a vulnerable group. The qualitative knowledge they were able to gather informed everything from the essential items they distribute to the promotional materials they developed.**

## 2.2.

# Targeted services for Black African and Caribbean communities



**Graph 2.** Percentage of respondent boroughs by HIV services tailored to Black African and Caribbean communities commissioned

As with general services, prevention services were commissioned more often than those addressing the psychosocial needs of Black African and Caribbean people living with HIV. PrEP awareness and access and HIV testing were also the most reported out of the services tailored towards Black communities at 88%. This data suggests a collective drive to encourage PrEP initiation and normalise testing within communities where people may not consider themselves eligible or the target audience.

### 2.2.1.

## PrEP awareness

Research has identified significant gender disparities in PrEP users as few women are successfully accessing PrEP in England.<sup>18</sup> It was found 75% of PrEP were Gay, Bisexual and other Men who have Sex with Men (GBMSM) so even though it's a key tool for Black women, the barriers for PrEP use need to be explored further. In the 2019 'It Starts With Me' campaign's survey, 53% of Black African people who responded knew what PrEP was.<sup>19</sup> However, amongst these many believed it to only be available to GBMSM.<sup>20</sup>

Although we can increase awareness through information and resources, it is important that these address the concerns within Black communities such as side effects for people

within their respective communities.

A wider conversation needs to be had with research groups around representation of Black African and Caribbean people in trials for PrEP effectiveness. Black communities are aware of the history of racial disparities in medical research so there must be a proactive effort to improve meaningful representation as this can positively impact their health decisions.

**Research that has proportionate representation of Black people living with HIV will equip the HIV sector with evidence and answers to address concerns and questions people have.**

## 2.2.2.

### Testing and sexual health promotion

**“ In my area, [the local authority] have a fixed target for STI, HIV testing and targets for working in the community. If we want to do something for the National HIV Testing Week, they pass on the message to local community venues to co-operate with us to host testing.”**  
– *Voluntary sector organisation representative*

Point-of-care testing was mentioned by one respondent as a means of improving the uptake of HIV testing amongst Black African and Caribbean communities. The impact of community-based testing cannot be overstated. Alongside other testing initiatives such as opt-out testing and self-sampling kits, point-of-care testing makes testing accessible to populations that face a disproportionate risk of HIV but have not been engaged at traditional testing venues.<sup>21</sup>

75% of respondents commissioned sexual health promotion and outreach tailored to reach Black communities. Outreach provides a key opportunity to address health messaging, myths and concerns within the Black African and Caribbean communities. Low HIV risk perception amongst groups such as Black African women can be a challenge to increasing regular HIV testing and PrEP uptake. Issues such as this are talking points worth addressing during outreach as well as through sexual health messaging and campaigns towards Black African and Caribbean communities.

## 2.2.3.

### Stigma projects

**“ We need to have a billboard, a podcast, a radio show that continuously talks about HIV within the Black community, but not in a negative way. In a way that people can access it. We have to be realistic: there is still stigma, shame, denial and discrimination and it is getting heavier within the Black community with HIV.”** – *Voluntary sector organisation representative on creative ways to address stigma and HIV messaging*

National Institute of Clinical Excellence (NICE) found perceived and experienced stigma hindered Black African engagement with testing amongst other factors.<sup>22</sup> Fear that diagnosis will lead to further association of HIV with Black communities or African people hindered testing in some Black African migrants. How the intersections of racism, xenophobia and HIV stigma impact testing needs to be explored and addressed in materials. Half of the respondents reported commissioning stigma-related projects for Black African and Caribbean communities. While some projects on stigma might be part of targeted sexual health promotion and outreach, it is important that the impact of stigma is addressed in some way throughout services.

## 2.2.4.

### **Mental health and psychosocial services**

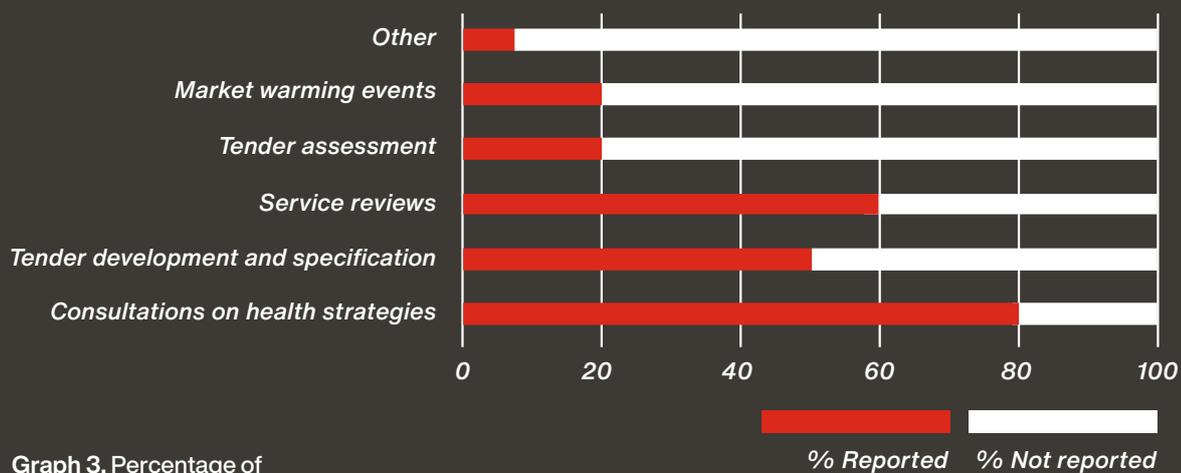
Mental health support (31%), counselling services (38%) and peer support (63%) were the least commissioned services of those tailored to Black communities. Where there is not emotional and psychological support tailored to address the needs of Black African and Caribbean people living with HIV, service providers should be expected to promote cultural competency within general services.

The PRIME Study highlighted the differences in the mental health of older women living with HIV of different ethnicities – Black Caribbean women were more likely to experience social isolation and psychological distress, followed by Black African women.<sup>23</sup> However, White British women were more likely to have a clinical diagnosis and be on antidepressants. This gap between who is accessing support and who is experiencing the worst outcomes highlights the need for providers to reflect on the cultural competency of their services. The recommendations from the study included provision of peer support for women living with HIV, particularly Black and ethnic minority women. The role of peer support as a key opportunity for Black African and Caribbean women living with HIV to be referred to further services that address their needs, e.g. around financial hardship, was also recognised in the PRIME study.

# How local authorities approach community involvement in HIV commissioning

## 3.1. Involvement of local community members

The findings suggested it was more common practice to include the ideas and opinions of those with lived experience at the beginning or when the service is being reviewed. One local authority respondent did not choose any of the options illustrated in Graph 3 and did not give any further details on other ways they might have involved local community members affected by HIV. This suggests a lack of consistent involvement of the local community in HIV programme design.



Graph 3. Percentage of boroughs who involve community members in HIV service design by commissioning process

85% of the commissioners reported involvement of community members in consultations. Additionally, nearly two thirds (62%) shared that local community members contributed to service development through service reviews. Use of workshops and consultation of community stakeholders including faith leaders came up often in written responses.

**“ The providers are continuously looking for ways to engage faith leaders in consultations, development and in service delivery, as gate keepers and influencers within the faith community.” – Local authority commissioner respondent**

Service reviews do provide a platform to notify commissioners of improvements that could be made to service delivery and effectiveness, but this is done at a time where options for substantial change will be limited. Similarly, consultation on strategic planning can be a positive step towards meaningful involvement and can encourage community members to present their thoughts on key themes and outcomes for HIV services.

Members of our roundtable discussion stated the importance of offering a range of opportunities to receive feedback from the community, including in-person. Commissioners often reported using surveys to collect feedback, with a few mentioning workshops. Working with community organisations or people with lived experience

may support the development of feedback surveys. Combining these with informal events or events organised in collaboration with community organisations may also draw out different feedback from those more likely to engage in person.

It seems there were fewer opportunities to involve people living with HIV as the projects reach the later stages. Co-production calls for continuous involvement of people with lived experience throughout the development of services. This can help ensure that the vision community members have is maintained from planning through to implementation and evaluation.

While examples of community involvement in service implementation were scarce in our findings, a few respondents did share how they created roles and spaces for community members. For example, service users were sometimes involved in tender interview panels, sexual health promotion campaigns and delivering other activities and events.

**“ Service users have been involved in providing peer support, leading workshops, outreach etc. with groups bringing their lived experiences and learnings to enrich service delivery.” – Local authority commissioner respondent**

**One local authority highlighted the success of their online hub in signposting people to get involved in their co-production group.**

## **candiNetwork**

**The candiNetwork online hub serves a dual purpose. It acts primarily as a directory of all the HIV services commissioned by Camden and Islington councils – there are opportunities to have a holistic assessment to help distinguish what support services fit your needs.**

**The hub also houses information about the councils' approach to co-production and its Network Co-production Group with easy**

**links for further contact. The Co-production Group is set up to establish a clear line of communication with people living with HIV so they can be deferred to for their opinions on HIV services.**

**The group has responsibility for the Local Innovation Fund so this suggests the group has some control over the direction of projects to address unmet needs.**

Less than a quarter of local authorities (23%) said they involved service users in market warming events and tender assessment. Market warming is meant to facilitate conversation between potential service providers and local authorities before the formal tender process has been initiated. The inclusion of service users and their experiences in early market engagement would drive sexual health providers to draft their bids with clearer understanding of the needs of the local community. As the voices of people with lived experience of HIV are fundamental for assessing success of services, their presence in these preliminary conversations would help to strengthen the commissioning objectives and wider vision.

Co-production cannot be achieved if community members give ideas at the beginning and then are next presented with a finished plan or the finished version of the service. Where they are not involved in the conversations between, this does not promote equal decision-making power. This makes the process less transparent and can remove a sense of control from people with lived experience.

Allocation of public health funding as a factor seemed to have had minimal impact. The five respondent local authorities who received the most public health grant per head in 2021 were not more likely to involve community members. One respondent was receiving

within the lower end of health grant allocation even though it involved community members more often than other boroughs. It should be recognised this does not eliminate funding as a barrier to community involvement as more funding allows for further innovation. The data suggests commissioners have been able to overcome this issue in some ways to still integrate a community voice into at least some of the service planning and delivery. There appeared to be a link between the type of service commissioned and the methods by which community members became involved. It tended to be the case that community members were least likely to be involved in the planning of market warming and tender assessment activities. However, the boroughs that did involve community members in the tender assessment and market warming, also tended to commission the least for Black communities e.g. stigma related projects and counselling services.

This indicates that more meaningful and earlier involvement can lead to better commissioning which meets communities' unmet holistic needs.



## 3.2. Procurement and tender

Sexual health service providers play a key role in co-production. When we asked commissioners about successes in community involvement, the work of service providers was often raised.

For example, a project by Positive East, Women4Women, was highlighted as an example of a service provider successfully involving community members with positive outcomes.

### Positive East's Women4Women Project

Women4Women, as a project, worked to empower Black African women to become community champions through training. This not only served to bridge the gap in communicating messages on HIV to Black African communities but the project provided tailored training to the women in areas including communication skills, self-advocacy and treatment literacy.

When speaking with a representative from Positive East, they shared that the women came from different backgrounds with varying levels of confidence and expertise. Training and workshops were tailored to the needs of the women and recognised their other responsibilities, what they were comfortable with and their personal goals for this experience. Project facilitators went through the effort of making the training CPD certified so the women could see the value of their work through the qualification.

After finishing the training that was provided by Queen Mary University of London and Barts NHS Trust, they would go onto lead conversations and speak at public speaking events on PrEP. One of the project's co-ordinators from Positive

East stated, 'the buzz [the women] got out of doing it – it made them want to do more.' The whole project centres around the women sharing the information they learned through workshops on demystifying HIV and sexual health. They were encouraged to take what they had learnt and share with people in their faith groups, host barbecues and dinners parties and lead on their projects where they encouraged conversation and share materials to engage their community further.

One of the other outcomes was how much Positive East were able to learn from this experience. Following discussions about what PrEP campaigns work, this sparked a discussion on how to talk about PrEP without framing it around risk because that approach did not motivate PrEP use.





**To continue seeing sexual health service providers engage in community involvement and encourage new projects that reach Black and other underrepresented communities, local authorities should allow for service users to interact with potential service providers during the procurement process. When service providers hear lived experience directly from those living with HIV, it broadens their understanding of the needs of the local community.**

Although the importance of service providers was highlighted, not many people with lived experience of HIV were included in that selection process. Half of all the boroughs reported not involving community members in procurement and tender of service providers in any way. If the aspirations for community participation is co-production, lack of community voices in the procurement process does not help to achieve this.

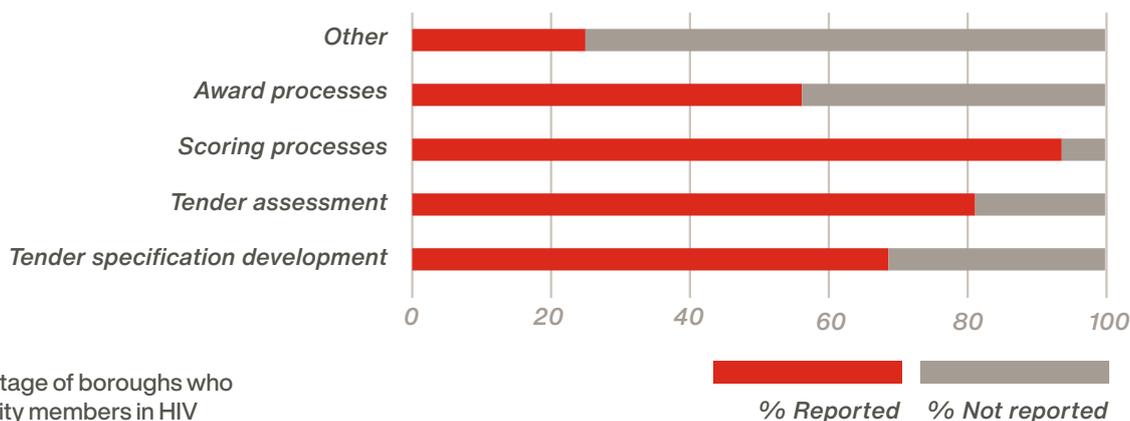
The most common way of including community members in procurement was through involving them at the stage where tender specification was being developed.

Having service users present for the development of tender specifications enables lived experience to be centred in the conversation. With community members in the room themselves, they are able to stress certain unmet needs and other key themes which might not otherwise be given sufficient weight.

However, the lack of community representation reported during the tender assessment stage (31%), in the scoring process (19%) and in the award process (13%) is concerning. While inclusion in tender specification is a useful method for ensuring community perspective is shared with potential service providers, there needs to be more continuity in involving service users throughout the whole process, from development to assessment. This allows for the expectations community members have of potential contract holders to directly influence the decision-making process more often.

Just over a third of our respondents involved community members in both the tender specification development and tender assessment. Marginalised communities often rely on agencies and commissioners to communicate their unmet needs and priorities to service providers. Without community representation in the room, there is a concern that not all the key messages and priorities of marginalised communities will be conveyed.

Community involvement when assessing bids ensures that the values of service users and wider members of the community are brought up consistently throughout the process. Service users are then able to interact with bids and identify the strengths of bidders that commissioners might not measure.



**Graph 5.** Percentage of boroughs who involve community members in HIV service design by procurement process.

### 3.3.

## Key Performance Indicators (KPIs) and strategic objectives

The approach commissioners had to KPIs, and strategic objectives varied across responses. KPIs were not always decided by the commissioners – sometimes it was left to be developed by, or negotiated with, the service provider organisation they offered the contract to. This reinforces the need for community members to have some say in assessing bids or communicating their perspective to potential bidders.

One response mentioned KPIs were developed with consultation from stakeholders including service users and were up for review annually. This creates an expectation where community stakeholders will provide regular feedback on how the success of service should be measured.

Whilst it was not typical across the board, there were a few local authorities who admitted to not having specific KPIs around Black African communities even where they had a comparatively larger Black population to other respondents. One commissioner acknowledged that while none of their KPIs were Black African and Caribbean specific, but they did measure. Factors such as success of PrEP outreach and rate of late diagnosis with demographic monitoring.

In local authorities where there was a focus on targeting marginalised groups, KPIs tended to share some key themes. For example, for KPIs targeting Black African and Caribbean communities, it was common to prioritise increasing PrEP uptake in the community.

One of the responses received demonstrated a very holistic approach to KPIs and areas of measurement, by explicitly including mental health and wellbeing alongside indicators on positive behaviour change and risk reduction, uptake of targeted sexual health promotion and stigma work for Black African and Caribbean communities.

Indicators of service success within KPIs – such as service uptake and pathway completion – were outlined as key priorities. One respondent highlighted how they had KPIs on relationship building within the local community.



**“ Working with community voluntary organisations particularly faith groups to increase the knowledge of HIV and with the aim of reducing stigma and discrimination, normalising conversations around HIV, promoting HIV testing and identifying community champions. – Sexual health commissioner respondent**

This example shows that relationship building with community leaders and grassroots organisations with knowledge of the local community can be included as a measurement of the success of HIV programmes. However, these areas are arguably more difficult to quantify. Good communication with community stakeholders is needed to develop services for key populations that effectively encourage testing and PrEP use.

One respondent noted that the function of KPIs may have been interpreted differently across local authorities. They explained KPIs are often agreed service targets that can have penalties when not met. Therefore, other aims of service such as reducing inequalities in population outcomes might fall under the category of ‘strategic objectives’ rather Key Performance Indicators. This might explain why some respondents did not have KPIs on services and engagement tailored to Black African and Caribbean communities. However, many local authorities did include KPIs on addressing health disparities, so it is not uncommon.

Monitoring the extent of community involvement could aid the understanding of whether progress has been made to meetings the needs of the local community. Focused KPIs could embed the value of knowledge and involvement of voluntary organisations – which if not present would highlight the fact that something important is missing. By establishing service user engagement as a key value throughout KPIs, it recognises the importance of it being measured, as well as working towards it being continually at the forefront of the minds of everyone involved.



# Barriers to Black African and Caribbean community involvement

**Our survey provided respondents an opportunity to share what they perceived as the barriers to community engagement with Black African and Caribbean communities.**

The issues raised reflect the issues commissioners themselves have noticed are preventing meaningful engagement with Black communities.

## 4.1. Cultural and religious barriers

**“ We have witnessed particular difficulty in engaging men who have sex with men from sub Saharan countries, in the UK. There are cultural, religious barriers that are hard to overcome where there is no language or tradition of discussing sex and sexual practice, managing sexual health. – Sexual health commissioner respondent**

Cultural differences were frequently identified as a factor in preventing meaningful engagement with Black African communities, especially when discussing sexual health and LGBTQ+ sexual practices. One of our roundtable members commented that this can sometimes be the case when the dominant culture in a person's country of origin is not accepting LGBTQ+ sex and identities. Where their country of origin and the culture they were brought up in antagonises or criminalises certain sexual behaviours, people find it difficult to feel safe sharing their status, sexual orientation or gender.

The roundtable group brought up how many Black African and Caribbean people hide information about their HIV status, identities, or sexual behaviours from their closest family and friends for fear of social isolation: growing up in an environment where it may feel unsafe to express sexuality or gender outside the accepted norm can be enough to discourage people from even acknowledging and sharing those parts of themselves. It can take time to come to terms with their identity even if they have moved to a country where there is different attitudes to sexual orientation and gender identity. This also makes it difficult to trust commissioners they have not met with this information.

The negative experiences of religion being used against someone can have similar effects: some people have witnessed faith being used to justify claiming HIV is a moral failure or punishment. Due to these experiences, the journey to reconcile an individual's status and faith is deeply personal and requires patience and time. Without the nuances that come with shared cultural or religious understanding and background, some commissioners may experience challenges of being able to engage with people when they do not have the same background, or awareness, of the experiences that shape a person's self-perception.

In recent years, the HIV sector has benefitted from the involvement and leadership from faith-based leaders and projects that have used alternative routes to addressing HIV stigma. NAZ's Joyful Noise choir is an example of how utilising the role of religion and culture in a person's life can improve their ability to have conversations around their physical, sexual, and emotional health. For people living with HIV, building a greater sense of community through peer support and shared activity among people who share the same religious or cultural heritage may introduce them to wider HIV activism. When the feelings of isolation can be overcome through establishing a new community of people living with HIV, some can feel confident enough to pursue a desire to make positive changes.

Peer leadership can be used to tackle barriers such as cultural and religious dynamics that impact people's relationship with their diagnosis. Peer leaders may be able to understand the journey it takes to come to terms with an HIV diagnosis and may have a shared cultural background that helps support other people on that journey. This can help where commissioners may not be in the position to understand the experience of accepting a diagnosis when someone is from a specific cultural and religious background.

When people living with HIV are supported through training, workshops, and qualifications to become peer advisers and lived experience champions, they bring their experiences of navigating life with HIV and use that knowledge to support others. This includes processing recent diagnoses and supporting local authorities in developing projects that acknowledge cultural nuance.

A wider discussion on mental health and trauma-informed wellbeing support for people involved in community engagement needs to take place. Access to a wellbeing fund, referral pathways to counselling or wellbeing activities being offered to community representatives could combat the emotional hardships brought on by discussing negative experiences. A commitment to wellbeing when involving community members in service design enables meaningful conversations about lived experience without exhausting or triggering vulnerable people.

**“ Just watching people come to the peer support when we had it – the look of trepidation on their face is just horrible. What we managed to do is that by the time they leave, as of their first meeting, they are looking forward to the next ones. – Voluntary sector member on working with GBMSM from Sub-Saharan Africa**

## 4.2. Language barriers

Language barriers can place an unreasonable amount of burden on community members and service users to quickly build a strong foundation of English. People who are taking on English as an Additional Language could support local authorities in improving the accessibility of HIV services. However, language support needs to be provided so people who speak other languages can be involved in the process of service planning, design and delivery. If co-production is to be successful, local authorities should make the process as accessible as possible.

Simplifying commissioning and healthcare jargon is a vital step to ensure spaces for shared discussion and decision-making do not exclude people where English is not their first language. In addition, voluntary sector representatives expressed how people living with HIV often do not speak about their healthcare the way commissioners do, which can create a breakdown in communication. Commissioners aiming to meaningfully involve their service users must communicate in a way that is familiar for them as individuals, prioritising their comprehension and participation. Proactive interventions to support people in improving their English skills and to translate key terms and phrases, such as resources, classes or translators, enables stronger participation from people.

**“ Most of the time you have to understand what’s going on before you even take part in it ... for our community, we might not understand, and we can’t challenge anything because we don’t know what’s going on in the conversation... for us it’s a big barrier. – Voluntary sector member on how language impacts community participation in service design**

By reaching those who might struggle with English, local authorities will benefit from the input of people who can inform them when their language is not simple or accessible enough in outreach work.

Anecdotally, our community stakeholder group also felt that resources available in HIV services need to be inclusive of less widely spoken languages, to avoid anyone being excluded because their native language is not included. Members of the group felt that not only should a greater diversity of languages be available, but they also encouraged different formats of communication. As there can be a difference between speaking and reading ability with language, local authorities should attempt to give options for types of engagement such as audio resources.

## **French African Welfare Association (FAWA)**

**French African Welfare Association (FAWA) provides translation and interpretation services. By doing this, they address the language disparities French speaking African people experience when trying to get HIV support. Previously they were also able to provide more regular peer support**

**programmes which built a sense of community for those who’s native language of French. Collaboration with organisations such as FAWA could strengthen communication with some of the most vulnerable people within a local community.**

## 4.3. Financial barriers

### **Black people living with HIV who are on treatment are more likely to experience financial difficulties than their White counterparts.<sup>24</sup>**

Being more at risk of experiencing poverty means people may be focused on establishing some security and covering their basic needs. This can leave them with limited time to dedicate towards activities where they aren't reimbursed.

Co-production can demand an extensive amount of time and energy from service users, depending on the type of the involvement. Those who are experiencing poverty and living with HIV are in a position where they must prioritise having a standard of living that makes it easier for them to maintain their health. Local authorities should identify and offer multiple opportunities for involvement in planning strategy, service design, service delivery and other co-production areas with varying levels of time and energy commitment.

One of the principles of co-production highlighted earlier is reciprocity: the idea that people are rewarded or receive something in return for their contributions. Reciprocity shows there is recognition of the value added by a person's contribution and people are more inclined and able to be involved, and contribute their best, when they are remunerated. Remuneration should also reflect the extent to which service users provide their emotional labour. The time spent supporting with service design may be small but HIV stigma and the burden that comes with managing the condition can be intertwined with difficult feelings and experiences of trauma. Financial compensation is the ideal option to reward, especially to people who are more likely to be in poverty, as it alleviates some financial stress and allows people to justify dedicating time to co-production activities. One survey participant shared that they provided vouchers for supermarkets to cover £25 and £40 worth of groceries.

Theories of co-production suggest that there are alternative options to financial remuneration that ensure community members receive a valuable reward, such as the development of new skills. Skills building – if done properly – can build a person's sense of responsibility, employability and confidence alongside teaching them valuable transferable skills. Where, and if possible, qualitative research should be done into other ways community members can feel like their contribution has been valued.

We recognise a one-size-fits-all approach could not be applied to various boroughs when it comes to remuneration and compensating expenses, but all should be having appropriate conversations and procedures to regularly review remuneration policies that reflect the needs of community members and the aims of community involvement. For areas considering establishing a fixed rate, as of 2023, the NHS pays their patient and public voice (PPV) expert advisors £150 for more than four hours per day and £75 for four hours or less per day.<sup>25</sup> Within this policy, it is noted that the payment is meant to reduce barriers to participation, foster diversity within their cohort PPV advisors and show appreciation for these contributions.<sup>26</sup> As these aims are similar to the principles we see as fundamental to community involvement at local level, this policy may be an example to reflect on when deciding how to approach reimbursement. Commissioners should note that for varying reasons some people may not be able to accept money or can only accept a certain amount. In this case an alternative form of remuneration should be discussed and made available.

## 4.4. Openness of commissioning authorities

A respondent to the survey highlighted that they considered the lack of 'commissioners willing to learn or listen to views' as a potential barrier to meaningful involvement and co-production. They could have been referring to difficulties accepting different opinions from people with lived experience or difficulties adjusting to co-production where their individual and organisational role may change. Commissioners who want to take this on also need to be supported to do so through leadership buy-in, adequate resource, and wider organisational openness to resulting change.

Power-sharing is a fundamental principle to co-production. The shift towards power-sharing requires the acknowledgment that the hierarchy that usually exists between commissioners and community members must be deconstructed. Commissioners and commissioning authorities must adopt and internalise a culture within which people with lived experience are not only fountains of new ideas and subjects of research, providing expertise that commissioners do not have. They also should have agency in the decision-making process.

To be ready to accept this expertise, commissioners at some level must consider deferring to community representatives on the needs of Black African and Caribbean communities affected by HIV. Time and care should be taken to acknowledge where there may be less understanding, be curious and engaged, as well as questioning assumptions previously held. Co-production requires changes and

learning at individual levels to co-design services. Training and workshops can play a role in supporting individual acceptance of co-production and understand the ways in which commissioners can open themselves up to change.

The process of co-production will not happen overnight. Local authorities must work towards changing how they understand the relationship between service users and commissioners. In some cases, respondents highlighted that co-production and community involvement was embedded into their responsibilities through written policies which create accountability. Policies and practices can play a role in this normalising co-production before it becomes a habit. Terms of reference for groups that manage HIV support programmes can be drafted to include representation for community representation regularly, if not at every meeting.

**Utilising effective learning practices can help facilitate change. Learning from people with lived experience may look like keeping a learning log on the knowledge being exchanged to be regularly updated to encourage reflection. Alternatively, a more dynamic approach is dedicating a portion of meeting time to discussion on what has been learnt. Making co-production the default approach through systems and internal structures can normalise the principles to lead to behaviours and attitudes changing.**

## 4.5.

# Disillusionment and lack of trust or faith

**“ Some of the barriers in getting people from [Black African and Caribbean Communities] involved in co-production is that people from this community often times feel that they are not heard and their contributions [are] not taken seriously. – Commissioner respondent**

Distrust of the healthcare system or statutory agencies is a product of health inequalities, which some commissioners acknowledged in their responses. Understanding the systemic marginalisation, the Black African and Caribbean communities face in the UK explains why they can be hesitant to work with local government or commissioners. Consistent experiences of discrimination by healthcare providers can mean Black communities are unsure whether they can rely on these systems.<sup>27</sup> If concerns and experiences of discrimination are left unaddressed, little progress can be made to improve the relationship between commissioners and prospective service users.

The disillusionment from Black communities is often the product of having their concerns and experiences ignored. Black people in the UK have had first-hand experience of prejudice in the healthcare system and have not personally felt or seen any progress. This is why more tokenistic approaches to service user participation do not properly engage with Black communities.

Working with grassroots Black-led community organisations can remedy this at some level. Community organisations and the staff within them can have the advantage of holding positions of respect and trust within their community. Collaboration with community stakeholders was found in some instances to have reduced concerns around the COVID-19 vaccine and increased vaccine uptake in some ethnic minority communities.<sup>28</sup> There has been success in cases where faith leaders are informed on the benefits of the vaccine so they can hold conversations within their

communities, being well-equipped to address their concerns. Mirroring this approach, which some local authorities have started to do, could prove beneficial when having discussions on PrEP, stigma, and HIV testing.

Collaboration between local authorities and community stakeholders would have to be reciprocal, transparent and built on a mutual understanding of the goals. Without this, there is the risk of the engagement with stakeholders coming off as insincere. Community organisations and stakeholders often are leaders within their community for a reason and will probably amplify the concerns of the community before supporting initiatives.

Being transparent over how involved community members can be with co-production might also reconcile some of the disillusionment. Co-production might be attractive to service users as it means they can be in the room to advocate for themselves, raising their opinions first-hand, and representing their cultural background and their HIV related needs. By making it clear what powers and responsibilities community members have in the co-production process, the involvement and interest from local communities can be grown.

## 4.6.

### Migration status

**Lack of participation of people from migrant communities was a common concern that respondents expressed. It was echoed within the community stakeholder group that migrants were very aware of the political climate and the attitudes expressed towards them moving to the UK.**

Many of the barriers already explored are often exacerbated when it comes to migrant communities. Local authorities need to be clear over how confidential process is and what community involvement entails as 'hostile environment' migration policies which has created fear within some migrant communities. Fears around being removed from the country can impact whether the migrants living with HIV engage with support services.<sup>29</sup> It may also impact their willingness to engage with local authorities as they are governmental bodies.

Where migrants had insecure status or are seeking asylum, their financial situations are made worse by policies such as 'No Recourse to Public Funds' and the limited right to work in some cases. These policies often mean they cannot afford food and travel expenses.<sup>30</sup> This limits their capacity to prioritise volunteering or non-funded work. Community involvement should include reimbursement or funded opportunities to engage migrants with HIV. Reimbursing them for their time will improve their financial position which means they are able to dedicate time to working with commissioners to co-create services. Where skills development or incentives can be offered, this should be explicitly mentioned in posts or any promotion of community engagement work, so migrants are aware that there is some advantage or benefit to offering their time to this work.

# The role of community organisations

During the roundtable discussion, it was highlighted by members that many of the barriers reported by commissioners could be seen as perceived barriers. This was the case because it was felt these barriers would not be as prominent if Black-led community organisations had more involvement in developing local services.

## 5.1. The expertise of community organisations

“ We are the community, most of us belong to the WhatsApp groups, we are ears on the ground. – A voluntary sector member during roundtable discussion

The people we heard from are not just service providers, they are often pillars of the communities they work with, building reciprocal relationships with the people they provide support to.

The knowledge Black-led community organisations have gained through working with Black people living with HIV provides them with the understanding and importance of cultural nuances and how that impacts the support people need. Cultural knowledge is not the only feature that distinguished them as organisations. It was continuously demonstrated how much they understand how to approach and centre the people they work with, for example, understanding that instead of rushing people to finish because it's the end of the session, they need to let the conversations come to a natural end. They recognise that forms of communication like WhatsApp or Telegram feel familiar to use and that familiarity can help foster safety between them and the people they support.

This person-centred approach creates a sense of respect and being prioritised through small details that can transform people's experiences with HIV care. The trust they have built within their community relationships means they are well-positioned to advocate and provide support that addresses the needs of the community. Black-led community organisations also regularly hear qualitative data about the experiences of Black people living with HIV.

This is why community organisations are an asset in developing services that effectively respond to the needs of Black communities at risk of HIV. However, the value of their work is not always recognised.

## 5.2.

# Obstacles faced by Black-led community organisations

One participant spoke about how community organisations have to create networks to widen their scope of influence and connections to hear about recent research or funded opportunities. Even where research is centred on the communities they serve, some organisations expressed being disappointed about not being informed when information is released or being invited to sit on advisory boards for research. This creates a dynamic where these community stakeholders with a wealth of quantitative, qualitative and anecdotal data are left out until it is decided they are useful.

It was shared by more than one voice within the group that there was an expectation that when asked to retrieve data from their local communities, community organisations are not given enough agency regarding the timeline from which they are expected to do so. Their work style and approach often requires patience and relationship building – they know people may not be readily willing to give this information without organisations having

established trust. Being given stringent timelines they were not consulted on also negatively influenced their ability to deliver the kind of projects and work that would see genuinely impactful outcomes. Negotiation of timeline and outcomes with all partners should be the norm.

In their experiences of commissioned work, many workshop participants spoke of not being able to get part of the budget to cover travel costs or food for people coming to peer support session. This meant that they could not execute their events in a way they predicted was the most effective or address the barriers that could prevent people from engaging. Additionally, without proportionate sustainable levels of funding, Black-led community organisations felt their ability to develop internally by investing in training and technology was hindered significantly.

Bureaucratic application requirements were a common theme when the discussion shifted to systemic barriers. Different participants shared how they were often automatically excluded from submitting a tender bid due to the eligibility criteria requiring that they have certain documents or larger annual incomes. One organisation expressed finding it difficult to get funding without three years of accounts which was hard to establish due to their size. Other members of the roundtable spoke about needing a better understanding what grant managers and funders were looking for in these application processes.

## 5.3.

### Partnership Work

**This creates a pressure to bid with larger organisations who have more experience navigating these application processes. While everyone recognised the value of how partnership work facilitates the sharing of knowledge, it can mean that smaller, Black-led organisations don't end up building their own skills and accounts if the partnership is not done well. Members shared that their organisations were allocated less funding and had less agency in some partnership projects.**

People shared instances where larger organisations bid for funding that was dependent on data being retrieved by Black-led organisations. Even though work was reliant on their data collection, the division of funding between partners did not reflect this, with Black-led organisations often receiving a disproportionately low allocation. Despite this, community organisations were not against the prospect of partnership work in the future. Instead, they highlighted partnership work can present opportunities for expertise sharing within the sector which improves the knowledge and skill within HIV support services. Instead of relying on a single supplier, representatives suggested that grassroots organisations could receive sustainable funding to do smaller targeted portions of a wider contract to do more intensive work within Black communities.

## 5.4

# Supporting the work of Black-led community organisations

Overcoming these systemic obstacles requires a multifaceted approach. Proactive communication and early engagement with Black-led community organisations will allow them to be aware of opportunities to work with local authorities. It may be necessary to target specific organisations and start building long lasting mutually beneficial relationships with them. All participants agreed their organisations would benefit from wider conversations including workshops and market warming events to engage with sexual health commissioners who manage procurement.

Creating opportunities through early market engagement to acknowledge and review how to ensure Black-led organisations are able to fully participate in tender processes is fundamental to ensure that service provision can effectively reach Black African and Caribbean communities.

Through collaboration with Black-led community-based organisations, commissioners will benefit from new innovative services and projects. For example, African Advocacy Foundation (AAF) was commissioned to deliver PrEP campaigns within Black African and Caribbean communities. With their understanding of the community's cultural, language and faith backgrounds, AAF were able to train local PrEP champions to speak about PrEP

within their communities. Voluntary sector organisations have the creativity and expertise to reach these communities, but their outreach work needs to be consistently funded so they can trial programmes of work to reach Black communities. Many of the members expressed a desire to work with commissioners to figure out details such as measurements of impact because they would benefit from upskilling.

Black-led organisations are both a bedrock of HIV support and an underutilised resource for those commissioning HIV services. As such, they should not have to choose between opportunities where they are undervalued and underfunded or not being able to provide services for their communities. Many organisations saw great success in supporting people's mental health and health-related habits through peer support groups, some of which have now had to be cut. Commissioners working in collaboration with these organisations will lead to genuine progress in the HIV response for Black African and Caribbean communities.

# Conclusion

Black African and Caribbean communities disproportionately account for a significant portion of the UK's rates of new diagnosis and late diagnosis. While White men saw a 15% decrease in new diagnoses rates from 2021 to 2022, new diagnoses in Black African women and men increased by 85% and 41% respectively. To address this inequality in HIV, the question we must answer is: 'How can HIV support and prevention services have a greater positive impact in the lives of Black African and Caribbean communities at risk of and living with HIV?'

The first step is empowering Black African and Caribbean people impacted by HIV and involving them in the decision-making processes that shape their HIV prevention and support services. This includes ensuring people with lived experience feel supported in their personal and professional development so community members are confident and well-equipped to participate in the commissioning process. Co-production aims to build a relationship between commissioners and people with lived experience where they work jointly to create services to support local communities. Through these relationships, it achieves a larger goal of making services that reflect and resolve the unmet needs of the local community.

If there is to be success in genuinely tackling health inequalities in HIV, work must be done to remove the barriers to meaningful involvement. Further research into this area is required to expand our understanding of co-production approaches outside of London and to hear about other barriers to community Black people living with HIV would identify. By addressing what prevents people with lived experience from getting involved, commissioners benefit from a greater diversity of opinions, experiences and cultures from the local community designing the services. At every stage, new perspective and knowledge will be shared that will lead to the best results. With fewer barriers, it then becomes more likely commissioners will interact with the experiences of the most underrepresented or vulnerable groups such as people with different levels of English language proficiency.

Commissioners would also benefit from building long-term working relationships with Black led community organisations. Their expertise means they are well positioned to inform consultations and to facilitate communication between commissioners and the communities they reach. Grassroots organisations who have strong links with

Black African communities unfortunately face challenges and barriers that prohibit their submitting bids for procurement contracts.

Market engagement and open dialogue between potential service providers and commissioners can inform better bids and can help smaller organisations upskill. Targeted specifications to reach key populations and encouraging the partnership between service providers could help Black-led organisations create programmes of work that will prove the most effective. In recent years many have seen cuts to funding which meant it was not possible to continue some services that deeply resonated with Black communities living with HIV.

Achieving co-production relies on more than just local authority commissioners. In order to trial different approaches and fund long term programmes that will end health disparities, commissioners need greater public health funding. To achieve the Government's goal of ending new HIV transmissions by 2030, addressing health inequalities within HIV

must be prioritised. An increase to the public health grant is essential. Without sufficient resources, it will be difficult to foster the type of genuine involvement that will have significant impact on the success of local HIV commissioning for Black African and Caribbean communities. Sustainable funding will enable more local authorities to implement our recommendations which should be undertaken urgently to improve the health outcomes of Black African and Caribbean communities.

# Footnotes

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- **Promotion Group (AAEGRO)**
- **Africa Advocacy Foundation (AAF)**
- **African Institute for Social Development (AISD)**
- **African Equality Foundation**
- **African Health Policy Network (AHPN)**
- **Catholics for AIDS Prevention & Support**
- **Embrace UK**
- **Find Your Four**
- **French African Welfare Association (FAWA)**
- **House of Rainbow**
- **Organisation of HIV Positive African Men (OPAM)**
- **4M Mentor Mothers Network**
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