



THAMES VALLEY POSITIVE SUPPORT EVALUATION REPORT

Barriers to accessing healthcare for those affected by HIV, and people from the LGBTQIA+ community living in East Berkshire (Slough, Windsor & Maidenhead and Bracknell)

Introduction

Established in 1985 Thames Valley Positive Support (TVPS) supports people affected by HIV living in Berkshire and Hampshire. In 2022 we broadened our service remit to offer support to the LGBTQIA+ community in Slough, Windsor, Maidenhead and surrounding area.

Across both groups we offer emotional and practical support with the aim of ensuring that anyone referred to our service can live the life they want to regardless of the stigma or discrimination they experience because of their gender identity, sexuality or HIV status.

Executive Summary

The Frimley Health and Care Community Engagement Fund awarded TVPS funding to hold focus groups with services users from both our HIV support service and LGBTQIA+ service. The fund provides grants to facilitate engagement and listening exercises with local communities to identify what matters to them. The aim of our project was to understand the barriers both groups encounter in accessing health care.

Project Overview

TVPS held 4 focus groups to ascertain the barriers to accessing health care. We quantified health care as being any setting that someone would access for medical care including GPs, hospitals, screening services and walk in centres. We quantified medical care as including routine screening, seeking advice for new concerns, and ongoing treatment for existing health concerns.

We kept the focus groups small (maximum of 8 people) to allow everyone time to talk, 9 people preferred to speak on a one to one basis with a member of staff. We were mindful that some conversations during the focus groups may be triggering and ensured both staff and our counsellor were available for anyone who needed further support.

The focus groups were planned for an hour although 2 were slightly longer, the information we collated from the groups was recorded anonymously All of those attending the groups live in the Frimley ICB area.

We held separate focus groups for those living with HIV to protect their confidentiality, all groups were held at our safe space in Slough.

For ease we have split our findings according to client group.

People living with HIV

We received feedback from 17 people living with HIV. We asked them what barriers they experience when accessing health care.

15 people worried about experiencing stigma if they shared their HIV status with healthcare professionals especially someone they had not received care from in the past

2 people had not told their GP

16 people worried about where their information was stored and who had access to their HIV status

12 people had operations in the last 5 years, all of them were last on the list to be seen and felt discriminated against, feeling that this was because of their HIV status

All of them said that when they disclosed their HIV status, no health professional had ever checked if they were undetectable and therefore untransmittable.

Feedback included:

"I wish all my healthcare could be through the sexual health clinic, they know my medical history, understand which medications interact with my HIV medication and the staff there are longstanding and provide excellent continuity of care, nowhere else matches their service."

"I felt discriminated against by a health care professional because of my HIV status, I saw HIV written in capitals on my notes for a procedure that was nothing to do with my HIV status. Its puts me off having anything else done."

"I refused to attend a physio appointment because the letter given to me by my GP said I was HIV positive, the physio appointment was for my knee and it wasn't in anyway related to my HIV. Why did the physio need to know? My HIV status should be private."

"I worry about calling my GP to get an appointment, my HIV status is on their records but in the past I've had to tell them I'm positive because the thing I needed to see my doctor about might have been related I wasn't sure, the GP receptionist goes to my church."

"I had some teeth taken out at Wexham, I was the last to be seen I'm sure it was because I've got HIV as the same thing happened last time. Its really unfair I'm undetectable why do we get treated like that when they could have operated on the person before me who might be undiagnosed with HIV."

"I had an operation at Heatherwood, I was last on the list, they said it was because I was positive I was mortified."

“I don’t think healthcare professionals understand about HIV, its not my job to keep trying to educate them but someone should.”

“Sometimes it feels like the sexual health clinic is very separated from other areas of clinical care, wouldn’t it be easier if the clinic was within the hospital setting, or with other blood borne viruses why is HIV segregated in this way – we go to a tucked away clinic like they’re ashamed of us.”

“When I was admitted to hospital I didn’t know if I should tell them about my HIV, I wasn’t admitted because of it but I couldn’t find a quiet time to let them know, it was so busy and the cubicle curtains were really flimsy so it didn’t feel confidential, in the end I wrote it on a text message and showed the nurse and she wondered what I was doing, it was so awkward.”

Summary of barriers to healthcare

- Many of the barriers were from situations where the focus group attendees had felt stigmatised or had been treated differently because of their HIV status.
- Some of the group will delay accessing treatment or care if they think their HIV diagnosis may need to be disclosed or if they feel they will be treated differently, for example being given the last appointment of the day.
- They are unlikely to attend referral appointments if the accompanying letter or referral form discloses their HIV status, especially if they feel it is unnecessary or unrelated to the health issue they are presenting with
- They find it difficult to self disclose in person if they feel their privacy is being compromised, for example in a busy A&E environment, they don’t feel they have a technique to overcome this
- Most of the group were very reluctant to contact their GP with an HIV related issue preferring to contact their sexual health clinic instead.
- They don’t know who has access to their HIV status within the NHS and who that information might be shared with, or why it would need to be shared
- They don’t trust that healthcare staff have a good enough knowledge of HIV to be able to support them without prejudice, this has led to mistrust and reluctance to engage with health care systems
- Several people cited layers of stigma which increased their barriers to accessing care, these included their ethnicity, their sexuality, their mental health issues or their substance use. They felt they experienced discrimination or inequality because of these, adding HIV just increased their feelings of stigma

- They fear being judged or discriminated against which often leads to a delay in seeking care. Some of these fears were based on perception rather than fact.
- Some of them have experienced situations where their presenting symptoms are attributed to HIV or their HIV medication by their GP, or a health care professional, only to be advised by their sexual health clinic that's its not HIV related. They end going backwards and forwards between services, this contributes to their frustration, increases their distrust of health services and increases their belief that health care services don't understand HIV.

Recommendations

HIV education opportunities for all health care staff to reduce lack of knowledge, stigma and misconceptions

A campaign to diminish stigma, using HIV positive peoples lived experience to help create awareness and normalise HIV

Work more closely with organisations like TVPS to strengthen partnership working and improve HIV positive patients trust in the NHS

Publicise U=U (undetectable = untransmittable) and train health care staff to understand its meaning so that HIV positive people are treated the same as their negative peers and don't feel they are discriminated against because of their HIV status.

People from the LGBTQIA+ community

We received feedback from 15 people from our LGBT community. We asked them what barriers they experience when accessing health care.

13 people worried about experiencing stigma if they shared their sexuality or gender with healthcare professionals especially someone they had not received care from in the past

1 person had not told any health care professional their preferred identity as they were too worried about the questions they might be asked

8 people were concerned about how information about them was stored in relation to sexuality or gender

11 people had no confidence that decisions made about their health took into account their sexuality or true gender

14 people believed that assumptions are made about them when they do share their sexuality or gender with a healthcare professional

9 people believed they were treated differently because of their gender, sexuality or requested pronouns

Feedback included:

“Every time I disclose my sexuality I’m asked questions about what it means, its happened several times at GP appointments, there only a limited time and half of it was taken up with my explanation, one time I was asked if I wanted to be referred to Talking Therapies, now I just lie and say I’m straight.”

“I’ve been misgendered so often I don’t bother correcting anyone anymore – even if I wear a pronoun badge they still get it wrong – if they can’t get that right how do I know they’re going to get my care right.”

“I try to avoid all healthcare settings for two reasons 1. Because I haven’t fully transitioned so I get stared at and 2. Because the NHS don’t recognise my correct gender ever, they only ever refer to whats on their system. I don’t think I even look like the gender they have on there it makes me angry I feel like a number rather than a person.”

“I’m put off accessing any healthcare especially if there are forms to fill in and the only box applicable to my gender or sexuality is ‘other’ and then I have to explain what other is.”

"It feels unfair that heterosexual people don't have to answer questions about their sexuality like I do."

"Screening programmes that are gender specific are a nightmare for me so I avoid them."

"I find the worse situations are when health care professionals don't ask more or any questions but there is a hostility because I don't conform to gender norms."

"I'm non binary, I never bother telling healthcare professionals because they either ignore it or panic. They should be trained to deal with this, being non binary should not cause this much angst."

"I don't like it when they make assumptions because of your sexuality ,I'm a gay man celibate but I've had healthcare professionals assume I'm very sexually active with multiple partners."

"I've delayed treatment before because I was so worried about being judged for who I am."

Summary of barriers to accessing healthcare

- They feel there is bias in health care settings and feel they are treated differently because of their sexuality or gender identity
- They worry that disclosing their true identity would be met with hostility or a lack of understanding
- There was a general consensus that health care providers lack training on LGBTQIA+ health issues, including a lack of understanding of transgender, non binary and intersex patient needs
- Some felt health care providers make assumptions about patients sexual practices or gender identities which could lead to a wrong diagnosis or incorrect signposting to other services. There was a strong feeling across the group that they were often stereotyped.
- As with our HIV group some people from our LGBTQIA+ focus groups experienced layers of stigma especially if they are neuro diverse or have mental health concerns. Some felt their sexuality, gender or pronoun choices were attributed to their neuro diversity or mental health as a means of explaining their choices rather than understanding their true identity.

Recommendations

Mandate training programmes on LGBTQIA+ health to improve competency and sensitivity

Develop health outreach programmes that connect with the LGBTQIA+ community

Standardise data collection across all health care settings in relation to sexual orientation and gender identity to address disparities

Work in partnership with TVOS to build trust with the LGBTQIA+ community and increase understanding

Review inclusive language in health care settings so that it doesn't alienate non binary or transgender people making them less likely to seek care.

Conclusion

Addressing the barriers to healthcare for the LGBTQIA+ and HIV community requires a multifaceted approach involving policy reform, provider education, and community engagement. By building an inclusive health care environment in partnership we can ensure that all our service users health care needs receive equitable and compassionate care, ultimately improving health outcomes and reducing disparities and stigma.