



Temporary Accommodation for People Living with HIV

A community-based research study, 2024

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Funded by



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Executive summary

Positive East is East London's dedicated HIV charity with over 30 years of experience, operating across the eight boroughs of Hackney, Tower Hamlets, Waltham Forest, City of London, Newham, Redbridge, Havering, and Barking & Dagenham.

This report, Temporary Accommodation for People Living with HIV, presents the findings of a qualitative research study that asked People Living with HIV (PLWHIV), primarily living in North-East London, about their experiences of living in Temporary Accommodation (TA). Their stories were gathered through online and paper questionnaires distributed during the summer months of 2023 via one-on-one interactions with Positive East clients, HIV clinics across East London, email channels, newsletters, and social media. Forty responses were received. Five in-depth interviews were held which provided the opportunity for richer stories and in-depth input from PLWHIV living in TA. A final focus group was held in late January 2024 with five participants who provided feedback on the themes and draft recommendations derived from the research. This amounted to a total of 50 participants involved in all three phases of the study.

Key findings of the research:

- + 70% of PLWHIV were not satisfied with their TA and identified **safety, privacy and/or discrimination**, including because of their HIV status, as key reasons why.
- + TA is not temporary: over **70% of PLWHIV had been in TA for longer than one year**, with some being in TA for as long as 10 years or more.
- + The **negative health impacts of being in TA for some people living with HIV can be severe**, including not adhering to treatment or maintaining their regular HIV care.
- + **Social networks are especially important to PLWHIV**, who often go to great lengths to develop and maintain them. Being housed in TA that is far from friends and family, and their chosen medical providers, impacts their wellbeing and the care they receive.

Based on these key findings, Positive East recommends:

- 1 **PLWHIV should be prioritised in allocating TA**, as good housing supports their health and wellbeing, and reduces risks of disease progression and transmission. As one focus group participant put it: **'A good living environment is good medicine for People Living with HIV'**.
- 2 **PLWHIV should not be placed in shared accommodation** due to their particular needs for privacy and confidentiality, and the significant risks of experiencing stigma and discrimination.
- 3 **Treatment and support needs must be considered in TA allocations**, including ensuring PLWHIV have access to their chosen medical providers and peer/social support networks.
- 4 **Local authorities should identify good TA providers** and share their good practices. Examples of what "good TA" looks like

should be solicited from PLWHIV who live in TA, highlighting the qualities and attributes of TA, such as the ones identified in this study, that make PLWHIV happy with their housing.

- 5 **Local authorities should carry out HIV training** among their TA providers and staff who allocate TA for them to better understand the severity of stigma around living with HIV as compared to other chronic health conditions.
- 6 **Health professionals providing housing support letters to PLWHIV** should highlight the unique needs of PLWHIV and the difficulties in maintaining their treatment regimes in shared accommodation settings, and the impact of patient-doctor relationships and social connections in patients adhering to their treatment regimens.

Study limitations

It is worth noting some possible limitations in this study, that could, but not necessarily did, affect results.

Sample size and selection bias: The primary group approached with invitations to participate in all three phases of the study were clients of Positive East, notwithstanding the larger distribution of surveys as is described elsewhere.

Language and communication: English was not the first language of almost 30% of respondents, while the survey was only made available in English. Most interviews and the focus group were conducted in English.

Transcription software: Software and apps used to record and transcribe interviews have

their limitations, and potentially do not always capture the full or accurate words used.

Relevant and appropriate efforts were made to address limitations and reduce any potential bias and impact on the research results, including, but not limited to:

- + Distribution of surveys and invitations to participate through wider channels, including HIV clinics settings, email networks, and social media
- + Where possible, conducting interviews and in-person surveys in languages other than English with staff who spoke in the native languages of participants
- + Using more than one brand of transcription software to capture recordings as accurately as possible

Introduction and background

What is Temporary Accommodation?

In the context of this research project, it might help to define what we generally mean by the term **Temporary Accommodation** (TA for short). TA is "accommodation councils offer to homeless households while they wait for their application for help to be processed and to be offered a settled home".¹ Trust for London further explains: "Local authorities, including London boroughs, have legal duties to provide accommodation to people who are homeless. Whilst they are waiting for a permanent solution – such as a home provided by a housing association – local authorities must house them in temporary accommodation such as nightly accommodation, the private rented sector or a bed and breakfast".²

There are different types of temporary accommodation types, but generally, they fit under the following categories:³

- + Bed and breakfasts
- + Hostels and hotels
- + Housing owned and managed by local authorities or housing associations
- + Privately rented accommodation
- + Nightly paid accommodation

The research was conducted with people who have lived or are currently living in the above types of accommodation.

Basis for the research

There have been many studies looking at the issue of temporary accommodation, across England and specifically in London, including its impacts on individuals and families, the fairness in allocations and access, the quality of housing, and a range of other issues related to TA.

A 2023 report by Shelter outlines important key facts about the current state of TA in the UK. Some of its findings include:⁴

- + 75% of households live in poor conditions, including 21% with a safety hazard.
- + 60% of households have spent more than 1 year in TA.
- + More than 25% of households were placed in housing more than one hour away from their previous home.
- + At least 25% of households have waited longer than 8 weeks for an urgent repair.
- + Almost 90% had difficulty with managing the costs of their TA, with over 1 in 4 falling behind in rental payments.

1 Shelter, Still Living in Limbo (2023).

2 Trust for London (2023), <https://trustforlondon.org.uk/data/temporary-accommodation-over-time>

3 Ibid

4 Shelter, Still Living in Limbo (2023).

The report also highlights the impact of TA on the health and wellbeing of individuals, noting that two-thirds of households reported that their TA had a negative impact on their physical and mental health. It is this last point which is of particular concern for people living with HIV, and the organisations that support them.

It is well-evidenced that housing and living conditions are important social determinants of a person's health and wellbeing.⁵

What we already know

From reviewing existing literature around TA, two things are evident:

- 1 There have been significant and important research studies over the years on TA and its challenges, both in London and across the UK.
- 2 However, there has not been much research when it comes to the specific issue of people living with HIV and the issues they face when living in TA. Previous research has been undertaken regarding PLWHIV and Housing, the last documented one being the 2013 report 'Housing and HIV: A survey into the housing advice and support needs of people living with HIV', by the National AIDS Trust (NAT).⁶

When it comes to overall research on TA in general, three recent reports stand out:

- + The Call for Evidence Findings: summary, analysis of themes and call to action, by the APPG for Households in Temporary Accommodation (January 2023)

For people living with HIV (PLWHIV), who often face unique needs and challenges in maintaining their health, the consequences of a poor housing environment can be even more severe. PLWHIV who live in TA run the real risk of having their health and wellbeing deteriorate if their housing situation does not adequately meet their needs, or, even worse, puts them in harm's way.

To explore how living in TA affects PLWHIV in North-East London, Positive East undertook this research project, funded by Trust for London, with this group of people.

- + Still Living in Limbo, by Shelter (2023)
- + Improving the health of people living in Temporary Accommodation in London, by Groundswell (September 2023)

The key findings of these reports provide valuable insight into the situation of TA in the UK, and an important context to this research project:

- + Healthcare and mobility needs are not adequately considered when allocating TA.⁷
- + The unpredictable nature of living in TA has significant impacts on mental health and emotional wellbeing.⁸
- + The mental and physical health of many people in TA worsen while in TA.⁹
- + People are often housed in TA that is a significant distance from their home area¹⁰
- + Safety issues are a serious concern for many living in TA.¹¹
- + TA is often not 'temporary'.¹²

⁵ World Health Organisation (2023), <https://www.who.int/health-topics/social-determinants-of-health>.

⁶ National AIDS Trust (2013), https://www.nat.org.uk/sites/default/files/publications/April_2013-Policy_Briefing_Housing_and_HIV.pdf

⁷ Groundswell (2023), Improving the health of people living in Temporary Accommodation.

⁸ Groundswell (2023), Improving the health of people living in Temporary Accommodation.

⁹ Shelter (2023), Still Living in Limbo.

¹⁰ Ibid

¹¹ APPG on Houses in Temporary Accommodation (January 2023), Call for evidence findings: summary, analysis of themes and call to action.

¹² Groundswell (2023), Improving the health of people living in Temporary Accommodation; Shelter (2023), Still Living in Limbo; Ibid.

People Living with HIV in TA

The report Positive Voices: The National Survey of People Living with HIV (Findings from the 2017 survey), published in January 2020, shows that **PLWHIV are three times as likely to live in TA compared to the overall population**.¹³ Routine feedback from Positive East clients also suggests that current system does not take into consideration their HIV-related needs: increased privacy, stigma-free housing, or proximity to their HIV clinic. A review of Positive East client data (people who accessed housing advice services) for a three-year period (2019-2022) showed 225 PLWHIV, many of whom are from minoritized backgrounds, had experience of living in TA.

While it is possible to live a full and happy life with HIV, societies, attitudes and government inaction make it a challenge. A 2021 survey by Britain Thinks and NAT on public attitudes towards HIV showed that 83% of the public agreed that PLWHIV face negative attitude from society and only a third agreed they have sympathy for all people living with HIV regardless of how they acquired it – demonstrating that a positive HIV diagnosis is seen to be the 'fault' of the individual.

These widespread negative perceptions and stigma make the experience of living in TA more challenging for PLWHIV. Not knowing how other people in a TA will react to sharing space with a PLWHIV, creates an environment of anxiety and fear for the HIV positive person. And that fear is genuine.

Positive East has supported people who have faced extreme levels of discrimination in their TA when other residents found out about their HIV status. There is a known case of one person who was forced out of their TA into street homelessness when their HIV status was found out, leaving all their personal belongings, including medication, at the accommodation.

The approach to housing PLWHIV is inadequate and often leads to PLWHIV being housed far away from their HIV clinic, being moved frequently, placed in accommodation with limited privacy and risk of forced disclosure, or within intolerant communities. Unstable and inadequate housing reduces quality of life, increases safety concerns, increases mental health issues, and worsens health outcomes for PLWHIV.

It is hoped that this research helps achieve three important goals:

- 3 To highlight to TA providers the severe impact of unsuitable TA on the health and wellbeing of PLWHIV.
- 4 To increase awareness within Local Councils of the needs of PLWHIV when it comes to housing, leading to these unique needs being embedded in local authorities' TA allocation policies and practice.
- 5 Empowerment of PLWHIV to share their experiences in TA and to self-advocate for better TA.

¹³ Data sources: Public Health England, Positive Voices (findings from 2017 survey) and Ministry of Housing, Communities & Local Government. Statutory homelessness and prevention and relief, October to December (Q4) 2017: England.

The research

Methodology

This research involved working primarily with PLWHIV residents in North-East London or accessing HIV treatment in HIV clinics based in North-East London.

The study was also open to others living with HIV who expressed an interest in the issue of TA. The study was carried out in the three phases outlined below.

Phase 1: Surveys

(Summer 2023)

Questionnaires were distributed through client contacts, HIV clinics and hostels across East London and through Positive East social media accounts, newsletter mail-outs, and by email distribution.

40 responses were received, of which:

- + 20 respondents were current TA residents.
- + 3 respondents had previously lived in TA.
- + 12 respondents were either currently living or had previously lived in TA (NB: The questionnaire was changed after the first 12 respondents, to split this choice into the 2 separate choices above. This was done as a result of feedback from clients early on in phase 1.)
- + 5 respondents had never lived in TA, so did not complete the bulk of the survey other than the demographic questions.

Phase 2: One-to-one interviews

(Summer/Autumn 2023)

This involved six semi-structured interviews: five in person and one by phone.

One interview was held in Spanish.

Phase 3: Focus Group

(Winter 2023)

A focus group was held in late January 2024 to review the highlights of the report and its draft recommendations and add to the outlined experiences of PLWHIV in TA. 5 people attended, all clients of Positive East. One person had been involved in the Phase 2 interviews, with the others being new to the study.

Breakdown of demographics (survey respondents)

Age

| | |
|-----|-------------|
| 8% | 26 to 35 |
| 73% | 36 to 55 |
| 18% | 55 and over |

Gender

| | |
|-----|-------------------|
| 58% | female |
| 40% | male |
| 2% | trans*/non-binary |

Sexuality

| | |
|-----|------------------|
| 70% | heterosexual |
| 25% | gay or bisexual |
| 5% | did not disclose |

Ethnicity

73% of respondents identified as from BAME ethnicities, with the majority (24 respondents) identifying as Black African.

Religion/religious affiliation

| | |
|-----|-----------|
| 68% | Christian |
| 13% | Muslim |

Immigration status

| | |
|-----|---|
| 35% | UK nationals |
| 30% | Indefinite leave to remain/settled status |
| 35% | Limited leave/seeking asylum in UK |

Family status

78% of respondents identified as single or divorced, with 30% of these having at least one dependant.

60% of all respondents had no children or other dependants, while the number of dependants for those who did have dependants ranged from one to six.

Disability status

50% considered themselves as living with a disability.

- 7 reported mental health issues
- 7 stated they had mobility issues and/or physical disabilities
- 8 people identified HIV as a disability they lived with*

Income levels (monthly)

| | |
|-----|---------------------|
| 20% | Below £300 |
| 20% | Between £301-£600 |
| 43% | Between £601-£1,200 |
| 17% | Above £1,200 |

Borough/place of residence

The highest number of responses to the survey (62.5%) came from people who lived in TA in Newham.

There were also multiple respondents from each of the following boroughs: Barking and Dagenham; Redbridge; Tower Hamlets; Lambeth; Hackney; Croydon

A handful were from other London boroughs, and even fewer from outside London.

* In general, most people with HIV do not consider themselves as having a disability, although it is defined as such in the Equality Act

The findings

Length of time in TA

Confirming what is known from several studies about how long people spend in TA, and anecdotal feedback from Positive East clients, TA is often not for a short period. 31% (11 people) had been in TA for up to one year. But

the remaining 69% had lived in TA for 2 or more years, with three participants having been in “temporary” accommodation for **more than 10 years**.

Reasons for living in TA

The most common contributing factor that people gave for living in TA was a **relationship breakdown, with low income or a drop in income and having been evicted as close**

second reasons. Medical/health reasons and leaving an unsafe home/domestic situation were other reasons some respondents gave as reasons for their ending up in TA.

Living situations

Prior to current TA

The study found out that 25% of the respondents had been moved from their previous TA to their current TA. 20% moved from private sector rented housing to TA, 17% moved from living with friends and family to TA, while 12% were street homeless before moving into TA.

These figures clearly show that a significant number of people are being moved from one TA to another.

The types of TA participants lived in varied, with the highest number in self-contained house or flat (40%) or in a private room within shared TA (20%). 14% respondents were in a shared room within a house or flat, while most of the

remaining 20% were in hotels, hostels, or bed & breakfast facilities.

Shared living space and size

Half of the participants (50%) shared some space in their TA, with 20% sharing with two or more people who were not part of their family or household.

14% respondents shared their bedroom space, while the kitchen/cooking area was the most shared space shared, followed by a living/ dining space. **Almost half of respondents felt the size of their TA was not adequate.**

Sharing their TA space was a particularly significant concern for people living with HIV, specifically, for example, in terms of privacy and disclosure, including having to hide their

“ I was initially in a room with ten other people, with all shared facilities. It made me uncomfortable as it was a small room with ten people. At first I didn’t mind taking medication but then it became a concern. Because I had to take it like regular times every day so I became responsible but every time they would see me take medication at the same time. One of them asked about the medication I was taking, so then I started feeling uncomfortable. And that’s when I put in the complaint to be moved ”

HIV medications. Given the high level of stigma associated with HIV, participants expressed great difficulty in safely storing their medication in shared TA. In some cases, they stored their medication in places other than at their TA, which then reduced their levels of adherence to their treatment regimens and possible treatment failure.

Income and costs

43% of those in TA reported a monthly income of between £601 and £1200, while almost the same number received £600 or less, including 20% who had a monthly income of less than £300. Of those who did have some monthly income, for over 50% this included some social assistance/benefits. 25% worked in jobs either full or part-time.

The costs of their TA were high for many. 66% of respondents were responsible for paying rent for their TA, with many also paying electricity,

water and other utilities or service charges on top of rent.

Despite most having at least some monthly income, almost 60% of participants admitted they struggled to cover their basic living costs (food, prescriptions, transportation). A further 34% were able to cover most of their basic costs but had little left at the end of the month for anything else, such as eating out, travelling, and other extras.

It is not difficult to see the link between having little or no income and living in TA, considering many of the participants indicated this as a reason they found themselves in need of TA in the first place. **Many find themselves in a catch 22 of not having the economic means to change their living situation, but their living situation prevents them from improving their economic means.**

“ I have very little left of money at the end of the month. I like to cook, with fresh food, and I have a friend who will come over and cook, and they are trying to get me to cook, but I’m afraid. The house is not bright enough, and I also haven’t used a cooker for quite a long time, at least two years. So sometimes I would like to go out somewhere [to eat], because I live on my own and am isolated. But by the end of the month, I will be left not with enough money to do anything else. I wish I could just work because then I can go where I want to go ”

Meeting the needs of PLWHIV

66% of those in TA were not satisfied with their TA, while 34% were either very or mostly satisfied.

The reasons people didn't feel satisfied with their TA were varied, and most participants provided more than one reason of the following reasons:

- + Not having any privacy
- + Not feeling safe in their TA
- + TA not in the area where resident wanted to live
- + TA didn't take into account their mobility or disability issues
- + Experiencing or being worried about discrimination or harassment
- + Housing in disrepair, or heating/water no working
- + TA not being pet friendly

One respondent added, after listing some of the reasons for which they weren't happy with their TA: "Too many to list, but here are the highlights".

Privacy and safety

Privacy and safety were cited as concerns for almost everyone (96%) who stated they were unhappy with their TA. Many were worried about safety issues, including anti-social behaviour, drug use by other residents, and crime within the TA or around the area where their TA was located. This mirrored findings from other recent research, where people admitted feeling unsafe in their TA, some to the point of being traumatised.¹⁴

The 2022 Positive Voices survey results provides clear examples of how PLWHIV continue to face harassment, discrimination and violence:¹⁵

- + Over 4% reported being verbally harassed because of their status.

“ Regarding my HIV, I don't feel a safe as I would with my own place. I know they are aware of my diagnosis, as I previously reported it to them. But I have sometimes found my medications in my room moved, not where I left it, so I don't know who might be reading it, looking at it ”

“ I am worried that people will find out I am HIV positive – no place to hide my medication and I am worried that my letters will be opened and people will find out ”

“ Stressed of not having a place [of my own], no privacy, one day my room door was opened while I was away and I keep my medication openly out and when I came back my door was open, and one of the roommates said she saw my room door opened ”

- + Almost 10% of PLWHIV who experienced physical violence believed it was because of their HIV status.
- + Over 12% of those reporting having been sexually assaulted felt it was due to their HIV status.

With many PLWHIV coming from a background of experiences facing discrimination and violence, it is understandable how privacy and safety are crucial qualities they seek in their housing.

¹⁴ APPG for Households in Temporary Accommodation, The Call for Evidence Findings: summary, analysis of themes and call to action (January 2023), <https://householdsintemporaryaccommodation.co.uk/reports/call-for-evidence-findings-summary-analysis-of-themes-and-call-to-action/>

¹⁵ Positive Voices: The National Survey of People Living with HIV, Findings from the 2022 survey (2024). <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report#Stigma>

Impact of TA location

The location of one's housing is important to everyone – people build community, social links, and access services in the places they live. 40% of respondents were not happy with their TA because they were living in areas other than where they wanted to live, and often this was because it was far from friends/family or medical providers.

Many PLWHIV count on their supportive network of friends, family, and medical providers to help them cope with and manage their lives, and living close to these networks is therefore important for their health and wellbeing. As outlined in the later section on Stigma and Discrimination, many PLWHIV do not feel safe disclosing their HIV status. On top of that, many PLWHIV admit to feeling ashamed of their HIV status.¹⁶

Stigma, including self-stigma, and fear of discrimination from others drive home the importance of supportive personal networks for PLWHIV and medical providers with whom they can build trusting relationships.

When people are provided TA outside areas they feel most at home, where they can't access these supports, especially from their peers, it has a negative impact on their emotional and psychological wellbeing, which in turn can affect their ability to live well with HIV. One interview participant had made great efforts to find an HIV medical provider near where he was staying that spoke his native language of Spanish, which was important in ensuring his good care and treatment as he

“ If I had a choice, I would pick [name of area removed to protect identity], because most of my friends are there, while here where I live they need to travel to, and they say they don't have the money to come see me. Sometimes I will top up their Oyster card so that they can come, because they support me a lot, with things like cleaning and cooking ”

¹⁶ Ibid.
¹⁷ Ibid.

was not yet able to communicate in English. He was later told he faced the risk of being housed a significant distance away threatening his ability to continue with this provider.

Mobility and disability issues

For PLWHIV who also live with disabilities, the study found out that their TA was not always appropriate. 30% of them unhappy with their TA because it didn't adequately take into account their other disabilities and issues of mobility and access.

“ I get worried about taking a shower, because of my impaired eyesight. There is nothing to hold on to and no special equipment since it is not my permanent home. So sometimes I feel unsafe [taking a shower] ”

Discrimination and harassment

26% of those unhappy with their TA disclosed discrimination and harassment as reasons for their discontent, with over 50% of these identifying their HIV status as the cause of the discrimination and/or harassment. Whether it is a fear of or actual experiences of discrimination, the impact of stigma is real. As evidenced in the findings from Positive Voices: National Survey of People Living with HIV (2022 Survey), high numbers of PLWHIV do not disclose their HIV status outside of healthcare settings: "Only 1 in 8 (12.9%) people had shared their HIV status with most people in their lives and 1 in 10 (10.4%) had not told anybody apart from healthcare staff"¹⁷ Our survey confirms that these experiences of stigma and discrimination provide a lens through which PLWHIV view their housing.

Others also identified their gender identity or sexual orientation as the reasons for the discrimination or harassment. Age or ethnicity/race were also listed by several respondents.

“ I was constantly worried of being discriminated against because of my HIV ”

Impact of living in TA on the health and wellbeing of PLWHIV

Living in unsuitable TA has a great impact on people's wellbeing. **Nearly 75% of those unhappy with their TA said that it affected their mental health**, while over 50% said it affected their relationships, friendships, and family life.

Over 30% stated that it had affected their physical health.

The impact of unsuitable TA (in disrepair, location, and so on) on the physical and mental health of people living with HIV cannot be understated, with respondents outlining a range of specific effects, including:

- + Feeling sick more often
- + Not eating well or exercising regularly
- + Worsened chronic health conditions since living in TA, including HIV-related conditions

Worryingly, 37% of those who said their TA affected their health stated that they had developed a new health condition that they believed was as a result of being in TA. The range of conditions reported included depression, anxiety, social anxiety, and other mental health issues, high blood pressure, obesity, and diabetes. Just under 50% admitted to not eating well or not exercising regularly.

And even more worryingly (specially regarding PLWHIV), 20% of respondents stated that living in their TA had resulted in them seeing their medical care providers less often or poor adherence to taking their HIV medication.

Four respondents stated that because of the state of their TA, they were not able to take care of their personal hygiene as well as they should, including keeping themselves, their clothing and bedding and their homes washed and clean.

“ It has impacted my PTSD a lot. The noise is constantly in my head, and I can't really settle ”

“ I can't bring friends, relatives or church members to a crowded house ”

“ A lot of times I feel like I'm very closed in. A lot of times, I'm asking for something, and then I feel like I'm doing something wrong. I often feel depressed, crying, sad and so on. And seeing that I don't have a solution because of my case, it affects me ”

“ I am always sneezing because of my house being very cold ”

“ When I was in a shared house. I ditched my appointments, I ditched my medication, because I didn't want to put medication in the house. Because I don't know that if I go out, someone can easily go into my room. So I stopped taking my medication for a very long time for about a year. That's one of the things which led me to hospital, was falling sick because I couldn't take my medication then ”

PLWHIV satisfaction with their TA

In advance of this research, there was a general belief that very little TA provision met the needs of PLWHIV. The assumption was that the situation would all be “doom and gloom”, in line with most studies carried out on TA in general. Therefore, it was unexpected when the study showed that 34% of the respondents expressed satisfaction with their TA.

They stated that they were satisfied because:

- + They had enough room and space
- + TA was near very good transport links
- + TA was self-contained and provisions with were not shared

“ I am not on the streets. I have a room, and I sleep well. However, it is not mine and is temporary and I need my own place permanently ”

“ I am grateful that I had somewhere to stay and it was clean. Although I did not have a lot of space, it was enough to meet my basic needs ”

- + TA being within reasonable reach to their treatment centre and support networks
- + Landlords were proactive in addressing disrepair issues raised

PLWHIV dissatisfaction with their TA

The respondents who were not happy with their TA (66%) highlighted the following reasons as the basis for their dissatisfaction:

- + Privacy, the most cited reason
- + Safety, noise and anti-social behaviours
- + Being in an area far from social networks and medical services

When PLWHIV who were dissatisfied with their TA tried to address issues of their housing (such as disrepair or noise, for example), which 60% had attempted to do, the issues were fully addressed for only 10% of these (just 2 people). For those who had not reported issues, the reasons they did not are worrying: 43% of them were afraid of discrimination, or being targeted if they raised issues, or feared being evicted. Others said they weren't listened to previously when they did raise issues. Fear and feelings of powerlessness were real factors in people not speaking out to improve their housing conditions, even when the situation was intolerable.

PLWHIV often experience stigma and discrimination, if not overt hostility and threatening behaviour. It is important for them to have housing that provides them with

“ I have never been happy with my TA and the property manager does nothing but take my money. The place is not fit for purpose, if I had more time, I would get environmental health to take a look, use one of those ads to take my landlord to court and the Council for allowing this to happen. The disrepair is dangerous ”

much-needed privacy, safety, security, and access to support networks. For many, their experience in TA is the opposite. The findings of this study show that the negative effects of this are numerous and significant, impacting physical and mental health and wellbeing, social connections, and their medical care and treatment.

People living with HIV, like everyone, want suitable and safe housing that meets their needs and the needs of their families and loved ones. When asked what the most important things were when it came to their housing, most of the answers were simple, yet compelling:

- + Safety and privacy
- + A place that is clean, spacious, and warm

- + “To live in a clean place, have a garden to grow flowers and plants, have a pet, where friends are able to visit if I’m unwell, to be able to cook without thinking where to keep stuff, and to be able to sleep” (direct words from one respondent)
- + And one which was repeated many times over: **to live in my own permanent home**

Key conclusions

66% of PLWHIV were not satisfied with their TA and identified safety, privacy and/or discrimination, including because of their HIV status, as key reasons why.

TA is not temporary. 70% of PLWHIV had been in TA for longer than one year, with some being in TA for as long as 10 years or more.

The negative health impacts of being in TA for some people living with HIV can be severe, including not adhering to treatment or maintaining their regular HIV care.

Social networks are especially important to PLWHIV, who often go to great lengths to develop and maintain them. Being housed in TA that is far from friends and family (and their chosen medical providers) impacts their wellbeing and the care they receive.

Recommendations for action

It is worth providing a reminder of the goals for this study:

- + To highlight to TA providers the severe impact of unsuitable TA on the health and wellbeing of PLWHIV.
- + To increase awareness within Local Councils of the needs of PLWHIV when it comes to housing, leading to these unique needs being embedded in local authorities' TA allocation policies and practice.
- + Empowerment of PLWHIV to share their experiences in TA and to self-advocate for better TA.

With these three goals in mind, based on the findings from this research and the opinions and stories shared by PLWHIV during this study, Positive East puts forward the following six recommendations for action:

- 1 PLWHIV should be prioritised in allocating TA**, as good housing supports their health and wellbeing, and reduces risks of disease progression and transmission. As one focus group participant put it: 'A good living environment is good medicine for People Living with HIV'.
- 2 PLWHIV should not be placed in shared accommodation** due to their particular needs for privacy and confidentiality, and the significant risks of experiencing stigma and discrimination.
- 3 Treatment and support needs must be considered in TA allocations**, including ensuring PLWHIV have access to their chosen medical providers and peer/social support networks.
- 4 Local authorities should identify good TA providers and share their good practices.** Examples of what "good TA" looks like should be solicited from PLWHIV who live in TA, highlighting the qualities and attributes of TA, such as the ones identified in this study, that make PLWHIV happy with their housing.
- 5 Local authorities should carry out HIV training among their TA providers and staff** who allocate TA for them to better understand the severity of stigma around living with HIV as compared to other chronic health conditions.
- 6 Health professionals providing housing support letters to PLWHIV should highlight the unique needs of PLWHIV and the difficulties in maintaining their treatment regimes** in shared accommodation settings, and the impact of patient-doctor relationships and social connections in patients adhering to their treatment regimens.

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All web links verified at time of production of this report.

Positive East
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