



**NATIONAL
AIDS
TRUST**

Securing rights
Stopping HIV

HIV and migration:

Understanding the
barriers faced by
people born
abroad living
with HIV in
the UK



June 2021

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Foreword

As migrants living with HIV, we were immediately interested in the role of Peer Expert for this project. We really believe that involving those with lived experience is key. Migrant involvement is crucial to any research seeking to better understand the barriers faced by migrants living with HIV in the UK. If we are determined to achieve the 2030 goal of ending new HIV transmissions in the UK, migrants must be involved.

Although of course we have our own experiences as migrants living with HIV in the UK, we understand that everybody has a different story to tell. We wanted to show the diversity of our community and capture as many different experiences as possible. The peer-led approach helped us create a safe environment for migrants living with HIV to share with us their stories.

The migrants living with HIV who participated in the research for this report were incredibly generous and honest about topics which sometimes can be difficult to speak about. The interviews were emotional, painful, inspiring, and joyful, and revealed so much about the experiences of migrants living with HIV in the UK.

Much of what we heard during the research was shocking but not a surprise for us. We were already aware of the barriers that many migrants living with HIV face. So many of the migrants living with HIV who participated in the research mentioned wanting to take part to improve the quality of life of future generations of migrants, specifically migrants affected by HIV.

We hope this report does justice to their aims, to their experiences and to their honesty, which we will always cherish. We also hope this work benefits our wider and diverse community of migrants affected by HIV. It has certainly helped us understand our own journeys.

Suzyo Charity Nyirenda

José Carlos Mejía Asserías

Peer Experts, National AIDS Trust

1. Introduction

HIV is a public health challenge which disproportionately affects migrants in the UK. Despite this, there is currently no shared understanding of the policies and interventions needed to combat HIV in the context of migration. National AIDS Trust (NAT) wanted to understand the barriers migrants face accessing HIV testing, treatment and care. This report explores these and makes recommendations to improve the health outcomes and quality of life of migrants living with or at risk of HIV in the UK. This project was kindly supported by Trust for London. There was a London-specific aspect to the research with all participants needing to have accessed HIV care in London at some stage. London is where the highest proportion of migrants living with HIV access HIV care. There are some findings which will be London specific. However, there is also wider relevance and learning for the whole of the UK and much of the data provided is UK-wide.

To end new transmissions of HIV by 2030, a UK goal, we must make progress for all population groups, including migrants. In order to do this, all migrants in the UK should have access to the HIV prevention, treatment and care they need. Migrants must be considered a key population in the UK's response to HIV by the Government, UK Health Security Agency and wider healthcare and HIV sectors.

In 2019, 62% (2195/3552) of all new HIV diagnoses in the UK (including people previously diagnosed abroad) were among migrants.¹ New diagnoses have declined over the past 10 years for people born in the UK and abroad, and rates of late diagnosis were similar, but slightly higher for migrants with HIV (51%, 541/1051) compared to people born in the UK (46%, 461/1000).² People who are diagnosed late have a tenfold risk of mortality within one year of diagnosis, are more at risk of ill-health and this also increases the risk of onward transmission.

Among the migrants living with HIV who participated in our research, all were pleased with the quality of care and support they received through HIV clinics and support services. However, there were barriers to accessing primary care services through GPs, as well as concerns about understanding of HIV among GPs.

The devastating impact of hostile environment policies on migrant access to healthcare was also startlingly clear. Specifically, fears and confusion around possible charges for NHS services, and the practice of data sharing between the NHS and the Home Office, had deterred people from engaging with HIV testing, treatment and care. There were also wider barriers to accessing care. These included a lack of access to information about healthcare entitlements, language barriers, poverty (which was often related to restrictions on the right to work and inability to access public funds), mental health problems and the impact of stigma and discrimination.

1 PHE data, provided upon request in email dated 21 April 2021.

2 Ibid.

This report builds on previous work by NAT. We successfully campaigned to end the memorandum of understanding (MoU) on data sharing between NHS Digital and the Home Office. In 2019, we published with the British HIV Association (BHIVA) guidance for healthcare and operational staff at immigration removal centres to ensure people living with or at risk of HIV receive the best possible care.³ We have campaigned to increase access to HIV testing for people seeking asylum in initial accommodation. With BHIVA, we advocated for the end to the dispersal of people living with HIV seeking asylum away from the area where they are receiving treatment.⁴ This reduces the likelihood of people seeking asylum experiencing interruptions to the care when moved away from their existing clinic without much prior warning or preparation for onwards treatment.

But there is more work to be done. This report is based directly on the experiences of migrants living with HIV. Our findings do not claim to be representative of all migrants affected by HIV in the UK, but do highlight the key issues and barriers. The findings and recommendations also extend beyond HIV alone, and we need to consider wider healthcare and socio-economic barriers migrants face in the UK if we are to be successful in improving HIV outcomes.

This is a call to action. Decision makers and health systems must make urgent progress to ensure barriers are removed, that support is in place to improve quality of life for migrants living with HIV, and that we end new HIV transmissions.



3 National AIDS Trust, British HIV Association, 'Immigration detention and HIV Advice for healthcare and operational staff' (2019) https://www.nat.org.uk/sites/default/files/publications/immigration_detention_and_hiv.pdf

4 National AIDS Trust. (2014). The Dispersal Process for Asylum Seekers Living with HIV. https://www.nat.org.uk/sites/default/files/publications/Sept_2014_Dispersal_HIV.pdf

1.1 Summary of recommendations

Home Office

- The Home Office should end the No Recourse to Public Funds policy which provides inadequate protection from destitution.
- Healthcare staff should not be responsible for upholding 'hostile environment' policies.
- Charging migrants for access to healthcare should be ended as a practice that does more harm than good and the Government should not consider any further expansion of charging as this will only do further harm to public health.
- End all data sharing between the NHS and the Home Office. This practice should end in all circumstances and should be communicated to migrants so that they regain trust in the health system.
- The Home Office and Department of Health and Social Care should proactively provide information on HIV testing and treatment entitlements to all migrants applying for a visa, asylum or reporting to the Home Office. This should include information on how the healthcare system works and how to register with a GP.
- Information provided by the Home Office and the Department of Health and Social Care to migrants about their healthcare entitlements should be available in key languages and include information about interpretation services. This must state clearly that NHS services are required to provide interpreters where needed and that interpretation services are free and confidential.
- The Home Office should implement the guidance recommending that people with diagnosed HIV are not routinely dispersed away from the area they are receiving treatment.
- The Home Office must replace confiscated mobile phones and provide mobile data so people in initial and contingency accommodation can access GPs and HIV clinics.
- The Home Office should urgently work to ensure that the standards set out in the guidance 'Immigration detention and HIV: Advice for healthcare and operational staff' are met and that staff are provided the necessary information and training to implement the guidance. This should include, but not be limited to, a pilot that is used for learning.
- The Government must reconsider how detention is used for immigration purposes and review the Adults at Risk policy to ensure that detention of all vulnerable people ends.

UK Health Security Agency

- The UK Health Security Agency should consider migrants a key population and collect and publish more granular data on specific groups, including reporting in the published HIV data tables and annual report on all communities with over 500 cases of new transmissions in the last five years.

Department of Health and Social Care

- The Government must ensure GPs are funded and supported to offer HIV testing to new registrants and those known to be from a country of high HIV prevalence, in line with NICE guidelines.
- The Department of Health and Social Care should outline actions for HIV prevention and increasing testing in migrant populations as part of the HIV Action Plan.
- The national, regional and local HIV prevention campaigns should target prevention campaigns at migrant populations, with messaging outlining that HIV prevention, testing and treatment is always free irrespective of immigration status.

Clinical Commissioning Groups

- Clinical Commissioning Groups and new Integrated Care Systems should ensure that there is access to mental health services that can meet the specific needs of migrants living with HIV. This should include psychological support based within HIV clinical services and simple referral pathways and co-working between HIV services, local voluntary sector services, and mental health services in the area.

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).

Health and Social Care Committee

- The Health and Social Care Committee should investigate the health and economic impacts of the current lack of permission to work and No Recourse to Public Funds policy on individual and public health.

NHS bodies

- The NHS must review GP registration models and practice to understand why migrants face difficulties registering and accessing care at the GP.
- The NHS must support Primary Care Networks (or equivalents) to ensure GPs have access to specialist HIV advice from HIV clinics where needed. The Royal College of General Practitioners and British HIV Association should be involved in developing these processes.
- Health Education England, The Northern Ireland Medical and Dental Training Agency, NHS Education for Scotland and Health Education and Improvement Wales must work with Local Education and Training Boards (LETBs) or deaneries to ensure GPs receive sufficient training to enable them to deliver primary care that complements specialist HIV care.
- When patients (including those born abroad) register with a GP, present at A&E or when the NHS takes blood samples across all kinds of healthcare settings, there must be opt-out, not opt-in, HIV testing.
- Opt-out HIV testing should be included in the initial accommodation service specification across the UK.
- HIV support services have previously been funded by Local Authorities as a legacy of the AIDS Support Grant which no longer exists. NHS England, Clinical Commissioning Groups and local authorities should work together through new Integrated Care System (ICS) structures to ensure that HIV support services are funded and available to all people living with HIV as a key component of HIV care.
- NHS England and NHS Improvement should revise the service specification for primary care in immigration removal centres to incorporate recommendations contained in guidance published by National AIDS Trust and BHIVA: 'Immigration detention and HIV: Advice for healthcare and operational staff'.⁵

The Department of Culture, Media and Sport

- The UK Government must expedite actions to address digital exclusion that are being led by the Department of Culture, Media and Sport in partnership with other departments and with the backing of HM Treasury. Access to key services such as healthcare for particularly excluded groups, such as migrants, must be prioritised so that no one is left without digital access.

HIV clinics and clinicians

- HIV clinics and support services must maintain a mix of online and face-to-face services after the pandemic to ensure marginalised populations including migrants are able to access testing, treatment and support.

Commissioners

- Commissioners and providers should work with local community-led organisations to ensure better codelivery of services that can effectively address HIV stigma.

5 National AIDS Trust and the British HIV Association. (2019). Immigration detention and HIV: Advice for healthcare and operational staff. https://www.nat.org.uk/sites/default/files/publications/immigration_detention_and_hiv.pdf

1.2 HIV

HIV (Human Immunodeficiency Virus) is a virus that, when untreated, progressively damages the immune system. There are more than 105,000 people living with HIV in the UK and 94% of these people are diagnosed. This means that around 1 in 17 people living with HIV in the UK do not know that they have the virus.

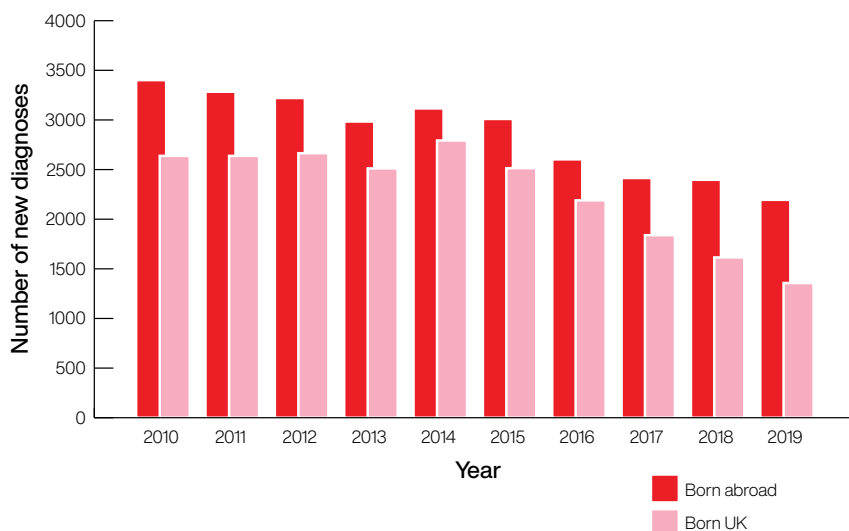
HIV can be passed on through some bodily fluids such as semen, vaginal fluids, blood, breast milk and rectal secretions. It cannot be passed on via saliva, urine or faeces. In the UK most transmissions are through sex without a condom, or without another form of protection (such as the HIV prevention drug, PrEP), when the person living with HIV is not on effective HIV treatment. This is usually when people have not yet been diagnosed.

HIV treatment is extremely effective and most people now start treatment as soon as they are diagnosed. Someone living with HIV, diagnosed early and on treatment can lead a full, active life with a normal life expectancy. Treatment reduces the level of HIV in the body to what is called an ‘undetectable viral load’. People living with HIV with an undetectable viral load cannot pass the virus on to sexual partners. This is known as U=U (Undetectable = Untransmittable). This is the case for the vast majority of people diagnosed with HIV in the UK; 98% of people diagnosed with HIV in the UK are on treatment, and 97% of those on treatment are virally suppressed which means they can’t pass the virus on.

The data on HIV and migration

Public Health England data showed that in 2019, 62% (2195/3552) of all new HIV diagnoses in the UK (including people previously diagnosed abroad) were among migrants and 38% were born in the UK (1357/3552) (Graph 1).

Graph 1: New HIV diagnoses 2010-2019



Migrants living with HIV are a diverse group and come from a range of countries and regions (see charts 1 and 2). For migrants identifying as gay and bisexual men (GBM) living with HIV, the largest proportion were born in Europe (41%). For heterosexual migrants living with HIV, the major proportion were born in Africa (68%).

Chart 1. New diagnoses among those born abroad by region of birth in 2019⁶

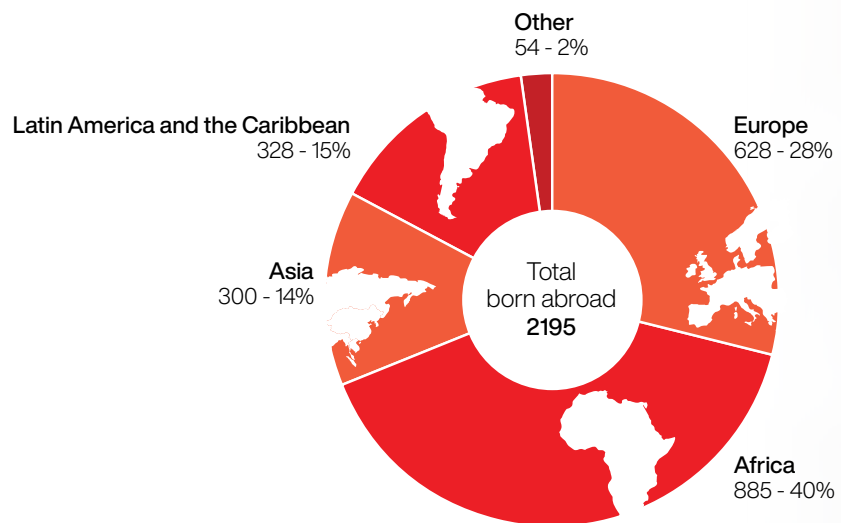
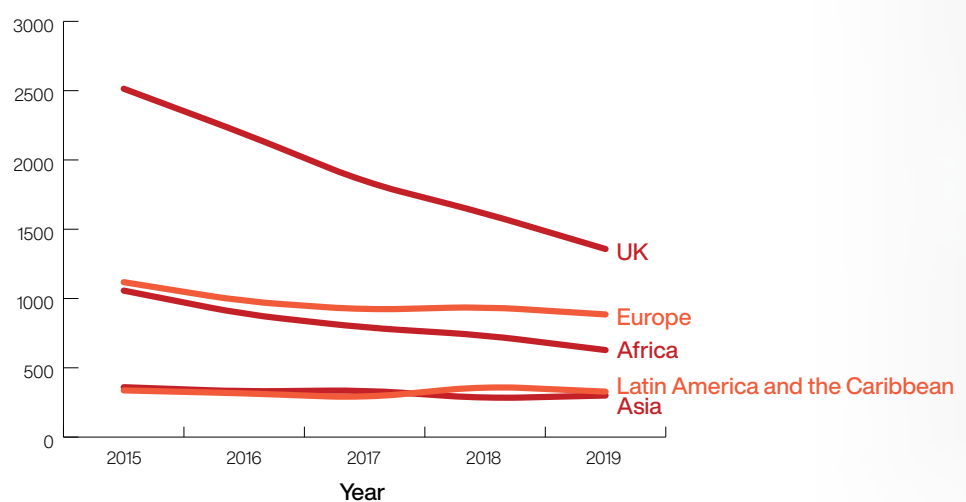


Chart 2. New diagnoses by region of birth, 2015 – 2019⁷



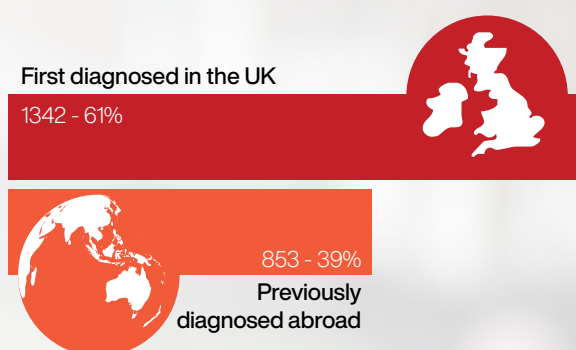
6 Public Health England. National HIV surveillance data tables to end December 2019. Tables No. 2: 2020.

7 Ibid.

Half of all migrants who were diagnosed with HIV in the UK in 2019 probably acquired HIV in the UK.

39% (835) 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.⁸

Chart 3: New diagnoses among migrants in the UK by place of first diagnosis, 2019



Although new HIV diagnoses have declined over the past 10 years for both people born in the UK and migrants, the decline is much steeper among people born in the UK.



⁸ 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/system/uploads/attachment_data/file/965765/HIV_in_the_UK_2019_towards_zero_HIV_transmissions_by_2030.pdf, 40.

1.3 Methodology

Peer Expert role

This project utilised a peer-led research design model. We employed three people living with HIV who were also migrants as Peer Experts to be a part of our research team. The team formulated interview questions and the Peer Experts led on interviewee recruitment and conducted the interviews.

Between March 2020 and January 2021, Peer Experts conducted in depth interviews with 22 people living with HIV and who were born abroad. All participants had to have accessed HIV care in London at some point since their arrival in the UK. The interviews took place in English and Spanish. Interpretation services were offered but not requested by any participants.

Peer Experts also led two focus groups with four participants each to better understand topics that emerged from the individual interviews. The first was on the impact of poverty on HIV care, and the second on how access to information affected engagement with HIV testing, treatment and care. Interpretation services were offered but not requested by any participants. Both focus groups were conducted in English.

Project advisory group

We convened an external project advisory group in March 2020. The group included migrants living with HIV, HIV clinicians, HIV support services, migrant support services, academics and other statutory partners including PHE and NHS England. We also held a wider stakeholder roundtable in January 2021 to share the initial findings from our research and draft recommendations. The roundtable was attended by the advisory group and representatives from migrant organisations.

Research participants

All interview participants were between the ages of 34 and 62 with median age of 47. All participants arrived in the UK between 1989 and 2020 with median year of arrival 2007. Thirteen participants were first diagnosed with HIV in the UK with the remaining nine first diagnosed abroad.

In addition, eight migrants living with HIV participated in two focus groups (four in each). We do not have the demographic data of these participants. All focus group participants were born abroad and living with HIV in the UK.

Chart 4: Interview participants by gender

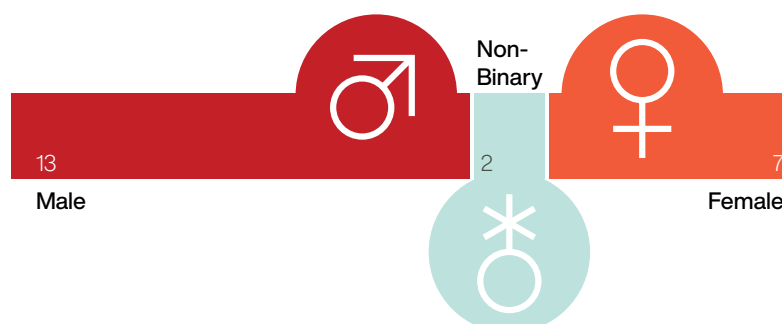


Chart 5: Interview participants by region of birth

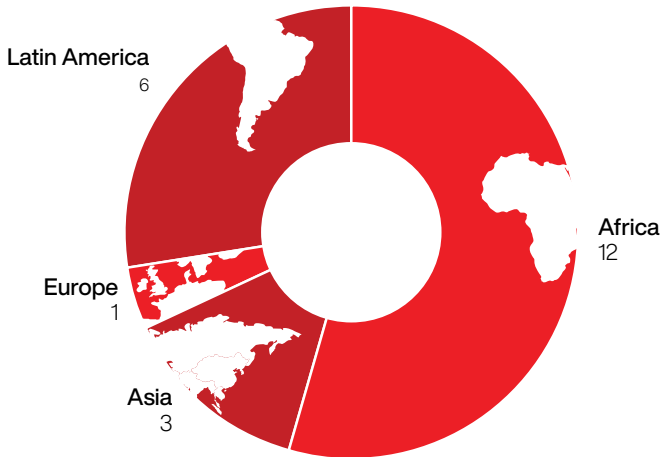


Chart 6: Stated sexual orientation of interview participants



Chart 7: Immigration status of interview participants at the time of interview

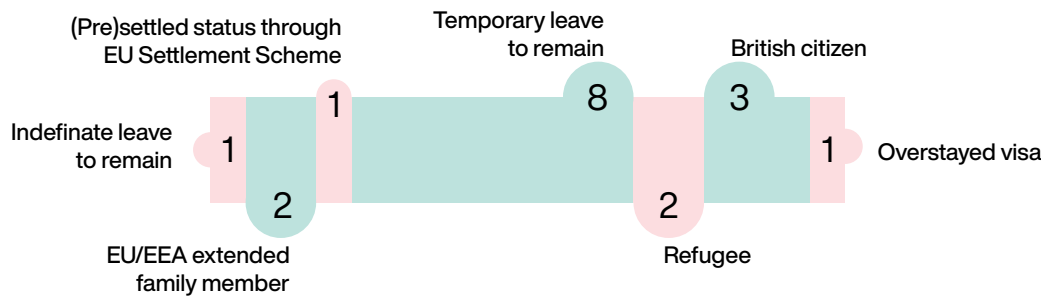


Chart 8: Employment status of interview participants who were employed

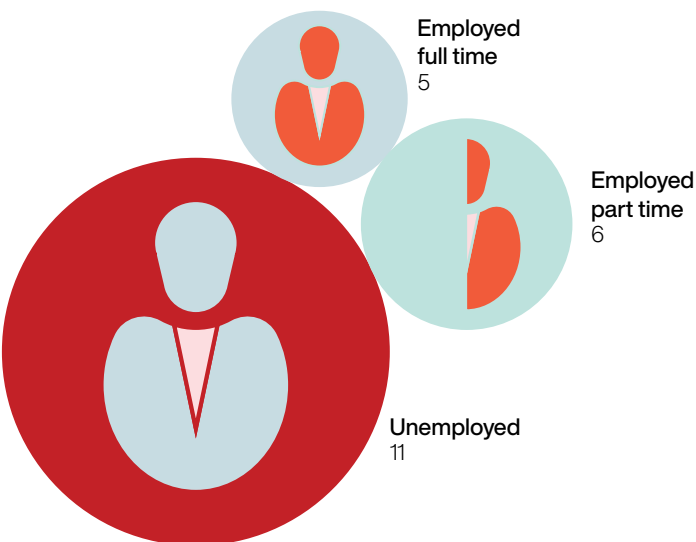


Chart 9: Stated religion of interview participants





Limitations of the research

This report does not assume all migrants living with HIV have the same experiences, needs or concerns. We tried to ensure that research participants have a breadth of experience. But, given the sensitive nature of the topic, some experiences of migrants living with HIV will not be represented. Many, but not all participants, were recruited through HIV support services, and our research shows that migrants with insecure immigration status reported more barriers accessing these services than those with secure immigration status. Only one interview participant did not have permission to be in the UK at the time of interview.

None of the participants were under the age of 30. There are a few potential reasons we struggled to engage this demographic, including the age at which people migrate to the UK and age at diagnosis. In 2019, most people diagnosed with HIV in the UK in 2019 were aged 25-49.

Women's voices are often missing from the discourse on HIV and are often underrepresented in HIV research. 7/22 (31%) of the interview participants identified as female, which is similar to the proportion of migrants diagnosed with HIV in 2019 who were female, 33% (721/2195). 7/12 (58%) participants born in Africa identified as female, which correlates with data from 2019. 58% (511/885) all new diagnoses among migrants born in Africa were female.⁹ No female migrants living with HIV born outside of Africa have been engaged in this research, despite there being 210 diagnoses among this group in 2019.¹⁰

We cannot be sure whether trans/non-binary representation is proportionate due to lack of data, but two interview participants identified as non-binary.

This project has largely spanned the COVID-19 pandemic. To ensure safety of participants and staff, interviews and focus groups had to be over the phone or video as opposed to in person as originally planned. We tried to support access as much as possible, however, the need to have access to either a phone or the internet may have excluded some people. Due to the sensitivity of the topic, participants often also had to find private spaces for interviews, which could be difficult for those in shared accommodation.

⁹ Public Health England. National HIV surveillance data tables to end December 2019. Tables No. 2: 2020.

¹⁰ Ibid.

2. Findings and recommendations

2.1 Experiences of care

2.1.1 Relationships with HIV clinicians

All interview participants were currently diagnosed with HIV and engaged with care. People living with HIV in the UK generally report high satisfaction with HIV clinical services.¹¹ This was the same for those we interviewed who were all engaged with care. They felt that their consultants were understanding of the impact HIV has on their overall health.

My doctor is very helpful; she is very kind I can ask all kinds of questions to her and she is always helpful to me.

– Male, 30s, born in Western Asia

All but one of the participants had an undetectable viral load at time of interview. Since Undetectable = Untransmittable, supporting migrants to engage with HIV care is hugely beneficial to improve their quality of life and to end new HIV transmissions.

Participants noticed a difference between HIV clinics and other areas of healthcare. Many reported going to their HIV clinic with non-HIV healthcare issues due to the trust they had in their clinicians and concerns about using other parts of the healthcare system.

2.1.2 Concern about accessing GPs

Participants were less positive about the care they had received from other areas of healthcare, particularly general practice.

I have found that most of the GPs that I have come to, when I have told them I am HIV positive, they don't take notice.

– Female, 60s, born in Southern Africa

Not all participants were registered with a GP. Some told us they were scared to register with a GP because they did not want to have to answer questions about their immigration status or show their biometric residence permits (BRP). One participant did not want to go to the GP before she applied for asylum since she didn't have an immigration status or address.

I did not want to answer overstayer and homeless questions because they are personal, and that I have to keep that to myself.

– Female, 40s, born in South Eastern Africa

¹¹ M Kall, C Kelly, M Auzenbergs, and V Delpech. (2020). Positive Voices: The National Survey of People Living with HIV - findings from the 2017 survey. Public Health England, London. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report_2019.pdf

None of the people we interviewed had been refused registration at a GP surgery, but some shared concerns about the potential to be reported to immigration enforcement if they tried to register with a GP.



To register for a GP, you couldn't just go to a GP because immigration would take you from there, you had to call around and ask friends which GP will take anyone.

– Male, 40s, born in West Africa

Another participant was encouraged by an HIV support service to register with a GP.



I was registered with a GP thank god. [...] not immediately but a year after in 2006 I was registered with a GP through Doctors of the World.

– Non-binary person, 60s, born in Southern Africa

All participants who shared concerns about registering with a GP were speaking about a period in which they had insecure immigration status. Those with secure immigration status did not share these concerns about GP registration. This suggests that migrants who do not have immigration status require more support to ensure they can access GP services.

Access to GP services is essential for migrants at risk of HIV. In spite of the barriers to access, heterosexual migrants with HIV who were diagnosed for the first time in the UK are twice as likely to be diagnosed in a GP surgery (20%) than heterosexuals born in the UK (10%).¹² The National Institute for Health and Care Excellence (NICE) recommends GP surgeries offer and recommend HIV testing to (among other criteria) new registrants living in high prevalence areas and those who are known to be from a country or group with a high rate of HIV infection and this shows how important this is.¹³

Among participants who had registered with a GP, there were mixed views. Some were happy, but others had concerns about their GP's understanding of HIV. Some GPs had admitted that they are not particularly knowledgeable about HIV, with one participant sharing that his GP had advised him to seek advice for a particular concern from the sexual health clinic because "the truth is that I'm not that familiar with HIV". This can result in patients being 'bounced' between primary care and HIV care.

Two participants reported difficulties getting GPs to write the necessary letters to the Home Office to support visa applications.

People living with HIV can choose whether their HIV clinic shares information with their GP. Participants who did share their status were overall impressed with the way their clinic and GP communicated. However, some still felt their GP did not listen to them or understand HIV well enough to appreciate their concerns.



I really trust my [HIV] doctor in Hammersmith. I like that if there is anything I know they will find it quicker than the GP.

– Male, 30s, born in Central Europe

¹² PHE data, provided upon request in email dated 21 April 2021.

¹³ National Institute for Health and Care Excellence. (2016). HIV testing: increasing uptake among people who may have undiagnosed HIV. NICE guideline [NG60] <https://www.nice.org.uk/guidance/ng60/resources/hiv-testing-increasing-uptake-among-people-who-may-have-undiagnosed-hiv-pdf-1837567043269>

Concerns about GPs' understanding of HIV, as well as a widespread reluctance to register with a GP practice, mean that migrants regularly go to their HIV clinic for non-HIV health needs. HIV clinics however are not commissioned to provide non-HIV services and cannot always address these needs. Everyone in the UK has the right to primary care, but many of the migrants we interviewed were not aware of this right.

Recommendations:

- The NHS must review GP registration models and practice to understand why migrants face difficulties registering and accessing care at the GP.
- The NHS must support Primary Care Networks (or equivalents) to ensure GPs have access to specialist HIV advice from HIV clinics where needed. The Royal College of General Practitioners and British HIV Association should be involved in developing these processes.
- The Government must ensure GPs are funded and supported to offer HIV testing to new registrants and those known to be from a country of high HIV prevalence, in line with NICE guidelines.
- Health Education England, The Northern Ireland Medical and Dental Training Agency, NHS Education for Scotland and Health Education and Improvement Wales must work with Local Education and Training Boards (LETBs) or deaneries to ensure GPs receive sufficient training to enable them to deliver primary care that complements specialist HIV care.

2.1.3 Limited access to testing and risk of late diagnosis

Of the 13 interview participants first diagnosed with HIV in the UK, eight were diagnosed late. Six participants were diagnosed late having been in the UK for more than 3-5 years, with the remaining two diagnosed late soon after arriving in the UK. Six were diagnosed either in Accident and Emergency or following referral to a sexual health clinic by another department after being treated for an indicator condition. An indicator condition is a health condition highly associated with HIV. They include pneumonia and chronic unexplained diarrhoea.

I was throwing up and having diarrhoea so the food which I was eating wasn't staying in my body and I became ill and very thin. And then after all this investigation that's when they referred me to go for a test.

– Female, 50s, born in Southern Africa

Similarly, a male in his 40s born in West Africa was experiencing persistent symptoms of fatigue, night sweats and unexplained weight loss. When he eventually went to Accident and Emergency he was diagnosed with HIV and tuberculosis. A doctor told him had he not come to hospital within two weeks, he could have died. He was advised that undiagnosed and untreated HIV had damaged his immune system and led to him developing tuberculosis disease.

Encouraging and facilitating migrants to proactively test for HIV reduces the likelihood that they will be diagnosed late, reducing their chances of mortality and ill-health and making it less likely that they will pass the virus on.

All of the GBM who were diagnosed with HIV in the UK were diagnosed in sexual health services and none were diagnosed late. This reflects a general trend where the proportion of GBM diagnosed late is lower than the heterosexual population.



We found that among interviewees, heterosexual migrants were not testing proactively and were more likely to be diagnosed late. Offering opt-out HIV testing across all kinds of healthcare settings would mean that migrants would more easily have the opportunity to test for HIV when they engage with the healthcare system. Failure to test on the occasions people do engage with healthcare is a missed opportunity to diagnose HIV in this population.

Recommendations:

- When patients (including those born abroad) register with a GP, present at A&E or when the NHS takes blood samples across all kinds of healthcare settings, there must be opt-out, not opt-in, HIV testing.
- The Department of Health and Social Care should outline actions for HIV prevention and increasing testing in migrant populations as part of the HIV Action Plan.
- The national, regional and local HIV prevention campaigns should target prevention campaigns at migrant populations, with messaging outlining that HIV prevention, testing and treatment is always free irrespective of immigration status.

2.1.4 The importance of HIV support services

HIV support services play an essential role in supporting migrants living with HIV in the UK. One person, who was suicidal after being diagnosed, told us how much she had benefited from peer support:



I was just amazed at the support I was getting because in Africa you don't get support. You're on your own...you can go and chat and meet other people. I thought I was the only one.

– Non-binary person, 60s, born in Southern Africa

Almost all interview participants had used a support service at one point since they had been in the UK. This may not be typical of all migrants living with HIV in the UK as recruitment was conducted in part through HIV support services in London. Also, migrants who are engaged with support services may be more willing to engage in research than those who are not even though participation was anonymous.

Support services were used for a wide variety of needs, often beyond HIV, including housing; financial hardship funds; help accessing benefits; immigration advice; and sexual health and relationship advice. HIV clinics played a crucial role in signposting migrants to support services. Many were referred to organisations when they were diagnosed to help them understand HIV and how to cope.

There were some who enjoyed and valued the wide range of people and experiences they'd been exposed to through support services.



The group was a mixture of straight and gay people, men and women, who were all newly diagnosed. Everyone had different experiences and I liked that. There was a woman in her fifties from an African country and it was so good to hear her experience.

– Male, 30s, born in Central Europe

Some participants also stressed the importance and value of culturally specific HIV support provided in their first language. One participant from Poland attended Polish workshops, not because of the language barrier but because he wanted to meet other Polish people living with HIV. One participant from Argentina stressed the importance of receiving support in Spanish. Another participant, a non-binary person from Latin America, noted that there aren't many specific services dedicated to Latin American migrants, let alone non-binary Latin American migrants.

Many people are scared when they arrive and have no access to information. There needs to be more projects that benefit the Latin American community – there aren't enough with a focus on Latin Americans.



- Male, 50s, born in Latin America

Many participants had engaged with HIV support services when they had no immigration status; the fact they were unable to access support elsewhere meant that they were a lifeline. However, it remained the case that among the migrants we interviewed, those with no immigration status reported being more reluctant to engage with support services. One HIV support service in London said that every year, approximately 100 people receive support but insist that no identifiable data on them is recorded for fear of being reported to the Home Office.

Since the Health and Social Care Act 2012, local authorities have been primarily responsible for sexual health services in England. The local authority public health budget was cut by £700 million in real terms between 2014/2015 and 2019/2020. This has resulted in a 25% cut in budgets for sexual health services. Whereas previously there was the AIDS Support Grant, there is no clear commissioning responsibility for HIV support services and few Clinical Commissioning Groups (CCGs) have taken this on. This, combined with the enormous pressure on local authority budgets, has resulted in a lack of adequate funding.¹⁴ This means that HIV support services are finding it harder to offer the culturally specific support that is needed.

Recommendations:

- 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).
- HIV support services have previously been funded by Local Authorities as a legacy of the AIDS Support Grant which no longer exists. NHS England, Clinical Commissioning Groups and local authorities should work together through new Integrated Care System (ICS) structures to ensure that HIV support services are funded and available to all people living with HIV as a key component of HIV care.

¹⁴ National AIDS Trust. (2017). HIV support services – The state of the nations. https://www.nat.org.uk/sites/default/files/publications/NAT_HIV_Support_Services_The_state_of_the%20nations%20_2017_FULLL.pdf

2.2 Damage caused by the ‘hostile environment’

‘Hostile environment’ policies were introduced in 2012 and aimed to make life more difficult for people without leave to remain in the UK by deterring them from accessing essential services, making it illegal to work, and making it illegal to let them property.

The hostile environment is also prominent in healthcare. Many secondary care services have a legal duty to assess patients’ eligibility for hospital treatment. Most hospitals have Overseas Visitors Managers to do these assessments. Patients who are unable to prove eligibility for NHS care can be charged 150% of the cost price of services. In addition, if a patient has a debt of greater than £500 outstanding for more than two months, NHS Trusts are currently required to share non-clinical patient data with the Home Office which can be used to track, detain and deport people.

2.2.1 NHS charging deters access to HIV testing and care

Testing and treatment for HIV is free to everyone in the UK, regardless of immigration status. Despite this, the hostile environment has a profound impact on the health and wellbeing of migrants living with or affected by HIV in the UK. Many participants told us that hostile environment policies deterred them from accessing testing, treatment and care, and that had contributed to their late diagnoses.



You are charging somebody who doesn’t have anything.

– Focus group participant

The charging system is complex. Some healthcare is free for everyone irrespective of immigration status. These services include GP and nurse consultations in primary care, accident and emergency services (not including any emergency services provided after being admitted as an inpatient, or at a follow-up outpatient appointment which are chargeable), and testing, treatment and care of some communicable diseases, including HIV.

This means that migrants who don’t have access to free care can get HIV treatment but will have to pay for specialist treatment for non-HIV health needs such as co-morbidities.

Although HIV care is free, the existence of charging is a barrier for all because people don’t always understand what they are entitled to and expect to get charged. Healthcare providers often don’t understand the system either so may give the wrong information to people or turn them away. Errors in the implementation of the charging system contribute to confusion.

One interview participant born in West Africa was billed for medical treatment for her daughter who sadly has since died. Despite receiving confirmation from the Trust that she was eligible for free NHS care, she was billed over £500,000 for her daughter's treatment which she has so far been unsuccessful in challenging. Bailiffs have visited her house, but she says they always leave feeling ashamed, and some even cry, when they see her family's circumstances. She reported being exhausted by keeping up with her own medication, caring for her children, and contesting the debt through legal action. As a result, she decided to take a break from her own HIV treatment.

I told them [the HIV clinic] let me take a break for myself. I just can't keep up with everything it's too much. They didn't want me to have a break, but they said if I feel it's what I want to do they would allow me to, so I took a break.



Although almost all participants reported positive experiences receiving HIV treatment and care in the UK, the hostile environment is still very present. A male in his 50s born in south-eastern Africa shared his experience of his first consultation with his new HIV clinician having moved to London. The consultant quizzed him for 50 minutes of the hour-long consultation about his immigration status, with only 10 minutes dedicated to his HIV. He was not clear why this happened.

2.2.2 Damage caused by NHS – Home Office data sharing

There was widespread fear of being reported to immigration enforcement if they did choose to access healthcare. Those with insecure immigration status were particularly concerned. One person, a female in her 30s born in West Africa, did not access any healthcare, including an HIV test, because she had overstayed her visa and was scared of being reported to the Home Office. She tested positive only when she was pregnant and had to go to hospital for antenatal care.

Another person, a victim of human trafficking in her 50s who was born in West Africa, was only diagnosed with HIV when she became very unwell and had to go to Accident and Emergency. She was scared to tell healthcare staff the truth about how she came to the UK because she thought they would report her to the police or immigration. When she was diagnosed, her CD4 count was only 25. Another male interviewee finally went to Accident and Emergency after months of severe back pain left untreated due to worries he would be detained if he went to hospital. He was diagnosed late with HIV and his back pain ceased with treatment, but he remains worried about his information being shared.



Being too afraid to access HIV testing and treatment means migrants risk being diagnosed late and have poor health outcomes. Overall, seven of the 12 participants first diagnosed with HIV in the UK were diagnosed late in Accident and Emergency or in hospital having been admitted for a serious illness (in many cases related to their HIV status and low CD4 count). Fears around data sharing deter people with diagnosed HIV from engaging with their treatment. HIV treatment involves taking medication every day. Missing doses can mean that the treatment stops working properly and HIV may become resistant to the medication. Longer interruptions to treatment will result in an increase in viral load. Data from PHE 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.¹⁵

One person we interviewed who had already been diagnosed in South Africa before coming to the UK did not access treatment for two years when she arrived.



I waited because I was undocumented, and people were saying it was criminal to come here and start treatment, so I delayed.

– Non-binary person, 60s, born in Southern Africa

Fear of data sharing extended beyond access to HIV testing and treatment. Everyone is able to register and visit a GP regardless of immigration status. In addition to the barriers migrants face accessing GP services explored in section 2.1.2, fear of data being shared with the Home Office affects willingness to register. One person said he was advised by his HIV clinician to register with a GP, but still prefers to go only to his HIV clinic because he knows he never has to share information about his immigration status.



...they never ask me for my BRP so I feel free, freer...[going to HIV clinic] than going to my GP where they will ask for all those details and everything.

– Male, 30s, born in West Africa

Others spoke about having to weigh up the fear of being reported with the need to access healthcare.



You have to make a decision - put at risk your health, and not access help, or put at risk your safety and stability and where you are.

– Male, 30s, born in Latin America

2.2.3 Migrants are unclear about what they are entitled to for free

Understanding of the charging system among the participants was poor. Some would have certainly paid the immigration health surcharge when applying for or renewing their visa. Many did not know what it was and were not clear they had paid it.



When I use something free, like flu vaccinations or other HPV vaccinations, I'm always thinking about it, do I have to pay for it or not? [...] My hospital didn't want any money, but I couldn't be sure.

– Male, 30s, born in Western Asia

¹⁵ 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/system/uploads/attachment_data/file/965765/HIV_in_the_UK_2019_towards_zero_HIV_transmissions_by_2030.pdf, 40.

Many were unaware of the details of the charging system, often basing what they thought of it on the healthcare systems in their country of origin. Some avoided engaging with healthcare on the assumption they would be charged. Many only learned when offered an HIV test that testing, treatment and care for HIV is free on the NHS. Improving access to information about the NHS among migrants at risk of HIV is explored below.

Immigration status of interview participants affected their concerns about being charged for healthcare, although even those with secure immigration status were worried. One asylum seeker who had already been diagnosed with HIV in South Africa did not access HIV care when he arrived in 2018 because he thought he would be charged.

I thought I had to wait until I got feedback [from the Home Office] but it was [their HIV support service] that told me that no I don't have to wait. I should just go.



– Male, 30s, born in West Africa

Some were concerned about the expansion of the charging system to include HIV care. One participant, a male in his 40s from Nigeria who has overstayed his visa, avoids all non-HIV related healthcare because of his status. He said he is worried that regulations will change after Brexit which will mean HIV care becomes chargeable.

Our research shows that charging migrants for any healthcare can deter them from engaging with all healthcare, including HIV testing, treatment and care. Ultimately this aspect of the hostile environment risks costing far more than it gains given that many of those charged simply cannot pay and are often deterred from accessing care until medical treatment becomes urgent and necessary (and potentially more costly). The impact on willingness to seek an HIV test, increasing likelihood of receiving a late diagnosis, is particularly clear. This has ramifications on individual and public health; those diagnosed late are more likely to have poorer health outcomes including co-morbidities and are more likely to pass the virus on when undiagnosed.

2.2.4 No evidence of so-called HIV 'health tourism'

'Health tourism' is the practice of choosing to travel abroad for medical treatment that is either unavailable or too expensive to access at home. For example, many people from the UK travel abroad to countries including Turkey for low-cost healthcare and/or shorter waiting times.

Among interview and focus group participants there was low, or no awareness of what HIV care was available to migrants in the UK before they travelled.

Furthermore, data from PHE shows that most migrants diagnosed with HIV in 2019 were diagnosed for the first time in the UK, meaning they either didn't have or didn't know they had HIV when they arrived.

Chart 10: New diagnoses among migrants in the UK by place of first diagnosis, 2019

Our research shows that even among those who were aware of their HIV status when they arrived, there was no evidence to suggest that their intention for migrating was to receive HIV treatment. In fact, many avoided HIV care on the assumption it was chargeable. The myth of health tourism is used politically to challenge rights to healthcare for migrants. Unsurprisingly it has an impact on migrants living with or at risk of HIV; many interview participants feel that the UK public believe they are here only to use the NHS.

There are also a high proportion of migrants living with HIV who acquire it after arrival in the UK. A study undertaken to examine probable country of HIV acquisition among people born abroad shows that, based on surveillance data from 2009 – 2018, 53% (49-57%) of GBM born abroad probably acquired HIV in the UK.¹⁶ Among heterosexuals born abroad, 53% probably acquired HIV post-migration.¹⁷

Recommendations:

- Healthcare staff should not be responsible for upholding ‘hostile environment’ policies.
- Charging migrants for access to healthcare should be ended as a practice that does more harm than good and the Government should not consider any further expansion of charging as this will only do further harm to public health.
- End all data sharing between the NHS and the Home Office. This practice should end in all circumstances and should be communicated to migrants so that they regain trust in the health system.

2.3 Wider barriers to engaging in care

2.3.1 Access to information about healthcare entitlements

Most participants were unaware of the quality and availability of HIV treatment in the UK before they arrived. Most found out that HIV testing and treatment was free through a friend, HIV support service, or doctor once they had been admitted to hospital for an illness often related to advanced HIV infection.

There is a lack of awareness among migrants about how to test. Similarly, there is a lack of information for migrants already diagnosed with HIV who want to access treatment.

16 Croxford, S. et al. (2020) Measuring endemic transmission of HIV in the United Kingdom: implications for HIV elimination, BHIVA Autumn Virtual Conference. Monday 23 November 2020.

17 Ibid.

One participant from Brazil was diagnosed in the UK in 2000 and said he only knew how to get an HIV test because he had worked as a cleaner at an HIV clinic in the late 1990s.

At the time with AIDS, the people used to die. I used to clean the rooms because not many cleaners want to do that job. [...] As a negative you do not have any support. It's only when you are positive that you have information.

”

– Male, 60s, born in Latin America

Many people we interviewed spoke about how hard it had been to find information about access to HIV testing, treatment and care in the UK. Some who had already been diagnosed with HIV before they arrived tried to find out about their healthcare entitlements in the UK but struggled. A male in his 50s born in Latin America, said that he had to find all the information for himself when he arrived. Nothing was accessible or provided to him. Another person from Latin America arrived in the UK with ten months of HIV medication, not knowing how or if it would be possible to get medication here.

Most people used the internet for information, but said it was tricky finding reliable sources especially as some said their level of English was not good when they first arrived.

I think it should have been clear enough in a letter that was sent to me that I have access to this, I have access to that. They should make it clear in a letter because it's new to me I haven't done it before I don't have anybody to ask how it's being done. So, if all that sort of information is clear in a letter [...], the asylum seeker or refugee will understand clearly what rights they have.

”

– Male, 30s, born in West Africa

Information provided should be targeted towards the migrant communities who need it. In order to inform which migrants are most in need of information about healthcare entitlements, we need more granular data to show which migrant groups are most affected by HIV. Data should inform the campaigns targeting HIV treatment and prevention among migrants and the development of generalised information and language support for migrants using the healthcare system.

Citizens of the EU and EEA who moved to the UK from 1 January 2021 for more than six months will no longer be able to access healthcare in the UK on the same terms as UK citizens; they will have to pay the immigration health surcharge. European migrants (figures not available to determine which are from EU countries) living with HIV made up 29% of all new diagnoses among migrants in 2019.¹⁸ All initiatives to improve access to information about HIV healthcare entitlements amongst migrants must take into account migrants from the EU and EEA no longer being able to access NHS as before.

18 PHE data, provided upon request in email dated 21 April 2021.

Recommendations:

- The Home Office and Department of Health and Social Care should proactively provide information on HIV testing and treatment entitlements to all migrants applying for a visa, asylum or reporting to the Home Office. This should include information on how the healthcare system works and how to register with a GP.
- The UK Health Security Agency should consider migrants a key population and collect and publish more granular data on specific groups, including reporting in the published HIV data tables and annual report on all communities with over 500 cases of new transmissions in the last five years.

2.3.2 Language as a barrier

Some participants had difficulties communicating with their HIV clinician and GP in English. They reported feeling like they could not ask the questions they needed to ask, or advocate for themselves in healthcare settings, because they didn't have the language to do so.

One participant, a non-binary person in his 30s from Latin America, admitted they delay accessing healthcare because they find it difficult to describe the condition as they don't have the words. Another, a Latin American in his 60s, occasionally travels to Portugal to receive medical care because of problems communicating with his doctors in the UK.



Sometimes I need to go to Portugal because I can speak Portuguese very well. I've lived here for 28 years and my English doesn't improve, sometimes you can't understand me. But when I talk with the doctor, I misunderstand the doctors.

Most were aware of interpretation services being available but did not feel comfortable asking to use them. One concern was around confidentiality, especially when a consultation is taking place over the phone which has become increasingly common during the COVID-19 pandemic. Participants were concerned that you don't know who the interpreter is because you can't see them. The fact you share a language might mean it's someone from within your community. There was also a sense of failure felt by some for needing an interpreter. Some felt ashamed that they couldn't communicate with healthcare professionals in English and that they had to adapt to the system and continue in English despite their health needs not being met.

A male in his 40s from Latin America, seeking asylum and housed in initial accommodation at the time of interview, does use an interpreter but feels that the interpreter provided by the clinic does not properly express what he says. He also reported that the interpreter refuses to acknowledge his sexual orientation. He depends on his treatment and he is worried about losing access to his treatment because of the ways and manners of his interpreter.

General Medical Council guidance states that all possible efforts must be made to ensure effective communication with patients, including making arrangements to meet patients' communication needs in languages other than English.¹⁹ NHS

¹⁹ General Medical Council. (2013). Good Medical Practice. Paragraph 32 https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530

England²⁰ and NHS Scotland²¹ guidance stipulates that a professional interpreter should always be offered for free and in preference of using friends or family. Where a professional interpreter is used, the healthcare professional should check there are no conflicts of interest between the interpreter and patient/family before starting the session. Healthcare staff should be encouraged to proactively offer interpretation services to people who may benefit given we know many are reluctant to ask.

Many people with good conversational fluency in English may not be able to understand or articulate themselves comfortably when speaking about their health and wellbeing. Migrants Organise and other community organisations have produced a Good Practice Guide to Interpreting which is available in Arabic, Bengali, Chinese, English and Somali, but it's now over ten years old and may not be in line with current guidelines²². There is a need for guidance in languages spoken by migrants who are more likely to be affected by HIV. Further data collection and research are required to deduce which key languages these are.

Recommendation:

- Information provided by the Home Office and the Department of Health and Social Care to migrants about their healthcare entitlements should be available in key languages and include information about interpretation services. This must state clearly that NHS services are required to provide interpreters where needed and that interpretation services are free and confidential.

2.3.3 HIV stigma and discrimination is a common experience

HIV stigma can have a devastating impact on anyone living with and communities affected by HIV, not just migrants. HIV stigma stops people from accessing HIV testing and treatment, hindering public health efforts, and significantly affecting the wellbeing of people living with HIV.

Almost all participants said that the perception of both migrants and of people living with HIV in the UK was unfair. Some of the perceived perceptions of HIV in the UK were not specific to migrants, but participants reported a general lack of tolerance towards migrants which intersected with HIV stigma and racism.

The perception of people living with HIV is that they are reckless, that they are to blame, that they are dirty.

”

– Male, 30s, born in Latin America

20 NHS England. (2018). Guidance for Commissioners: Interpreting and Translation Services in Primary Care. <https://www.england.nhs.uk/publication/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care/>

21 NHS Scotland. (2020). Interpreting, communication support and translation national policy. <http://www.healthscotland.scot/publications/interpreting-communication-support-and-translation-national-policy>

22 Migrants Organise. (2010). Good Practice Guide to Interpreting (Arabic, Bengoli, Chinese, English, Somali). <https://www.migrantsorganise.org/?p=21539>



“

The first thing is ‘they’re here to take our benefits from us, they are here again to reduce our health, they are here again to take our taxes’; I wish most of them would understand that most of us left good things back home. There wouldn’t any reason for us to be here if not that we are running for our lives.

- Male, 30s, born in West Africa

All participants said public perception of migrants and of HIV had not impacted their access to healthcare. But, the perception of HIV and migrants in their communities, including among family, co-workers and people at their church, did.

“

In my case it was my family which was discriminating against me and that affected me a lot. My brother, sister, nephew, nieces didn’t want to talk to me because they thought I was sick. It is particularly bad because you feel your family should support you.

- Male, 50s, born in South Eastern Africa

Perceptions of HIV in participants’ country of origin also affected access to HIV testing and care. There have been many advances in HIV science and medicine even in the last decade, but many people in the UK still remember the tombstone advert from the late 1980s and have a poor understanding of what it means to be living with HIV today. Similarly, some migrants may have an outdated understanding of HIV and experiences of stigma in the context of their own country of origin, which impacts their willingness to test for HIV. One participant who had worked in the medical field in Malawi refused to take an HIV test multiple times when offered by A&E doctors, believing that if he tested positive there was no treatment that would help him.

There were also reports of people working to address some of the community and culture-specific stigmas they experience. One participant from Southern Africa in her 60s felt she was playing her part in raising awareness of HIV in her community, and in turn reducing stigma, by speaking in her church and in local schools about HIV.

Recommendation:

- Commissioners and providers should work with local community-led organisations to ensure better codelivery of services that can effectively address HIV stigma.

2.3.4 Initial accommodation and dispersal can disrupt care

People seeking asylum are often dispersed away from London. This is especially problematic for those who have established HIV care in London and have support networks in place. Since 2012, it has been recommended that people living with HIV should not routinely be dispersed away from their existing clinic. However, this continues to occur; three participants were dispersed from London after 2012. One relied on an HIV support service in the city to which he was dispersed to connect him to a new HIV clinic.

Those who are placed into initial accommodation, which is voluntary, temporary accommodation for people seeking asylum, should have access to health checks that include HIV testing and link-up to necessary HIV care. Six people we interviewed had been provided with initial accommodation, and all had been diagnosed with HIV before they arrived in initial accommodation. Positively, none reported an interruption in their access to HIV treatment and care.

One person, a male in his 40s from Latin America, arrived in the UK during the COVID-19 pandemic and has been provided with initial accommodation. He had a reception health screen when he arrived. He was referred to an HIV specialist and received his medication three days later. He had brought very little medication with him and his treatment was not interrupted.

Migrant rights organisations have raised concerns about how COVID-19 has impacted the provision of HIV testing, treatment and care to individuals in initial accommodation.²³ Usually, when decisions on claims for asylum are made, people are exiting initial accommodation. However, because of the pandemic, this is happening at a much slower rate and, as a result, people seeking asylum are placed in contingency accommodation with little to no healthcare provisions. Most healthcare is being offered over the phone but not everyone seeking asylum has access to a phone in initial accommodation. There are also reports of phones being confiscated by the Home Office and these must be replaced to ensure people in initial and contingency accommodation can access the healthcare they need.²⁴

Recommendations:

- Opt-out HIV testing should be included in the initial accommodation service specification across the UK.
- The Home Office should implement the guidance recommending that people with diagnosed HIV are not routinely dispersed away from the area they are receiving treatment.
- The Home Office must replace confiscated mobile phones and provide mobile data so people in initial and contingency accommodation can access GPs and HIV clinics.

23 Refugee Council. (2021). "I sat watching life go by my window for so long": The experiences of people seeking asylum living in hotel accommodation. <https://media.refugeecouncil.org.uk/wp-content/uploads/2021/04/23053224/I-sat-watching-my-life-go-by-my-window-for-so-long-23rd-April-2021-1.pdf>. See also British Red Cross. (2021). Far from a home: why asylum accommodation needs reform. <https://www.redcross.org.uk/far-from-a-home>.

24 Ibid.

2.3.5 Immigration detention

None of the participants had ever been held in an Immigration Removal Centre (IRC). However, we know from advocacy work related to this and other projects that there continue to be instances where a person living with HIV in an IRC has been unable to access HIV treatment, sometimes for prolonged periods of time.

In 2002 the Home Office published standards stating that “All detainees must have available to them the same range and quality of services as the general public receives from the National Health Service”.²⁵ Unfortunately, we know that for people living with HIV this is often not the case.

Despite the name, a significant proportion of people who are held in immigration removal centres are not removed from the UK. Detention periods vary, with approximately one third of people held for more than 28 days while some have been detained for years. Of the 24,512 people released from immigration detention in 2019, 61% were released into the community.²⁶ This was an increase on previous years, but since 2015 this figure has consistently been higher than 50%. During the COVID-19 pandemic in 2020, release into the community (largely on immigration bail) increased significantly.²⁷ There are therefore considerable public health benefits associated with ensuring access to appropriate HIV-related care for those that need it.

There are a wide range of issues with the use of detention for immigration purposes, not least the human rights implications of the principle of removing liberty in this context (IRCs are part of an administrative not criminal procedure) and the practices within detention settings. Limits to HIV testing, prevention and treatment in detention are a breach of human rights, risk the health and wellbeing of individuals, and are harmful to public health. Further, the Adults at Risk Policy is not working effectively to prevent detention of people living with HIV in cases where they may be particularly vulnerable.

HIV prevention should be promoted in all detention facilities via opt-out testing and access to sexual health information and services. Those who are diagnosed with HIV should receive high quality treatment and care. Continuity of care for people who have already been prescribed HIV treatment should be prioritised when they enter the immigration removal centre. It is also essential that individuals living with HIV are supported to adhere to their treatment regimen as missing doses compromises the efficacy of the treatment and could result in drug resistance and poorer health outcomes.

To address some of the issues faced by migrants who have been subjected to the detention system, NAT and BHIVA have published ‘Immigration detention and HIV: Advice for healthcare and operational staff’ outlining how IRC and Short-Term Holding Facility (STHF) staff and the Home Office can meet their obligations under the law, and ensure that people living with HIV in immigration detention receive the best possible treatment and care and are treated with respect. Following a court

25 Home Office. (2002). Detention Services Operating Standards Manual for Immigration Removal Centres. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/257352/operatingstandards_manual.pdf

26 The Migration Observatory at The University of Oxford. (2020). Migration Observatory analysis of Home Office Immigration Statistics, Immigration detention data tables, year ending December 2019, Table Det_D03. <https://migrationobservatory.ox.ac.uk/resources/briefings/immigration-detention-in-the-uk/>

27 Home Office. Immigration detention summary tables Dt05, Dt05q, Detailed immigration detention datasets Det D03, <https://www.gov.uk/government/statistics/immigration-statistics-year-ending-march-2020/how-many-people-are-detained-or-retained#data-tables>

case in 2019 that revealed discriminatory behaviour of IRC staff,²⁸ the Home Office recognised action needed to be taken to prevent this happening again. Within the National Asylum Stakeholder Forum (NASF) Detention sub-group, the Home Office has therefore agreed to a pilot to support implementation of the NAT/BHIVA guidance. This will be vital to understanding the barriers to, and opportunities for achieving the ambitions of the guidance.

Recommendations:

- NHS England and NHS Improvement should revise the service specification for primary care in immigration removal centres to incorporate recommendations contained in guidance published by National AIDS Trust and BHIVA: 'Immigration detention and HIV: Advice for healthcare and operational staff'.²⁹
- The Home Office should urgently work to ensure that the standards set out in the guidance 'Immigration detention and HIV: Advice for healthcare and operational staff' are met and that staff are provided the necessary information and training to implement the guidance. This should include, but not be limited to, a pilot that is used for learning.
- The Government must reconsider how detention is used for immigration purposes and review the Adults at Risk policy to ensure that detention of all vulnerable people ends.

2.3.6 Poverty and financial insecurity impacts HIV care

We know that many migrants, as well as many people living with HIV, are disproportionately affected by poverty. It was clear that poverty intersects with issues around access to HIV and wider healthcare, poorer mental health and wellbeing. Poverty forces people into situations more likely to put them at risk of acquiring HIV and makes it harder for them to engage with care and access effective treatment to stay healthy once living with HIV.

It's difficult if you have no money. It's difficult to go to the hospital when you don't have any money. If you're already ill and you need a cab and you don't have money you will struggle to get to the hospital. Sometimes it's difficult just to afford a bus.

”

– Focus group participant

One quarter of those we interviewed had experienced homelessness since arriving in the UK.

Hostile environment policies prohibiting people with certain immigration statuses from working also drive poverty among the migrant population. One quarter of all interview participants were currently not working because they did not have the right to work. Not being able to work increased fears around having to pay for healthcare and intersected with insecure immigration status and fears of data sharing between the NHS and the Home Office.

28 Diane Taylor. 13 January 2020. Woman 'feared for life' after guards restrained her in immigration centre. The Guardian. <https://www.theguardian.com/uk-news/2020/jan/13/woman-feared-for-life-after-guards-restrained-her-in-immigration-centre>

29 National AIDS Trust, British HIV Association, 'Immigration detention and HIV Advice for healthcare and operational staff' (2019) https://www.nat.org.uk/sites/default/files/publications/immigration_detention_and_hiv.pdf



When you don't have any status it's very difficult. We're not even allowed to work so if someone has no status in the country, how are they going to get the money? If you really don't have status you can't do anything.

- Focus group participant

Additionally, many migrants subject to immigration control have 'no recourse to public funds' (NRPF). This means they have no entitlement to most welfare benefits, pushing them further into poverty. For those who are seeking asylum, they only receive £39.63 per week. There is little understanding of the health implications of this policy, although our findings were that poverty impacted on HIV and other health and wellbeing outcomes. Many participants relied on hardship funds from voluntary sector organisations; this is not sustainable and can only ever meet short-term, immediate needs.



I didn't qualify because I was an overstayer I was living undocumented. Because of that I couldn't qualify for any support. The only support I was getting was from the community.

- Non-binary person, 60s, born in Southern Africa

Food insecurity and the cost of travelling to medical appointments were factors which participants felt particularly affected migrants living with HIV. Good nutrition is key to support the immune system and reduce the risk of developing heart disease, diabetes and osteoporosis. It is particularly important for people living with HIV as longer-term side effects of HIV medication include osteoporosis, heart disease and metabolic changes. Furthermore, some HIV medication must be taken with food. Some participants spoke about their difficulties affording food due to being unable to work or access benefits.



If you don't have enough money to travel it becomes a problem. Also food in the house. There's nothing worse than being sick and having no food.

- Focus group participant



When you're on a low income it affects you in a lot of ways. Stress because you can't manage. Some people can go into depression, you feel helpless. It's very important to have a little bit of cash so you can survive so you can control your HIV.

- Focus group participant

This severe financial insecurity can also mean migrants are forced into transactional relationships, exchanging sex for accommodation or immigration status. This makes people even more vulnerable to harm such as domestic violence, including coercive control. Insecure housing status can also compromise ability to access treatment or prevention.



They were asking for too much. They wanted proof of address, they wanted bills, and the place I was staying the person who was accommodating me wouldn't release all these documents. You know how it is like, you have to sleep with me else I won't do some certain things with you. I won't assist you in certain ways. So, I couldn't get any support from anywhere.

- Male, 30s, born in West Africa

Recommendations:

- The Health and Social Care Committee should investigate the health and economic impacts of the current lack of permission to work and No Recourse to Public Funds policy on individual and public health.
- The Home Office should end the No Recourse to Public Funds policy which provides inadequate protection from destitution.

2.3.7 Migrants with HIV often have significant mental health support needs

We know that people living with HIV are more likely to have poor mental health. Concerns around immigration status, racism, HIV stigma and financial insecurity compound this and most participants reported struggling with their mental health since they had been in the UK.

Poor mental health had a direct impact on adherence to HIV treatment among those who had felt suicidal in the past.

I wasn't on anything [medication] again. Because at that time a lot of things were going on in my head. I was actually thinking of suicide... I was just saying let's just end everything, it's no use I can't go back home, I can't do anything. That's when I decided to seek asylum.

”

– Male, 30s, born in West Africa

Another participant reported not taking their medication when their application for refugee status was refused and they were feeling suicidal. Their application has since been granted, but they still struggle with the ongoing impact on their mental health and receive regular treatment for depression and anxiety.

Almost all participants said they feel isolated and lonely. Many said that public perceptions of migrants and of people living with HIV made them feel alone. One person from Turkey said living with family but feeling unable to share his HIV status with anyone contributed to his isolation. Another person from Pakistan said he does not have any relatives or friends in the UK, so he is on his own with little support.





I can't do a lot of things because of that [public perception of migrants]. It made me be a little bit on my own. Not socialise very well. It's been difficult.

– Male, 40s, born in West Africa

Most participants who reported poor mental health said they relied on support services to manage it. Some had success in accessing psychological support on the NHS. One person was referred to a psychiatrist by his HIV clinician to help him come to terms with his diagnosis:



I had to see a psychiatrist. I had to accept my condition. I had a few mental issues let's put it that way. [...] It was due to the HIV diagnosis and things around stigma about it, who to tell and who not to tell, and there were things going on with my mind which were affecting my mental health and my every day-to-day life, so I had to get help with that.

– Male, 30s, born in Western Asia

Not all were so fortunate. Another person from Mexico has been unable to access mental health support because of the enormous waiting list for psychological services.

Recommendations:

- Clinical Commissioning Groups and new Integrated Care Systems should ensure that there is access to mental health services that can meet the specific needs of migrants living with HIV. This should include psychological support based within HIV clinical services and simple referral pathways and co-working between HIV services, local voluntary sector services, and mental health services in the area.

2.3.8 COVID-19 has impacted access to services and support

The interviews and focus groups with migrants living with HIV took place during the COVID-19 pandemic. Some participants mentioned the impact the pandemic had on access to healthcare, mental health services in particular. Concerns about the pandemic often intersected concerns about long-term financial insecurity.

One focus group participant, who worked in education, lost her job in March 2020 when schools were closed. Since she had Indefinite Leave to Remain, she was eligible for Universal Credit. It usually takes around five weeks to receive the first payment, therefore, she relied on an HIV support service to refer her to a food bank to help her through that period.

I am worried about what's going to happen... with COVID, work, finances. Right now, with COVID I am worried a bit about accessing healthcare. I am worried about things collapsing.

”

- Male, 30s, born in Latin America

Almost all participants had reported feeling lonely since arriving in the UK, and the lack of face-to-face peer support during the pandemic has exacerbated this for some.

I depend on [peer] support groups, and I need them. I've been badly affected because I depend on them. I'm feeling lonely because I'm far away from everyone. Usually, we support each other but now we're just meeting on Zoom.

”

- Male, 40s, born in South Eastern Africa

Recommendations:

- HIV clinics and support services must maintain a mix of online and face-to-face services after the pandemic to ensure marginalised populations including migrants are able to access testing, treatment and support.
- The UK Government must expedite actions to address digital exclusion that are being led by the Department of Culture, Media and Sport in partnership with other departments and with the backing of HM Treasury. Access to key services such as healthcare for particularly excluded groups, such as migrants, must be prioritised so that no one is left without digital access.

3. Conclusion

The term 'migrants' describes a hugely diverse group of people within UK society, with a wide range of backgrounds, viewpoints and experiences. In this project, we aimed to find out more about the disproportionate impact of HIV on people living in the UK born abroad, and to better understand how migration status might affect HIV and other outcomes. We worked with paid peer experts, all migrants living with HIV in London, who co-led the design and delivery of the research that has fed into this report. This unique project and report provide invaluable insight into the experiences of migrants living with HIV and why we see some of the disproportionate impact of HIV on migrant populations.

Migrants face significant barriers accessing HIV testing, treatment and care in the UK. If we are to be successful in achieving our aim of ending new HIV transmissions by 2030, migrants must be considered a key population in the UK's response to HIV by the Government, UK Health Security Agency and wider healthcare and HIV sectors. London and other Fast Track Cities should also be considering the specific inequalities affecting migrants and how these affect HIV outcomes.

The publication of more granular data on those living with HIV who were born abroad should inform better targeted campaigns and initiatives. All actions undertaken should be co-designed with community; migrants living with or at risk of HIV must be involved, leading initiatives and tailoring services.

A significant proportion of people we spoke to shared concerns about accessing primary care services through GPs, as well as concerns about the level of understanding of HIV among GPs. This resulted in many choosing to go to their HIV clinic for non-HIV related health needs. People also faced further barriers that prevented them from seeking out HIV testing and care. Many delayed accessing HIV testing and treatment after arriving in the UK, largely due to hostile environment policies. Even some of those previously diagnosed abroad delayed accessing treatment after arrival.

Fears and confusion around being charged for NHS services, and the practice of data sharing between the NHS and the Home Office, were the greatest deterrents to accessing HIV testing, treatment and care. The hostile environment must be dismantled in healthcare settings so that migrants regain trust in the health system. Given the lack of proactive testing by some migrants, opt-out testing should be implemented where possible across all healthcare settings to reduce missed opportunities to diagnose and treat HIV.

It is essential that migrants are aware of their HIV healthcare entitlements and have access to accurate, up-to-date information available in key languages. The Government should provide this information to migrants as they interact with the immigration system.

If we are to be successful in improving HIV outcomes, it is crucial to address wider healthcare and socio-economic barriers affecting key populations, including migrants. Poor mental health, stigma and discrimination, language barriers and poverty all have a profound impact on migrants living with or at possible risk of HIV. Further research is required to understand the health and economic impacts of current policies preventing paid work and No Recourse to Public Funds on individual and public health.

HIV support services are essential in supporting migrants living with HIV in the UK, and should be funded and available in every area in order to provide culturally specific support to address the specific and complex needs of migrants living with HIV in the UK.

Our recommendations provide decision makers working in Government, immigration and healthcare focus points to target actions. These recommendations must be urgently implemented in order to improve the HIV health outcomes and quality of life of migrants living with or at risk of HIV in the UK.

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Advisory Group

Adamma Aghaizu

Anna Miller

Christine Kelly

Denis Onyango

Dr David Asboe

Dr Rageshri Dhairyawan

Emma Ginn

Fatima Wurie

James Skinner

Khaiser Khan

Lisa Doyle

Mina Kakaiya

Sophie Strachan

Steve Worrall

Public Health England

Doctors of the World UK

NHS England Health & Justice

Africa Advocacy Foundation

Chelsea and Westminster Hospital NHS Trust

Barts Health NHS Trust

Medical Justice

Public Health England

Medact

NAZ

Refugee Council

Activist

Sophia Forum

Positive East





We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.

Aztec House, 397-405 Archway Road, London, N6 4EY
T: +44 (0)20 7814 6767
E: info@nat.org.uk

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No. 297977 and a Company Limited by Guarantee No.
2175938, (registered in England and Wales)

Registered Office: Aztec House,
397-405 Archway Road, London, N6 4EY