

# Lambeth Southwark and Lewisham HIV care and support service review

Who needs care and support and what is the  
best way to provide support?

September 2022



Lambeth Public Health  
Data analysis provided by Southwark Public Health



## Contents

1. Introduction .....	3
2. What do we know about people living with HIV in LSL? .....	4
a. Age of People Living with HIV (PLHIV) .....	5
b. Routes of transmission .....	5
c. Deprivation .....	6
c. Ethnicity .....	7
d. HIV treatment and viral suppression.....	8
2. Which groups of people living with HIV are most likely to need support? .....	9
a. Viral Suppression.....	9
c. Migrants .....	10
d. Other groups.....	10
e. METRO service current service users.....	11
3. What support do PLHIV and their family need? .....	11
a. 2020 Qualitative feedback from community HIV prevention providers and specialist HIV clinics.....	11
b. 2022 Qualitative feedback from community HIV prevention providers and specialist HIV clinics.....	12
c. 2020 Qualitative feedback from service users .....	12
d. 2022 Qualitative feedback from service users .....	13
e. 2022 Qualitative feedback from local residents not living with HIV .....	14
f. Qualitative feedback from other professionals working with PLHIV .....	14
g. 2022 Qualitative feedback from other professionals working with PLHIV .....	16
d. National Survey Findings.....	16
5. Overview of the current service and who is using it .....	18
a. Governance and structure of the Family Support Service and Positive People’s Network .....	18
b. Family Support Service.....	19
c. Positive People’s Network .....	20
5. Who else provides services for residents of LSL and therefore what support do we need to commission? .....	21
6. Evidence of what works to support PLHIV.....	22
a. Standards of Care for PLHIV .....	22
b. Peer support .....	23
7. Benchmarking against provision in other areas .....	23
7. Recommendations for an HIV care and support Service .....	24

## 1. Introduction

This report is to support the review of the HIV care and support service in Lambeth Southwark and Lewisham (LSL). It aims to address the following questions:

1. What do we know about people living with HIV (PLHIV) in LSL?
2. Of these people, who is most likely to need support?
3. What support do they need?
4. What works to support PLHIV?
5. What support is provided in other areas of London or other parts of the country? This includes benchmarking against other areas.
6. What other organisations provide services for PLHIV in LSL and therefore what support do we need to commission to fill any gaps?

The purpose of the HIV care and support commissioned service in LSL is to support people living with HIV (PLHIV) and their families to live well and to remain engaged with treatment services. Remaining engaged with treatment is important for the individual to live well as well as to reduce the risk of onwards transmission of HIV. PLHIV receiving appropriate and consistent medical treatment which reduces the viral load to undetectable levels are unable to pass the infection to others (U=U).

Thirty years on from the beginning of the HIV / AIDS crisis in the UK, knowledge and understanding of HIV has increased dramatically, bringing real advances in HIV treatment and prevention. An HIV diagnosis today means living with a long-term condition and HIV is no longer the fatal infection that it was 20 years ago.

But HIV is different from other long-term conditions because, unfortunately, HIV is not yet without stigma, although London is committed to reaching the Fast Track Cities target of zero stigma and discrimination associated with HIV by 2030. This stigma creates additional barriers and challenges for PLHIV to engage with - and remain engaged with treatment as well as to seeking or receiving support for other health conditions or non-health needs.

Unlike many other long-term conditions, HIV is an infectious disease, and so there is a risk to other people if an individual does not remain engaged with treatment (and therefore not U=U). For these reasons, there remains a need to provide a non-clinical care support service for PLHIV.

Local reports produced in the last two years can be used to help answer the above questions. In particular:

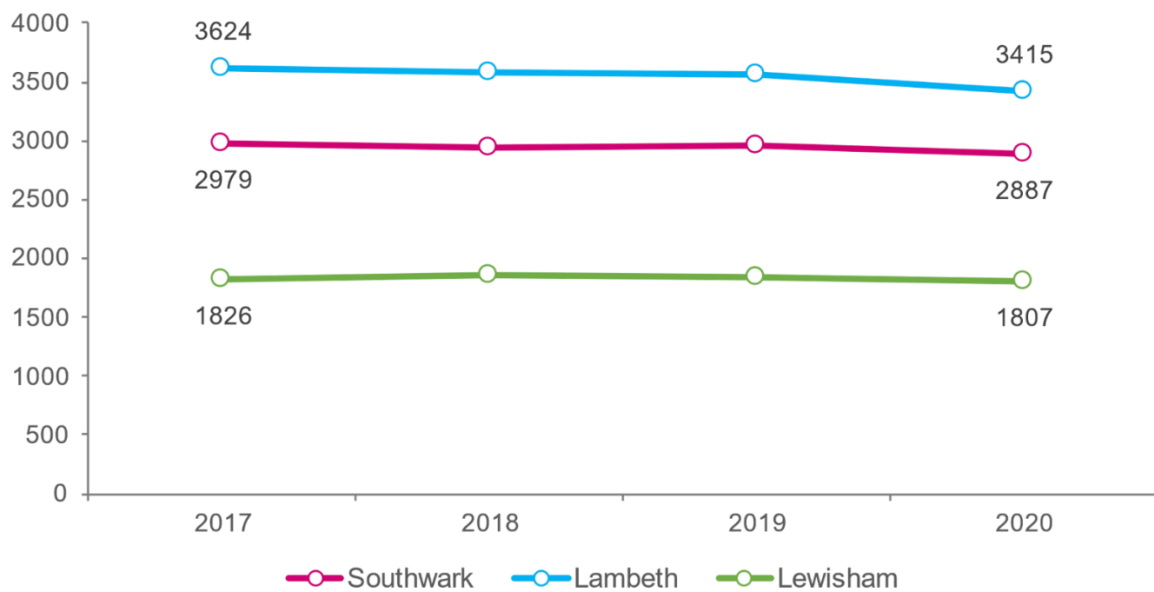
- HIV Joint Strategic Needs Assessment Lambeth, Southwark and Lewisham: HIV prevention. Sept 2019
- HIV Joint Strategic Needs Assessment Lambeth, Southwark and Lewisham: Experiences of Living with HIV in Lambeth, Southwark and Lewisham. Dec 2019
- Review of METRO service provision. February 2020.
- Lambeth, Southwark and Lewisham sexual health strategy intelligence briefing. March 2019

In addition, updated data was analysed and provided by the Southwark public health team.

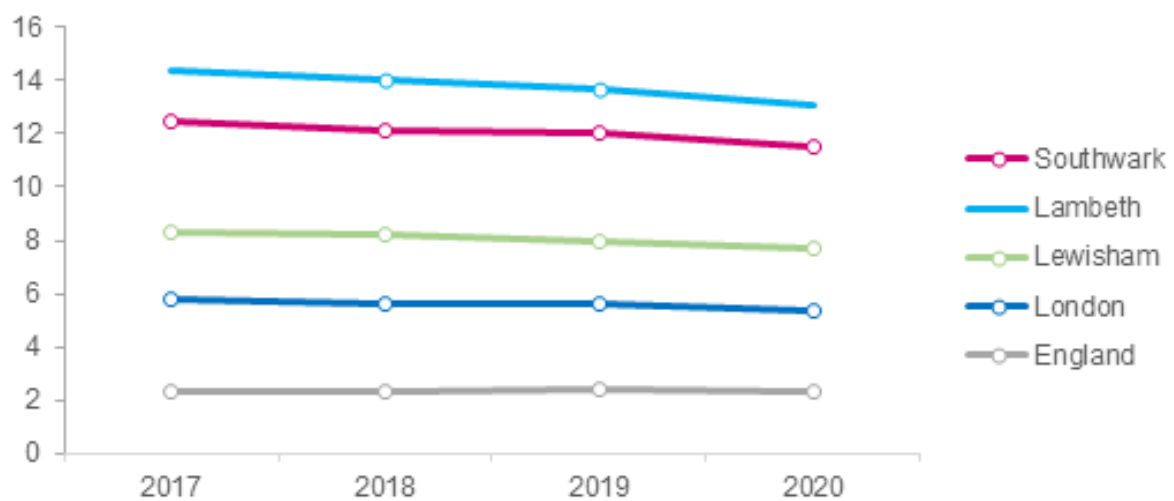
## 2. What do we know about people living with HIV in LSL?

The number of PLHIV in LSL has remained broadly similar (decreased very slightly) between 2017 and 2020 (**Figure 1**). In 2020 there were 8,109 PLHIV across the three boroughs. The diagnosed prevalence rate for all three boroughs is significantly worse (higher) than the London and England averages<sup>1</sup> although has decreased for all three boroughs since 2017 (**Figure 2**). The diagnosis rate of new HIV infections has decreased for all boroughs and the gap between the boroughs and London and England has narrowed<sup>2</sup> (**Figure 3**).

**Figure 1: Number of residents living with HIV and accessing care 2017 to 2020**  
(source: UKHSA HIV data tables)



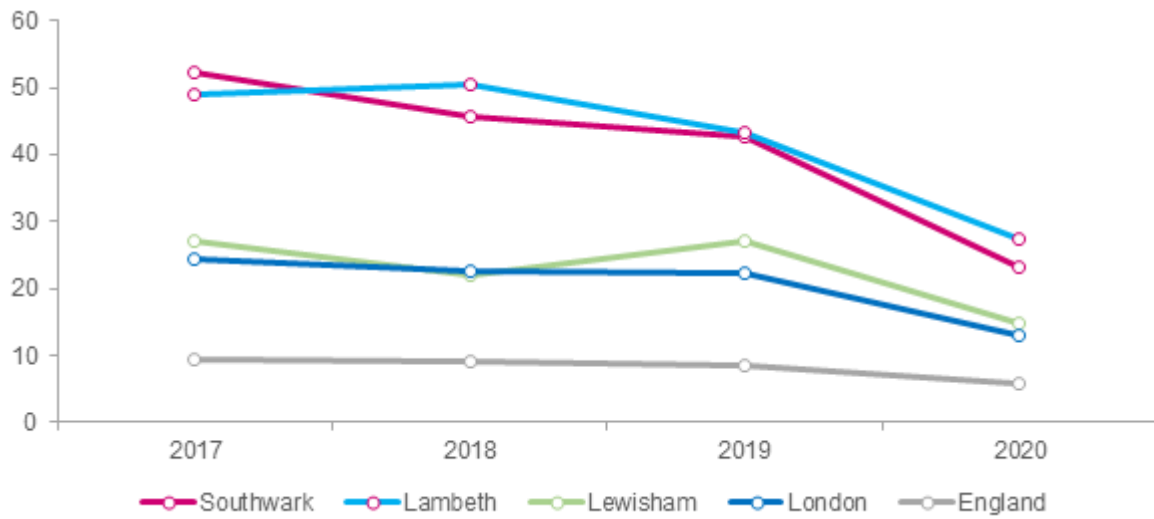
**Figure 2: HIV diagnosed prevalence per 1,000 people aged 15-59 years** (source OHID Fingertips)



<sup>1</sup> OHID Fingertips

<sup>2</sup> OHID Fingertips

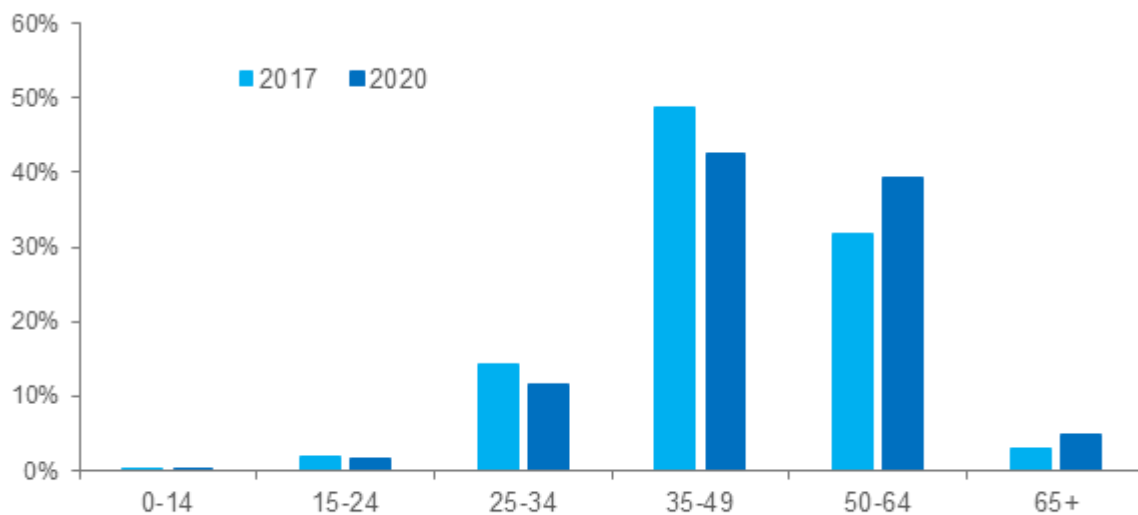
**Figure 3: New HIV diagnosis rate per 100,000 people aged 15+ years (source OHID Fingertips)**



**a. Age of People Living with HIV (PLHIV)**

Between 2017 and 2020 the number of individuals accessing care for HIV decreased in all age groups under 50 and increased among those aged 50 and over. Those aged 35-64 made up the biggest proportion of people accessing care in both 2017 and 2020 (**Figure 4**). While the numbers of people accessing care in the youngest and oldest age groups are proportionally smaller than other age groups, those people may face particular challenges requiring support to live well with HIV (see section 2 and 3).

**Figure 4: New diagnoses by age group (%) 2017 and 2020 (Source UKHSA HIV data tables)**



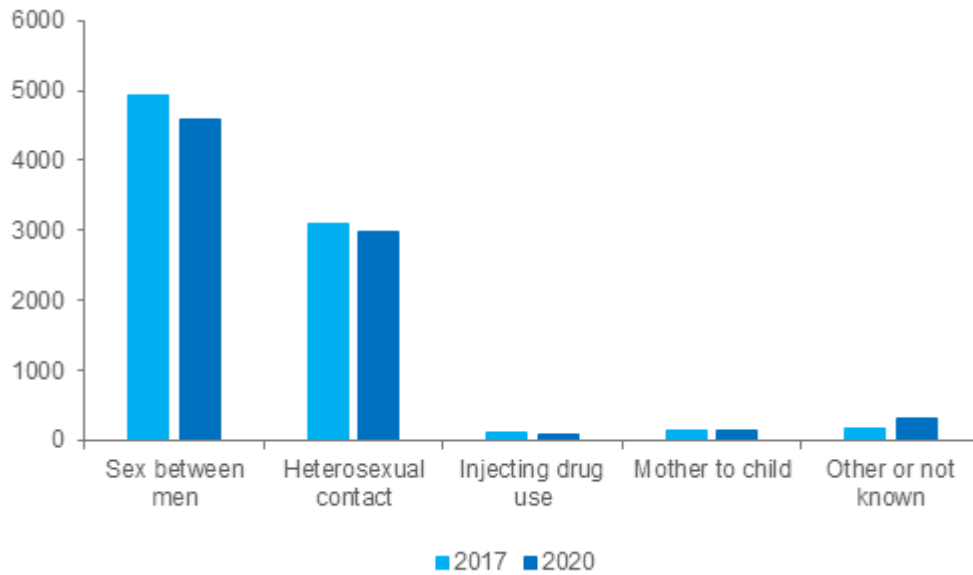
**b. Routes of transmission**

In 2020, as in 2017, the most often reported route of transmission of HIV was sex between men. The second highest is Heterosexual contact. When looking at new diagnoses, the number of new diagnoses in LSL has reduced considerably between 2017 and 2020 and the

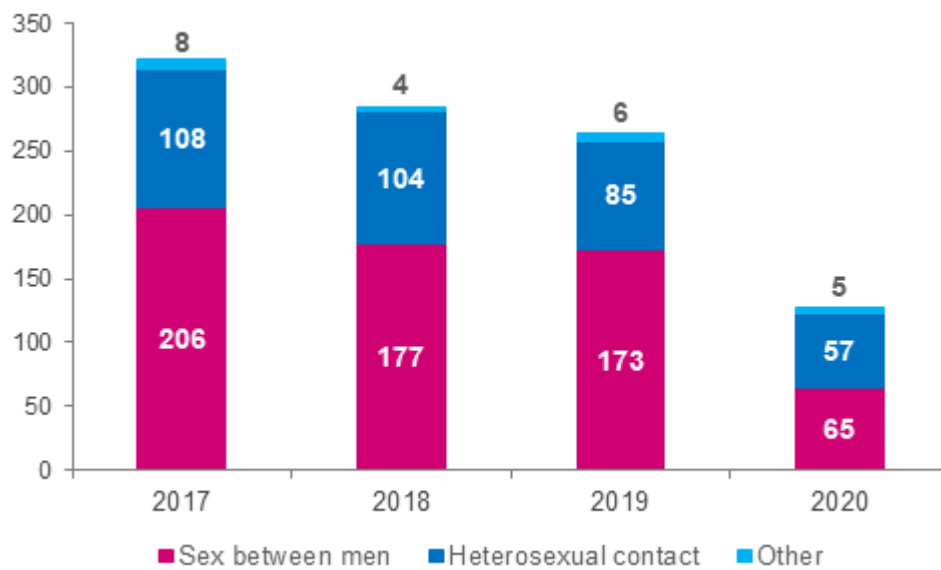


proportion where the probable route of transmission was sex between men has reduced from 64% to 51% (Figure 6).

**Figure 5: Number of residents with diagnosed HIV and accessing care by probable route of transmission across LSL 2017-2020 (Source: UKHSA HIV data tables)**



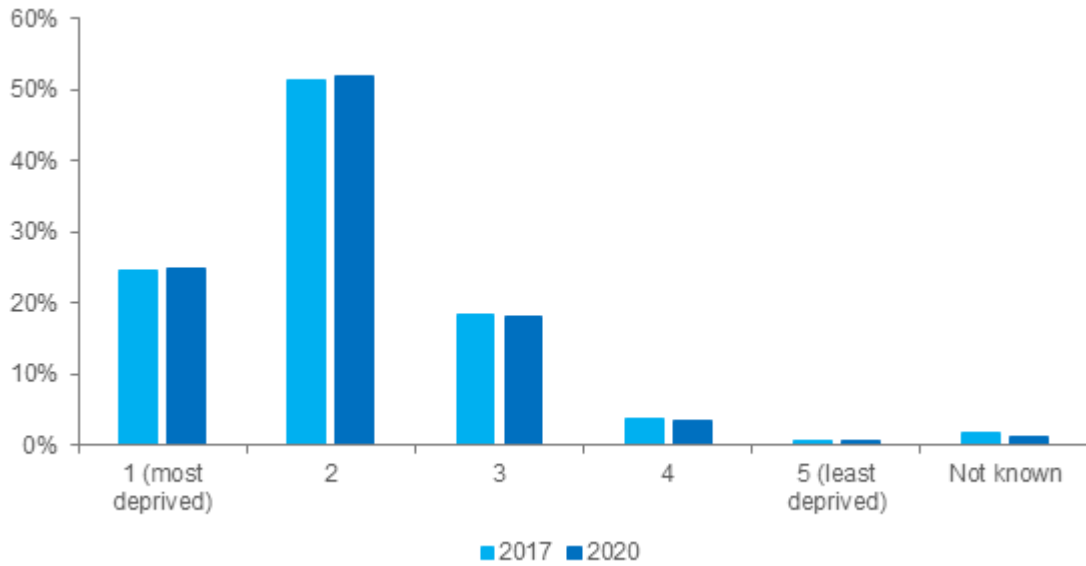
**Figure 6: Number of new HIV diagnoses in LSL by exposure type, between 2017 and 2020 (Source: UKHSA HIV data tables)**



### c. Deprivation

In both 2020 and 2017, the highest proportion of residents seen for care lived in areas ranked in the second most deprived area of LSL; the second highest proportion lived in the most deprived areas.

**Figure 7: Percentage of residents seen for HIV care by Index of Multiple Deprivation LSL 2017-2020 (Source: UKHSA HIV data tables)**



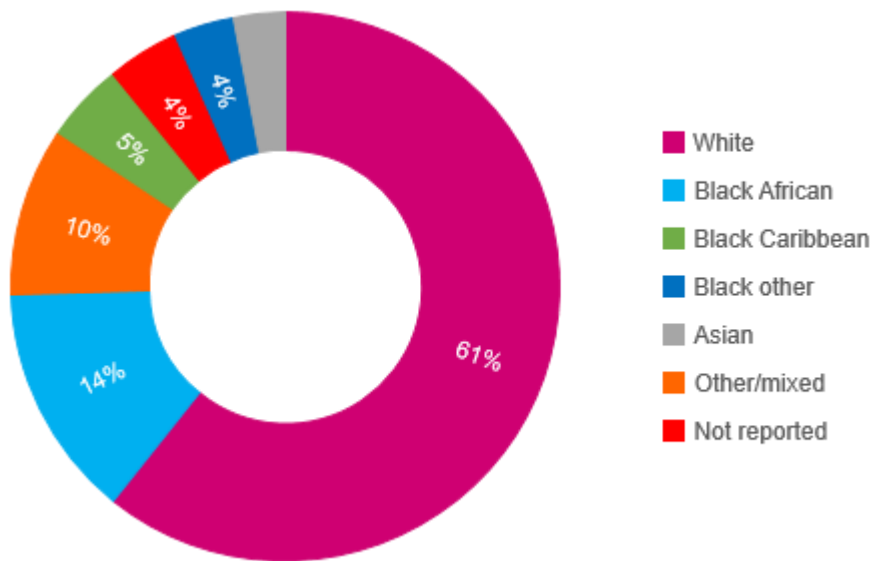
**c. Ethnicity**

When looking at the ethnicity of PLHIV for 2017-2020, we need to consider males and females separately. In males, 61% of the 6,076 LSL residents accessing HIV care were of White ethnicity; the second highest proportion, at 14%, is of Black African ethnicity (Figure 8). Among females, however, 64% of the 1,971 LSL residents accessing HIV care were of Black African ethnicity. This suggests that, while HIV services need to be accessible and appropriate for males and females of many different ethnicities, some groups may need more support.

**Figure 8: Proportion of all diagnosed HIV cases seen for care by sex and ethnicity in LSL, 2020 (Source: UKHSA HIV data tables)**

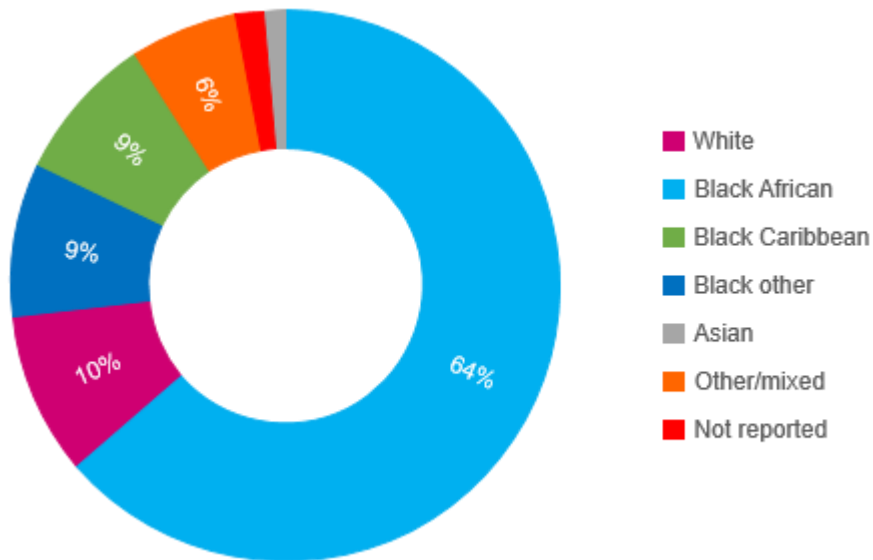
**Male**

**N= 6,076**



## Female

N= 1,971

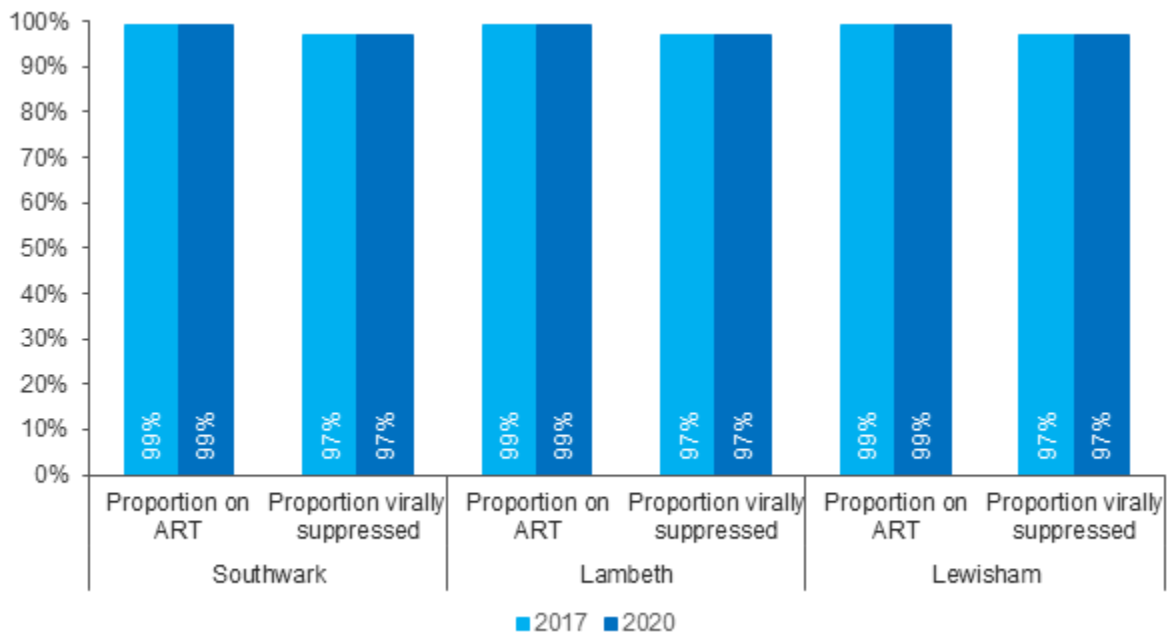


### d. HIV treatment and viral suppression

In each of the three boroughs, 99% of HIV-positive residents were receiving antiretroviral therapy (ART) in both 2017 and 2020 and 97% of HIV-positive residents were virally suppressed (ie, with a viral load too low to pass on the infection).

(Figure 9). This data, however, does not clearly show if some (or any) groups are less likely to be virally suppressed and therefore more in need of HIV care and support.

**Figure 9: Proportion of HIV positive residents on ART and proportion virally suppressed by borough 2017 and 2020 (UKHSA HIV data tables)**





The data in this section should be considered alongside other sources of information within this report and elsewhere (e.g., survey and focus group feedback). The data we have suggests that HIV services should aim to provide support for:

- people of all ages, given that needs may vary by age group,
- those who are living in the two most deprived areas of the boroughs,
- heterosexual men and women, as well as men who have sex with men,
- males and females of all ethnic backgrounds, noting the particularly high prevalence among females of Black African ethnicity and males of White ethnicity. This needs to be considered alongside information about groups most in need of support.

## 2. Which groups of people living with HIV are most likely to need support?

Many PLHIV will not need non-clinical care and support; others will.

Some indicators (including not being virally suppressed, late diagnosis, not fully engaging with treatment) might be helpful suggesters of the people who need more support. Therefore looking at which groups of people have these indicators can help us target services.

Some of the data on these issues is from national data collections and, while this is useful, it is important to consider that the characteristics of the population of LSL differs from the national population - so not all national data is relevant to the LSL setting.

### a. Viral Suppression

Nationally in 2020 it was estimated that 9% (8,800) of the estimated 97,740 (95% CrI 96,400 to 100,060) PLHIV in England had transmissible levels of virus, e.g., were not virally suppressed / U=U.<sup>3</sup> This was due to being undiagnosed (24%); diagnosed but not receiving specialist care (37%); in care but not receiving treatment (6%); or on treatment but not virally suppressed (9%). For the remaining 24% there was no data on viral suppression.

In 2020, national data<sup>4</sup> showed that viral suppression was lower in:

- Younger age groups (under 25 years)
- Intravenous (injecting) drug users
- Vertical transmission groups (infection passed on from mother during pregnancy)
- People of Black ethnicity

In addition, viral suppression is lower among migrant groups (39% of migrants diagnosed with HIV had previously been diagnosed abroad. Data from 2018 shows that among migrants born and previously diagnosed abroad, 36% did not access care within one year of their arrival in the UK and 46% received a late diagnosis at the time of their first HIV positive test in the UK<sup>5</sup>)

This suggests that people from these groups may be more likely to need HIV care and support.

### b. Late Diagnosis

---

<sup>3</sup> [HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report \(publishing.service.gov.uk\)](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/91111/hiv-testing-new-hiv-diagnoses-outcomes-and-quality-of-care-for-people-accessing-hiv-services-2021-report.pdf)

<sup>4</sup> [HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report \(publishing.service.gov.uk\)](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/91111/hiv-testing-new-hiv-diagnoses-outcomes-and-quality-of-care-for-people-accessing-hiv-services-2021-report.pdf)

<sup>5</sup> O'Halloran C, Sun S, Nash S, Brown A, Croxford S, Connor N, Sullivan AK, Delpech V, Gill ON. (2019). HIV in the United Kingdom: Towards Zero 2030. Public Health England, London, <https://assets.publishing.service.gov.uk/government/uploads/>

In 2020, 42% of new diagnoses made in England were late. This was higher in heterosexual men and women (55% and 51% respectively) compared with 29% among gay and bisexual men. The percentage of new diagnoses made late increased in higher age groups. Late diagnoses were also higher in women (51%) than men (38%), in those of Black African ethnicity (54%).<sup>1</sup>

Qualitative feedback from local needs assessments<sup>6</sup> reported that Clinical Nurse Specialist (CNS) teams engaged with some particularly vulnerable groups, including older people who are housebound, those living in hostels or temporary accommodation, and those whose mental illness may prevent them engaging in care. CNSs also reported that more resource was needed to reach all the people in need. The health inclusion team (HIT) also reported engaging with PLHIV who were homeless and supporting them with taking blood samples and supplying ARV medication. This suggests that people from these vulnerable groups are more likely to need support from a Care and Support service, and may also need additional services to enable them to remain fully engaged with care.

### c. Migrants

Qualitative feedback from the voluntary and community sector<sup>3,4</sup> supported the need for support for migrants, describing migrants' concerns around data sharing or having to pay for treatment.

The [National AIDS Trust on HIV and Migration](#) explored the difficulties and barriers faced by those born in another country and made a number of recommendations. Two of the recommendations were directed to HIV support services:

- *'Tailored mental health, housing, welfare and financial support services should be prioritised for migrants living with HIV, and support services should consider how they can remove barriers to access for migrants.'*
- *'Tailored services for migrants should be culturally specific and include paid participation by migrants where possible (this may be difficult due to restrictions on right to work for many migrants).'*

A recommendation for commissioners was that commissioners and providers should work with local community-led organisations to ensure better co-delivery of services that can effectively address HIV stigma.

A further recommendation for integrated care systems (ICSs) was that psychological support should be based within HIV clinical services, with simple referral pathways and co-working between HIV services, local voluntary sector services, and mental health services in the area.

### d. Other groups

Feedback from community HIV prevention providers and specialist HIV clinics<sup>6,8</sup> found that people experiencing homelessness, IV drug users or asylum seekers were particularly vulnerable to disengaging with treatment.

Prisoners were also described as a group at particular need. Support for this group of people, however, is beyond the scope of this care and support service.

---

<sup>6</sup> Experiences of living with HIV in Lambeth, Southwark and Lewisham. Exploring stigma and barriers to accessing HIV treatment and support services. Southwark Council. December 2019

Although the numbers are relatively small compared with other age groups, there are small numbers of children and young people in LSL living with HIV. Children and their families may need particular support to live well with HIV.

#### e. METRO service current service users

A review of METRO services published in February 2020<sup>7</sup> found that the family service was largely accessed by heterosexual females, aged 36-45. Just over three quarters of clients were of Black African ethnicity.

Clients accessing the Positive People's network were 57% female, 83% heterosexual, 86% aged over 36 years. 63% of clients were of Black African ethnicity.

### 3. What support do PLHIV and their family need?

People who are living with HIV and are also experiencing more complex life circumstances (for instance mental health problems, intravenous (IV) drug use, seeking asylum, other long-term health issues, and/or social issues) seem to be particularly vulnerable to not keeping to their treatment or following up on support. For these individuals, taking anti-retroviral treatment (ARTs) may be lower on their priority list than other issues.

#### a. 2020 Qualitative feedback from community HIV prevention providers and specialist HIV clinics<sup>7</sup>

A review of the HIV service in February 2020 highlighted that:

- Service users of Black, Asian and Multi-Ethnic backgrounds reported that it was important that the service reflected and/or included their culture partly due to stigma in some communities. Service providers and clinics felt that Black African females were particularly impacted by stigma.
- HIV clinic staff reported that many patients who did not follow up on HIV treatment had mental health issues. Mental health was therefore felt to be a significant cause of lost patients, and the mental health specialists working with HIV individuals are vital.
- Logistical issues may cause delays in patients attending their initial appointment in the HIV clinic.
- Patients may not feel ready to commence HIV treatment when first offered it in the HIV clinic – this is particularly true where people are diagnosed with HIV via a screening for another medical issue.
- Patients still frequently don't consent to their GP knowing they have an HIV diagnosis.
- Complex personal problems (including social and mental health) may limit a person's ability to continue coming for treatment.
- Patients may not engage with Partner Notification. (Supporting people who have been diagnosed with a sexually transmitted infection (STI) to notify their partners can help to prevent reinfection and reduce the transmission of STIs. It can also ensure that their partners are tested, and if necessary treated, as soon as possible to prevent health complications).
- Some clinic outreach services target care to complex cases of HIV they know need extra support.
- Some individuals will not divulge their HIV diagnosis to family/friends because of concerns around how they will be perceived; this leads to them either not continuing treatment and care or visiting HIV clinics far from home to reduce the risk of seeing anyone they know.
- There is a need for highly accessible 1:1 peer support attached to clinics.

---

<sup>7</sup> METRO services review, February 2020.

## b. 2022 Qualitative feedback from community HIV prevention providers and specialist HIV clinics

After three years of the Covid pandemic, it was necessary to re-engage stakeholders in the review of the service. Here are some insights:



08.22 - End of



08.22 - Lambeth



08.22 - Lambeth

Read full reports here: [Online Consultation](#) [Southwark and Lew](#) [Southwark and Lew](#)

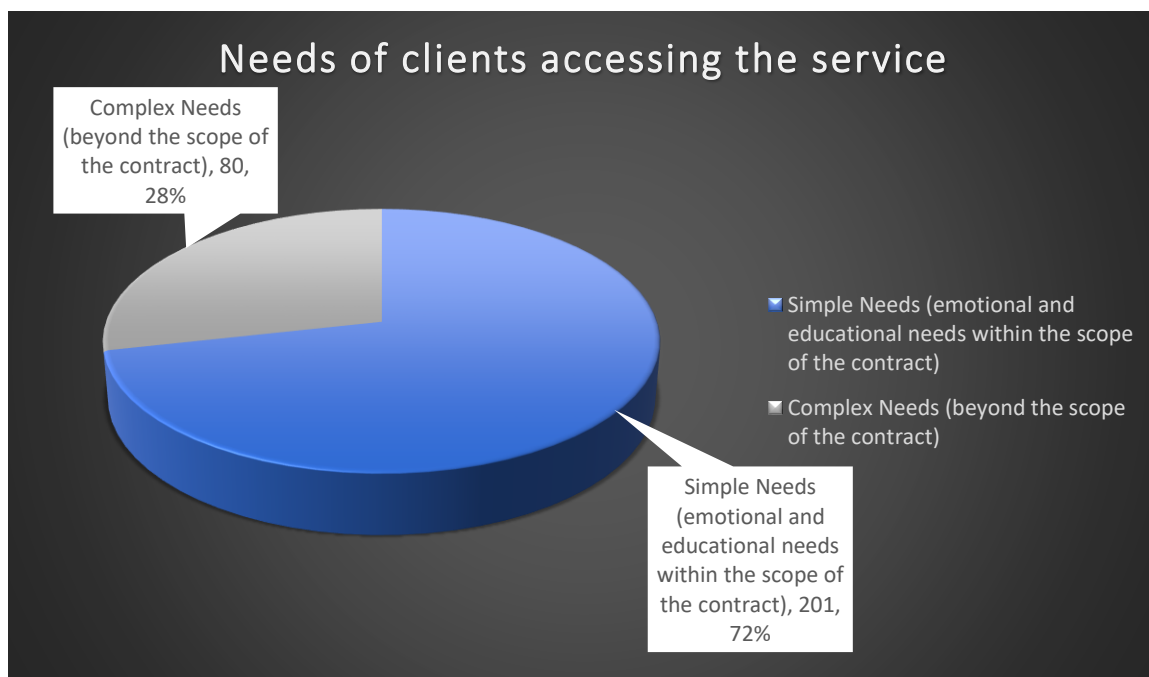
## c. 2020 Qualitative feedback from service users<sup>8</sup>

A review of the service in February 2020 highlighted that:

- Some heterosexual women from Black, Asian or Multi-ethnic backgrounds felt that not all clinicians understood their cultural or religious context. It is therefore important that a care and support service offers support with genuine understanding of cultural background. Some Black heterosexual women felt that they were well supported by their current provider because they could attend a women's-only group where they met people similar to them. They felt there was an understanding of their culture and the challenges facing them. However, some reported it difficult to find an appropriate community and voluntary sector (CVS) support group and that they did not always feel comfortable in groups with LGBTQ+ PLHIV.
- Some PLHIV reported being unable to attend clinics because they couldn't afford the bus/tube fare. [Note, this review was in 2019 and the current cost of living crisis is likely to have made the cost of travel more unaffordable for some]
- Some service users wanted text message reminders for appointments and were concerned that the clinic would not contact them if they missed an appointment.
- The majority of service users (n=19) mentioned that CVS support services were a major source of community and peer support. A small number commented that no family or acquaintances outside of support services knew about their status. One said that attending the current service had stopped his loneliness and improved his depression.
- Many service users (n=12) said that they found it difficult to access CVS support services due to irregular opening hours, lack of local services and inability to pay for transport to attend meetings.
- Some mothers (n=4) said that they were unable to access all the support they needed due to lack of access to childcare.
- A peer support service attached to clinics was felt to be useful.
- Many PLHIV find self-imposed stigma to be an issue. Lack of disclosure to families, healthcare providers and employers is common, with many fearing the impact of revealing their status. Some asked for more help in knowing what to say when disclosing.<sup>8,6</sup>

---

<sup>8</sup> HIV Joint Strategic Needs Assessment, Lambeth, Southwark, Lewisham. HIV Prevention Sept 2019



This information is not monitored as part of registration forms, KPIs or other behaviour change surveys, but is collected and collated through client notes and other formal and informal discussions. Although the disaggregation is not scientific, the majority of clients (201 of 281/ 72%) have been designated as having simple needs within the scope of the contract and provided services. However, 80 (28%) clients with more complex needs required additional support within or outside of METRO's Positive People Network (PPN).

#### d. 2022 Qualitative feedback from service users

After three years of the Covid pandemic, it was necessary to re-engage stakeholders in the review of the service. A survey was put on Lambeth, Southwark and Lewisham council consultation websites. 77 responses were received to the survey aimed at people living with HIV and their families (26 stated that they were from Lambeth, 26 from Southwark and 18 from Lewisham).

- More men than women responded to this survey (58% as compared to 42%).
- The largest single group of responders (36%) were aged 45-54.
- 35% of respondents described themselves as Black or Black British (African), with 30% describing themselves as White British.
- 82% stated that they had a disability or long-term health condition.
- 46% identified as heterosexual, 46% as gay.

Due to the relatively small sample size, a brief summary of responses is provided:

- Of those who responded, just under 80% said they had needed help from local non-clinical care and support services in the last 12 months. The most frequently used services were 'advice about health and wellbeing' (49%), 'I needed someone to advocate on my behalf' (44%), 'advice about housing' (41%) and 'I wanted to meet other people/families in a similar situation to mine' (41%). Of those who answered the question 'If the service didn't exist, what would you have done?', 35% said 'nothing', whilst 32% said they would search for local organisations which supported their needs. 47% of respondents said they had accessed the service more than five times in the last 12 months with the majority of those saying they had accessed the service in person, and that the staff were 'extremely' or 'very' helpful.

- Of those who responded, the largest single group (31%) said that they or a member of their family had first accessed care and support services straight away, after diagnosis. 88% said that they were able to use the service at the time and day that it was needed. Where services were not used, 46% of respondents said it was because of lack of information.
- The most well-used services were 'counselling' (58%), 'advocacy' (58%) and 'empowering people to have confidence, take personal control and choice in managing their sexual healthcare and service use' (54%).
- 55% of respondents had heard of the METRO Charity, 35% had heard of the African Advocacy Foundation, 35% had heard of Catholics for AIDS Prevention and Support, whilst 31% had not heard of any of those agencies. Other support agencies mentioned included 'addiction support and mental health services', 'Terence Higgins Trust', 'Citizens Advice', 'Body and Soul'.

#### e. 2022 Qualitative feedback from local residents not living with HIV

Residents' views and feedback were not included in the 2020 review, but were included in the recent consultation, particularly to measure stigma. 64 respondents took the survey (39 stated that they were from Lambeth, 11 from Southwark and 9 from Lewisham and four stated that they lived elsewhere).

- Approximately equal numbers of men and women responded to this survey.
- The largest single group of responders (31%) were aged 45-54.
- 37% described themselves as White British, 20% Black or Black British (African) and 13% Black or Black British (Caribbean).
- 64% stated that they did not have a disability or long-term health condition.
- 52% identified as heterosexual, 26% as gay, whilst 11% preferred not to say.
- 72% of responded said they knew someone living with HIV, resident in Lambeth, Southwark or Lewisham. Roughly the same percentage (52% as opposed to 48%) were aware of non-clinical care and support services for people living with HIV and their families. Priority services included 'advice about health and wellbeing' (81%), 'sex and relationship health advice' (74%) and 'counselling for mental health' (74%). The largest single group of respondents (80%) thought that services should be provided in NHS clinics.
- Awareness of METRO Charity, African Advocacy Foundation and Catholics for AIDS Prevention and Support was lower than for those living with HIV and their families, with 50% of respondents saying they had not heard about any of the organisations.

#### f. Qualitative feedback from other professionals working with PLHIV

The review of the service in February 2020<sup>7</sup> highlighted that:

- Services to support patients – particularly those from very vulnerable groups such as homeless people and sex-workers – with attending appointments and engaging with treatment, was very important. In some cases, professionals took blood samples from clients who were unwilling to go to clinics. While this is beyond the scope of the care and support service, it demonstrates the need for support and suggests that a care and support service should be closely linked other clinical support services.
- One Clinical Nursing Service (CNS) team reported spending a significant amount of time providing welfare, immigration, physiotherapy and housing support to the most vulnerable and expressed an urgent need for more specialised support.



- Some CNS reported needing to provide phone reminders for appointments for PLHIV who cannot read appointment letters in English.
- Emotional and mental health support for PLHIV who do not meet referral criteria for specialist mental health services provided by South London and Maudsley Trust needs to be provided.
- Increased access to specialist mental health support is needed. Some of the most vulnerable PLHIV need mental health support but do not qualify for South London and Maudsley support. However, due to the sometimes chaotic nature of their lifestyle, they may have been discharged from generic mental health services.
- Community and Voluntary Sector (VCS) providers expressed concern that some male heterosexual PLHIV are not receiving any form of community support. Some CVS service providers said that they have always struggled to reach male heterosexuals, despite multiple attempts over the years.
- A large number of providers said that they felt there were not enough CVS support services for older people, who often need additional support relating to complex issues including loneliness, poor mobility and co-morbidities (both HIV and another serious illness).
- Some service providers (n=5) expressed concern that some male heterosexual PLHIV are not receiving any form of community support. Some CVS service providers (n=3) said that they have always struggled to reach male heterosexuals, despite multiple attempts over the years.

Quotes from stakeholder engagement <sup>3,4</sup> illustrate the types of challenges and extent of need

'Honestly, sometimes I feel overwhelmed because I know if I wasn't in this person's life they wouldn't take ARVs or engage in any healthcare.' - **HIV Clinical Nurse Specialist**

'So many people on my caseload don't speak or read English well. I have to pick up their letters from their house and put the appointment dates in my diary. I then have to ring them on the day to remind them. It would be ok if I had just a few of these, but it is becoming more and more common...many of them have no family to accompany them so I sometimes have to take them to the clinics myself.' - **HIV Clinical Nurse Specialist**

'When you are homeless you just need a doctor to come to you and say you are worth caring for...'

- **Service user (White MSM, aged 30-40)**

'How can I get a young sex worker who gets paid five pounds for sex by some man who doesn't care about her to take ARVs to protect him?'

- **Health Inclusion Team Member**

'When you are on the streets all you can think about is stopping your stuff getting nicked or whether someone is going to piss on you tonight...not whether you have taken your meds. I got my meds nicked so many times, how could I take them then?' - **Service user (White MSM, aged 30-40)**

- 'It can be lonely, often everything is aimed at young sexually active people, nothing for older people. There used to be!'
- 'It's very depressing not being able to come out and let your relatives know about your diagnosis.'
- 'People don't know what life means with HIV. In my community you will be put down or they will not speak to you if they know. I need the friends I have in my group who understand what I have to do and advise me.'

Others valued the support:

- 'Peer support in groups helps me in my life and supports not just me but my children as well.'
- 'Support in groups and our retreat weekend have been really important for me.'

Suggestions for provision of care and support services included:

- 'Just don't ignore faith issues even if this leads to difficult tensions or interceptions.'
- 'Please sustain the funding for these services, things are really bad for a lot of us because of the crisis.'
- 'More promotional work needs to be done for people to know about and access the already limited services available to them.'

The previously conducted needs assessments<sup>6,8</sup> concluded with the following points of what is needed from a care and support service:

- 'One-stop-shop' HIV clinics - welfare support workers, peer support workers and mental health services available in all HIV clinics.
- HIV consultants and specialist nurses must be able to signpost all PLHIV to support services in clinics.
- Integrate welfare support into community HIV CNS teams to provide information on income benefits, housing and immigration.
- With an ageing HIV population in the UK, older PLHIV may need support accessing physiotherapy and occupational therapy. There are also increasing issues relating to poor access to housing for older PLHIV, which prevents them from socialising with their friends and family and accessing clinics.
- Peer support integrated into community CNS teams may help with appointment reminders, accompanying vulnerable PLHIV to clinics and providing social support to the most vulnerable.

#### g. 2022 Qualitative feedback from other professionals working with PLHIV

- 'It would be beneficial for residents to know more about the services offered. I don't!'
- 'I have witnessed first-hand the impact of withdrawing support services for people with HIV. The social aspects of living with HIV cannot be underestimated and without those being addressed, the medical outcomes will undoubtedly be poor.'
- 'Non-clinical HIV care and support services are absolutely vital in helping people living with HIV to come to terms with their diagnosis and engage with HIV services to effectively treat their long-term health condition.'
- '...commissioners need to be aware and understand the extraordinary value they get from volunteer HIV care and support service providers. In terms of workload and giving grants to people, they greatly help to reduce the pressures that commissioners and the NHS services have.'

#### d. National Survey Findings

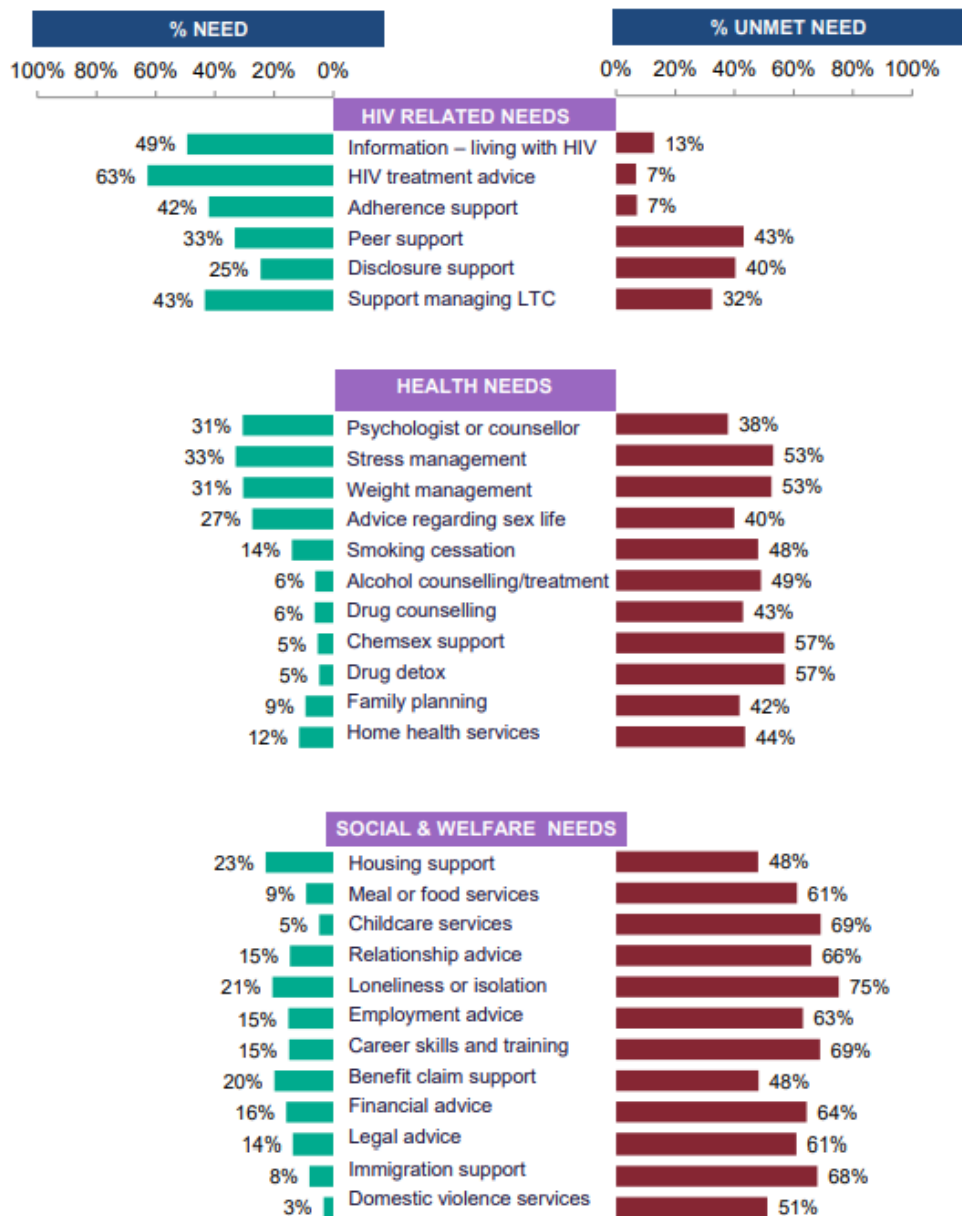
[Positive Voices](#) is a national survey of PLHIV run in partnership between [The UK Health Security Agency \(UKHSA\)](#) (previously PHE), University College London and Imperial College London.<sup>7</sup> The survey fieldwork is currently being conducted, with results expected later in 2022. While this will report on experiences of PLHIV across the country, and not specific to LSL, the findings are still of use. Key findings from the previous survey round, conducted in 2017, show that mental ill health was a primary concern among people with HIV, who are also more likely to experience mental ill health compared with the general population. Over 1 in 3 (37%) people with HIV were diagnosed with a clinical mental health disorder in their lifetime. Around half (49%) of people with HIV reported symptoms of depression and anxiety on the day of the survey; much higher than in the general population (30%).<sup>5</sup>

The unemployment rate among people with HIV was 14%, more than triple the 4% unemployment rate in the general UK population during the same period. This is despite people who participated in the survey being highly educated<sup>5</sup>.

Financial difficulties were common; over half (53%) of those living with HIV did not always have enough money for their basic needs (such as food, rent, gas, electricity) and almost a third (30%) had fallen behind with some or all of their bills. One in 4 (28%) were in receipt of at least one form of means-tested welfare benefit and 15% were in receipt of a disability benefit.<sup>5</sup>

Survey participants were asked about using or needing 29 different types of HIV, health and social services in the previous year. Common health-related needs were stress management (33%), psychologist or counsellor (31%), weight management (31%) and help or advice regarding their sex life (27%). The greatest social and welfare needs were for housing support (23%), help dealing with loneliness and isolation (21%), and help claiming benefits (20%). The greatest unmet need was for help dealing with loneliness and isolation: 75% of those who asked for this help did not receive it. Similarly, 69% of the people needing career skills and training and 63% asking for employment advice did not have their needs met. Their needs were also unmet for weight management (53%), stopping smoking (48%) and peer support or social contact with other people with HIV (43%). In contrast, the areas where the needs of people with HIV were mostly met included: HIV treatment advice (93% of need met), HIV treatment support (93% of need met), and information about living with HIV (87% of need met).<sup>5</sup>

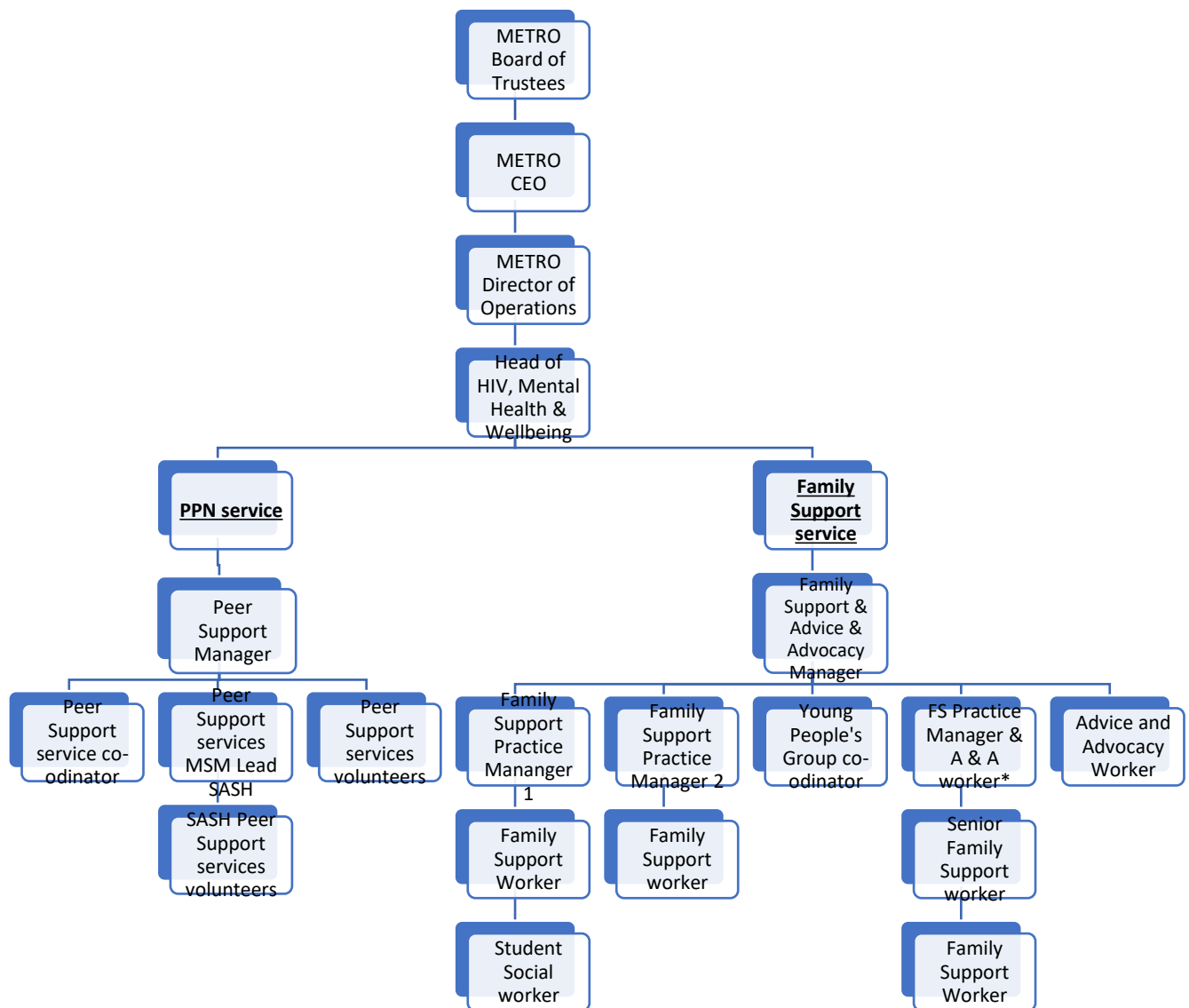
**Figure 1: Met and unmet HIV, health, social and welfare needs of people living with HIV**



Source: Positive Voices<sup>5</sup>

## 5. Overview of the current service and who is using it

### a. Governance and structure of the Family Support Service and Positive People’s Network



## b. Family Support Service

The main reason that families accessed the Family Support service was for emotional support, followed by holistic family support, then advice and advocacy.<sup>4</sup> The report found that 79% of service users were experiencing a mental health issue and 21% reported a physical health issue. The report concluded that clients had varied needs including domestic violence, religious complications, divorce and struggling with single parenthood. The primary interventions that clients access the service for were Advice and Advocacy, emotional support, and support with improving or maintaining mental well-being. The report noted that the service does not disaggregate different needs of clients but provides a holistic support programme for clients.<sup>4</sup>

The report also emphasised that many clients required support for financial hardship, with a significant number stating that they are unemployed or giving no indication of employment status, and many clients had no recourse to public funds. For these service users METRO either provides necessary support or signposts to organisations in which clients' HIV status would not be a barrier to accessing support.<sup>4</sup>

The Family Support service is child/young person focused. However, it is for the benefit of the whole family. METRO works with families where a child under the age of 18 or young person under the age of 25 is living with or affected by HIV.

The team provides support to individual families often within their own home. The service has qualified social workers conduct holistic assessments with each family and then form a plan together of what the support will look like. This can range from helping families with key HIV issues/needs such as:

- Adherence to HIV medication and beliefs around this
- Psychological support to come to terms with HIV stigma and how to talk about issues within the family
- Mental health and emotional support in order to cope with diagnosis and HIV disclosure issues within the family
- Help with testing and treatment of children with HIV
- Dealing with social isolation
- Children's educational needs
- Family breakdown issues due to HIV status/diagnosis
- Support around domestic violence.

The programme consists of these main areas of support:

- Building positive relationships with children and young people living with or affected by HIV
- Working closely with parents and carers to meet the children's/young people's needs
- Offering advice and assistance to parents/carers in a way that encourages independence and confidence
- Providing **one to one** individual tailored family support provided in people's homes from a family support practitioner. A Practice manager and family support worker will share the interventions involved in the individual family support plan of work.
- Outreach sessions in HIV clinics, providing a mixture of family support, group support and one to one referral/assessment sessions in a range of South London clinics, including:
  - Harrison Wing at Guy's and St. Thomas's NHS Trust
  - Alexis Clinic at Lewisham and Greenwich NHS Trust
  - Caldecott clinic at King's College NHS Trust
- Group work support through referral into a parent's group and young people's group
- Signposting and networking with other support agencies such as IAPT, Citizen's Advice Bureaus, local council housing departments, immigration advice and support, benefits, debt and welfare advice, group work and counselling support.

### c. Positive People's Network

The programme consists of three main support agencies partnering to deliver the LSL Peer support contract. These are:

- METRO, focusing mainly on the needs of all people living with HIV in the three boroughs through delivery of its HIV positive wellbeing group work programme and mentoring scheme, and the needs of gay men living with HIV, through its range of groups.
- AAF (Africa Advocacy Foundation), based in Catford, focusing mainly on the needs of African people living with HIV and providing a range of support activities and groups, including a Muslim faith group.
- CAPS (Catholics for AIDS Support and Prevention), based in Stockwell, and delivering a range of faith-based support groups which are open to people of all faiths.



The pre-Covid monthly programme of the PPN is detailed below:

1. **METRO HIV positive wellbeing hub group** – a group for all people living with HIV to come to a mixed group and talk about health and living with HIV. The group decide the topics that they want to focus on, and outside speakers are invited to facilitate a discussion. Meets monthly at METRO Vauxhall Offices.
2. **METRO +PALS group for MSM** – meets twice a month on a Wednesday and Saturday. This is a group that meets for peer support in a range of external venues, focusing on external activities, e.g., theatre, watching a film, doing a creative workshop and also has outside speakers facilitate topics. Meets twice a month.
3. **Africa Advocacy Foundation: Group for Africans living with HIV** - Meets once a week at AAF in Catford. The group provides a rolling programme of support with outside speakers and facilitated discussions. AAF also provides a monthly group for people from the Muslim faith discussing topics that are HIV related, but from an integrating faith perspective.
4. **CAPS** – CAPS runs groups every two weeks, in a range of locations, and provides a summer residential which clients can access. CAPS monthly drop-in group is open to people of all faiths. A Positive Catholics group for people of faith is run once a month.
5. **METRO Positive Mind groups** – Meet in six-week cycles with six groups per year and with holiday time built in. These groups are for people with issues around low mood, depression and stress. Delivered in deliberately small groups so that they can go in depth together. Facilitators use techniques from CBT and mindfulness to teach in an empowering way.
6. **METRO parents' group** – This group meets once a month and is a support group for parents living with HIV in LSL. It meets frequently at external venues, as well as METRO Vauxhall.
7. **METRO young people's group** – Meets twice a month and is a group for young people living with and affected by HIV. The group has an alternating workshop element, and a social element. The group meets at METRO Vauxhall, as well as a Church venue in Tooting Bec.

Individuals accessed the Positive People's Network for a wide range of reasons. The most common were food insecurity, mental health, invisible disabilities, immigration issues, welfare, co-morbidities (another chronic illness as well as HIV) and social isolation. Client needs are often complicated, and some clients required support in more than one area. LSL clients accessed the services for reasons split evenly between:

- to improve their knowledge (24%) or increase confidence related to living with HIV (24%),
- improve their physical and emotional well-being (26%) and
- meet others living with HIV (26%).

This data implied the need for a broad approach in the HIV services provided for clients living in LSL.<sup>4</sup>

5. Who else provides services for residents of LSL and therefore what support do we need to commission?

As outlined in the HIV prevention needs assessment,<sup>4</sup> there are a range of non-clinical support services for PLHIV in LSL from providers including HIV clinics, South London and Maudsley, VCS providers and with a range of funding arrangements including local authority public health, Elton John Aids Foundation, Fast Track Cities, and, in future, the ICS. Due to this variety of provision, funding and therefore capacity across LSL, not all PLHIV in LSL will be accessing the same type or extent of support.

Given the difference in provision by NHS trusts, it is important that a service is commissioned for all PLHIV resident in LSL.

Conversations with three HIV consultants as part of this review found that non-clinical care and support was highly valued by the clinicians and that, despite some clinics offering support beyond that currently commissioned by LSL, there remains a significant need for further support to help patients to remain engaged with HIV treatment. In particular, clinicians reported that care and support services that are co-located in clinical spaces were helpful in giving patients the non-clinical support they need.

## 6. Evidence of what works to support PLHIV

### a. Standards of Care for PLHIV

The British HIV Association (BHIVA) published standards of care for people living with HIV (PLHIV) in 2018.<sup>8</sup> This encompasses all aspects of care and a number of these relate to non-clinical care and support. In particular:

- Standard 2 (person-centred care) states that *'services consciously adopt the perspectives of individuals, families and communities to respond to their needs and preferences in humane and holistic ways; the person is a participant, not just a beneficiary of the health system'*.
- Standard 3a (Access to and retention in care) states that:
  - *'People newly diagnosed with HIV should [...] be able to access psychological and peer support within two weeks of receiving their HIV positive result.'*
  - *'HIV outpatient units should have an agreed pathway to enable access to peer support.'*
  - *'HIV outpatient units should have an agreed pathway to enable access to financial and housing advice and support.'*
  - *'People living with HIV should expect to have access to peer and psychological support when required'*
- Standard 3b (outpatient care) states that *'Specialist HIV outpatient services should provide easy access to multidisciplinary support, in particular: specialist nursing; sexual health services; specialist adherence support; specialist HIV pharmacy advice; dispensing services; dietetics; mental healthcare; counselling; and peer and advocacy support. There should be ready access to, or information about, services that can provide advice about social care and benefits entitlements'*.
- Standard 6a (emotional well-being) states that:
  - *All people living with HIV should have access to peer and psychosocial support, and advice according to national standards. There should be agreed pathways in place for those with more serious psychological or cognitive difficulties, which ensure early detection of the problems and prompt referral to appropriate services.*
  - *Peer support should be discussed and made available to all people living with HIV, and form part of their clinical care pathway options.*
- Standard 7a (young adults and adolescents living with HIV) states that:

- *All people living with HIV should have access to peer and psychosocial support, and advice according to national standards. There should be agreed pathways in place for those with more serious psychological or cognitive difficulties, which ensure early detection of the problems and prompt referral to appropriate services.*
- *Peer support should be discussed and made available to all people living with HIV, and form part of their clinical care pathway options.*
- Standard 7b (early to middle adulthood) states that
  - *Where appropriate, continuity with education, training and employment should be supported*
  - *Where continuity is not appropriate, care providers should provide support to help people maintain adequate income, housing and social support[...]linking people to community and other support services.*
  - *Care providers should support people living with HIV and act as their advocates if there is evidence that they are being discriminated against in education, training or employment on the basis of HIV.*
- Standard 7c (older age) states that:
  - *Peer support may be particularly important for those diagnosed in older age, as many people will have had no previous exposure to people living with HIV or HIV-related issues. This may be crucial for engagement and retention in care. Peer support needs for those living long term and ageing with HIV will differ from other groups, as issues such as historic stigma and discrimination, community-level loss and survivor guilt may play out quite differently.*
  - *It is important to ensure that provision of sources of support and information are relevant and acceptable – not all older adults will be as familiar with online resources as younger people.*

While these standards relate to aspects of care beyond the scope of the HIV care and support service, it is clear that they do consider the provision of peer support, whole-person support and community support for issues including housing, income and social needs to be of high importance.

#### b. Peer support

National standards for peer support in HIV were published by Positively UK in partnership with a range of HIV organisations.<sup>9</sup> This describes the value of peer support in enabling PLHIV to live well with their condition, as emphasised by patients, peer support workers and HIV clinicians. It acknowledges that quality of life goes beyond clinical outcomes, encompassing physical, mental, emotional, social and spiritual well-being. Peer support is described as having important benefits for the individual, financial benefits for the health and social support system as well as wider social and community benefits.

### 7. Benchmarking against provision in other areas

As part of this review, contact was made with other boroughs in London, and some selected locations outside of London to understand HIV care and support in other areas. Only two local authorities responded. One did not have a specific HIV care and support service, but provided some support through more general sexual health promotion services. The other responding local authority in London commissioned a service providing HIV care and support which aims to:

- Provide peer support, advice and means of engagement
- Empower service users through information
- Provide practical, mental health, emotional and intellectual support
- Lessen the sense of isolation

- Help mitigate concerns and fears
- Support service users come to terms with diagnosis
- Support service users develop inner strengths and resources
- Help promote self-management and reduce (self) stigma
- Improve accessibility to the service offer (including online/face to face and out of hours services)

## 7. Recommendations for an HIV care and support Service

The specification for a care and support service will be informed by this review as well as views of service users, professionals and other local residents sought through the engagement exercise.

Based on the information within this report, recommendations are that an HIV care and support service should:

### **A. Overarching Responsibilities**

- The service will be one collective pathway for support. The provider will design and plan interventions, based on needs assessment and local knowledge of those at risk of HIV infection and undiagnosed HIV, or groups and populations in high proximity to HIV. These interventions will be planned and delivered in line with [NICE Guidance PH6](#) (2007), [NICE Guidance PH49](#) (2014) and [NICE Guideline NG60](#) (2016), BHIVA standards of care for PLHIV and any other relevant guidance (e.g. National standards for peer support in HIV).
- The provider will need good links with clinical services and be responsible for maintaining those links, e.g., through making referrals and promoting clinical services. The provider carries the responsibility for embedded routes of partnership working between clinical and community-based services between the provider and partners.

### **B. Services and activities**

- Interventions (including peer-to-peer, therapy and counselling) will include group work, outreach, one-to-one brief interventions, and will use social marketing and digital outreach in order to meet the outcomes set out in the specification. These interventions will go beyond simple information giving, and support behaviour change with positive outcomes for health and wellbeing. Stakeholder feedback shows there is a deep frustration expressed by PLHIV concerning not being able to easily access mental support or therapy.
- The service will contribute to reducing health inequalities by ensuring equity of access for all people with, or affected by, an HIV diagnosis. Services should be informed by knowledge about the groups most likely to need support (cultural background, age, gender, sexuality, disability etc), and ensure that services are tailored to meet the needs of these groups. Targeted services should be co-designed to ensure that barriers are appropriately addressed. The service must have a presence in HIV clinic settings as well as in the community, ideally providing support alongside other services e.g., mental health, welfare or housing advice etc

### **D. Promotion, education and information**

- The service will promote its relevant services to, professionals and service users in a variety of formats. Promotional activity should not be limited to leaflets, emails or web content, app and social media content but should also include engagement with a range

of services and service user groups through meetings, workshops, and community events.

- The care and support service will assess and provide or signpost to appropriate support for complex personal and social problems including immigration, housing, benefits advice, employment, loneliness and isolation and other health issues.

### **C. Location(s) and Hours of Service Delivery**

- The main service will be delivered within the London Boroughs of Lambeth, Southwark and Lewisham (LSL), including locations in clinical spaces. Locations can be incorporated within the service to ensure service users can benefit from a wider range of services.
- It is imperative that the service offers virtual sessions/appointments as well as in-person. The service will need to be flexible around hours of service, address childcare if this would be a barrier to patients' ability to attend treatment sessions, especially vulnerable or single parents.

[Ends]