



# Listening to the experiences of people living with HIV.

January 2026



## The WHAT? Centre

The What? Centre is a Young Person's advice and counselling service. Their core work is providing one-on-one counselling for young people on a range of issues. They also specialise in supporting LGBTQ+ individuals and host LGBTQ+ support groups.



Beehive is a sexual health and LGBTQ+ support service based at The What? Centre. They provide sexually transmitted infection (STI) testing, advice, counselling and support groups. The HIV support group meets monthly.

## What we did

We joined the HIV support group for one of their monthly sessions. During the meeting we spoke to people attending and explored their experiences of health and social care. We wanted to listen to the experiences of people who don't often have their voices heard, including people who live with HIV.

We set out to explore:

- Peoples experiences of accessing primary care services.
- People's experiences of care with HIV.
- People's wider experiences of health and social care services.



**We spoke with 4 people who live with HIV.**

As we only spoke to four people living with HIV, the experiences shared may not reflect the experiences of all people living with HIV in Dudley borough.

# Experiences of GP services

“GPs need to have more awareness of HIV. They should know the basics about HIV, like how I don’t shake things off as quickly.”

Three of the people we spoke to were registered with a Dudley borough GP and one was registered with a GP in Sandwell.

Participants told us that they feel GPs often lack sufficient knowledge of HIV and how it impacts their health.

“Training about HIV needs to be rolled out to GPs.”

One person told us that they were prescribed Gaviscon by their GP, which their consultant immediately changed as it was not suitable to be prescribed with their HIV medications.

“I was prescribed Gaviscon by my GP. When I saw my consultant they said that I can’t take it because of my HIV medication. GPs should know that I can’t have certain medications.”

Another person felt that their GP did not understand the full impact of HIV on their wider health and said they don’t “shake things off as quickly” as other patients.

“It takes me longer to heal from an infection.”

This feedback suggests that some GPs may not know of the wider impacts of HIV and potential interactions with antiretroviral therapy, support from specialist services could assist the primary care team when treating people with HIV.

# Experiences of GP services

“GPs should know and make an effort.”



We heard from a person who feels that when discussing other issues, their doctor put it down to HIV, even when their viral load is well managed.

**“If I tell the doctors about something, they say it’s my HIV, but my viral load is very low. Some doctors don’t understand that.”**

This suggests that HIV can sometimes be seen as a primary diagnosis and leave patients feeling as though other symptoms and conditions are overlooked.

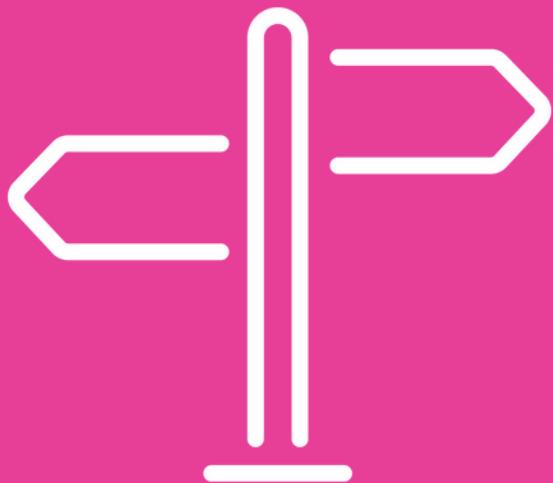
Some staff members demonstrate a lack of understanding towards people living with HIV, with one person who believes their GP was cleaning the practice due to their status.\*

**“I have noticed my GP cleaning everything down when I have visited and I think it’s because they know my status.”**

*\*Standard universal infection control procedures are sufficient to prevent transmission of HIV within a clinical setting, extra cleaning beyond normal infection control is not required when treating someone with HIV (General Medical Council, 2009)*

# Booking primary care appointments

“I went for my pneumonia vaccine as the consultant told me I could have one. I called the GP and was booked in for the next day. They also gave me my shingles vaccine.”



People attending the group told us they felt personal questions asked as part of triage processes were “invasive” and could cause distress when booking appointments.

*“The receptionist always asks me why I need to book an appointment. I feel it’s an invasion of my privacy. They’re not medically trained. We should be able to see a doctor if we’re ill due to our status. It’s not fair to be asked what’s wrong with me, what if it’s personal.”*

Disclosing personal information can be particularly difficult for people who have HIV and may have previously experienced stigma.

Triage systems are in place in the majority of GP practices to provide a way of assessing patient need and arrange appointments to prioritise those with the highest need.

However, these triage systems can cause confusion, one participant thought ‘triage’ was “something to do with pregnancy” and other patients did not understand why they should disclose medical information to call handlers.

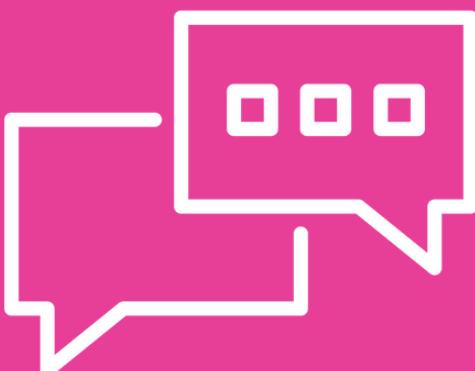
GP practices might consider patient education campaigns to communicate these new processes and call handlers could maintain awareness that patients may have different levels of knowledge of triage processes.

One participant told us that they would like it to be easier to book longer appointments to discuss multiple issues or complex health conditions.

*“I went to the GP with a headache and other symptoms. The GP told me I was only allowed to talk about one thing at a time.”*

# Communication

“Sometimes I have received feedback in a letter, but it wasn’t discussed in my face to face appointment.”



We heard how issues with communicating test results and prescriptions led to confusion, delays and complications with treatment.

One patient received an email stating they needed a GP appointment for test results, after a receptionist told them the results were “okay”.

“I went for a blood test and a scan. I called up and spoke to the receptionist who told me the results were ok. Three days later I received an email to say I needed to book an appointment to see a GP. They were thyroid results and it was important.”

Another person ran out of their blood pressure medication for two days because the prescription was delayed due to miscommunication.

Language barriers can also lead to confusion.

“English is my second language, when I get frustrated I stutter or I can’t remember English words.”

Digital and automated system can also lead to issues with communication.

“When I try to book appointments online, half the time the app is playing up.”

Maintaining clear communication with patients, in a way that meets individual need, can improve trust and patient outcomes.

## Specialist care

"They take us the way we are."



Experiences of specialist HIV outpatient appointments were overwhelmingly positive, with participants saying they received respectful and dignified treatment.

**"They treat me like a princess. I am treated with respect and dignity and I forget I've got HIV."**

Another person said they receive "good service at Russells Hall Hospital HIV Clinic."

Participants spoke briefly about their experiences of accessing NHS dental services. There was a mix of feedback with some people saying they attend their dentist regularly.

**"I go every six months to the dentist and I have no issues."**

One person told us that they are unable to book dental appointments over the phone.

**"I have to go in and book appointments as I can't get through on the phone."**

We heard from one person who said the cost of dental treatment has prevented them from seeking care.

## Dentistry

**"My denture is hurting but it's too expensive to replace."**



# Recommendations

Participants provided feedback on a range of healthcare services. Whilst we heard stories of people being treated with dignity, quick appointments and friendly staff, feedback suggested possible gaps in clinician knowledge, communication barriers and issues booking appointments.

A major concern raised was the perception of stigma and lack of understanding by some staff about the management of HIV.



## Triage systems

- Services that use triage should let patients know what triage is and how it works.
- Maintain patient dignity and confidentiality during the triage process.
- Reassure patients that only necessary clinical information is taken during the triage process and is kept confidential.



## Knowledge

- Consider consulting external professionals with more knowledge of HIV treatment and management when faced with knowledge gaps.
- Direct patients to specialist where appropriate.
- Educate staff on HIV and its impact on health and infection control.



## Dignity and care

- Maintain professional and caring manner to ensure patients feel respected and understood.
- Uphold patient privacy and ensure HIV status is not shared without the express permission of the patient or if clinically relevant.
- Ensure sensitive information is not discussed where other patients or members of the public can overhear.

# Responses

*"Thank you so much for providing this lovely feedback from our patients, we truly appreciate their positive comments.*

*We take great pride in providing high-quality care and are delighted to hear that our patients feel safe and supported by our team."*

**-Oak Clinic Team**

*"This report highlights the importance that people living with HIV (PLWH) have their voices heard and the necessary changes are made to ensure their medical needs are met.*

*Sadly, stigma around HIV still exists. However, I feel with a bit of education, this could really help improve the experiences of PLWH when accessing health care services, and remove any barriers in doing so.*

*Thank you to our group members for bravely sharing their stories, and to Healthwatch Dudley for their vital work and giving underrepresented communities a voice."*

**-Luke Spaull, Project Co-ordinator, The What? Centre**



# Thank you

Thank you to The What? Centre for inviting us to speak to and hear from people who are living with HIV.

We want to thank the people who candidly shared their experiences with us, their feedback has highlighted gaps in clinician awareness of HIV and barriers to care.

## Note

Quotes and comments may have been edited for clarity or to maintain anonymity.

## References

General Medical Council. (2009). Confidentiality: disclosing information about serious communicable diseases.



**If you would like this report in another language or format please contact us.**

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to quality**

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