



## **A powerful insight into the needs of people living with HIV**

Healthwatch Leeds is here to help local people get the best out of their local health and care services and to bring that voice to those who plan and deliver services in Leeds.



Healthwatch Leeds is the independent voice of local people for health and social care services in Leeds. We make sure service providers and commissioners - the people who plan and buy health and social care services - listen to the concerns of people and use the information to shape and improve their services.

We work hard to make sure that we include the people whose voices are not usually heard.

© Healthwatch Leeds 2015

The text of this document (this excludes, where present, the Royal Arms and all departmental and agency logos) may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not in a misleading context.

The material must be acknowledged as Healthwatch Leeds copyright and the document title specified.

Where third party material has been identified, permission from the respective copyright holder must be sought.

Any enquiries regarding this publication should be sent to us at [info@healthwatchleeds.co.uk](mailto:info@healthwatchleeds.co.uk)

You can download this publication from [www.healthwatchleeds.co.uk](http://www.healthwatchleeds.co.uk)



# Contents

4-5	Summary/Background
6	Why we did it/What we did
7-8	Who we spoke to/What we found
8-12	Findings & Comments
13	Recommendations
14	Conclusion
15	Next Steps/Acknowledgements/ References

### Summary

In January 2014 we sought the views of people living with HIV in Leeds, regarding health and social care services. Concerns were raised about stigma and discrimination whilst accessing dental services. Following this, we carried out a survey about access to dental care with people living with HIV in Leeds. It aimed to understand the experience and barriers faced by people living with HIV when accessing a dentist.

We hope that our findings will provide an evidence base that will ultimately lead to commissioners, dental care providers and health care planners working together to reduce challenges for people living with HIV at dental practices.

A total of 300 questionnaires were distributed, of which 253 were returned, yielding an 84% response rate. This report provides a powerful insight into the needs of people living with HIV representing the views of 20% of the total numbers who currently have a diagnosis of HIV.

### Key findings

The majority of respondents said they were not satisfied with the care and treatment at their dental practice.

Key themes arising from the survey are:

- Concern and fear from patients that disclosing their HIV status will have an adverse effect on their treatment
- Breaches of the Equality Act 2010 by dentists refusing treatment to patients that have disclosed their HIV status
- Breaches of NHS staff contractual responsibilities with regards to confidentiality
- 30% of respondents highlighted that their choice of appointment times were restricted. Others were asked to find another dentist following disclosure
- A significant number of respondents were concerned with their dentist's lack of knowledge and awareness of HIV



- A lack of dentists taking on NHS patients, further limits access and choice for people living with HIV
- Only 8% of respondents stated that they had received a positive overall experience. For example they felt involved in discussions about treatment and payment plans, or they received good advice and information.



### Background

HIV continues to be a serious health condition in the UK. Public Health England figures show an estimated 107,800 people were living with HIV in the UK in 2013.

Of these, 24% are undiagnosed and do not know about their HIV infection. The two groups most affected are men who have sex with men and Black African heterosexual men and women. In 2013 Leeds was providing HIV related care to around 1200 people. (1)

Dental care is an important part of everyone's general health care. It is particularly important for people living with HIV as certain medication can increase tooth decay and infections.

Our research shows that access to dental services is limited and there remains high levels of stigma and discrimination for those living with HIV.

### Why we did it

The rationale for this project came from listening to the views and experiences of people affected by and living with HIV in Leeds. Initially, we spoke with 35 people both men and women at BHA Leeds Skyline. BHA Leeds Skyline supports people who live with or are affected by HIV. Service users raised concerns about their treatment and care whilst seeking dental treatment.

Service users told us they were reluctant to disclose their HIV status for the fear of stigma and discrimination. Those who disclosed their status to their dental practice said they were usually given the last appointment of the day. Those that challenged this, reported that they were told that all equipment was disinfected after the last appointment. Participants were anxious about the lack of confidentiality of their status being shared with other practice staff.

This feedback prompted the Healthwatch board to agree that this concern needed further exploration, and that further research into this issue should be done.

### What we did

We compiled a survey which was made available at one of the departments at St James's University Hospital (SJUH), the Leeds Centre for Sexual Health and BHA Leeds Skyline. The survey was open for six weeks from mid-November to the end of December 2014. The questionnaire had a mixture of closed, open and multiple choice questions and included comment boxes throughout.

Due to the nature and high sensitivity of this subject it comprised a postal self-completion questionnaire which was purposefully designed to give people privacy and protect their anonymity. If people required further information and support, this was provided by staff at each service.

**The questionnaire allowed us to explore the following key areas:**

- Reasons for not having a dentist
- Disclosure of HIV status to dental practice
- Experience after disclosure
- Discrimination and staff attitude
- Treatment and appointment barriers





### Who we spoke to

From a total of 300 surveys distributed, we received 253 completed responses. The majority (55%) of respondents were male and 45% were female. 40% reported being from an African background and 35% from the gay community. These are the two communities who have the highest prevalence of people living with HIV in the UK.

### What we found

#### Reasons for not having a dentist:

We asked respondents whether they were currently registered with a dentist. 40% said they were not registered with a dentist. Respondents who were not registered were asked the reasons why they were not registered.

One third of the respondents (34%) stated that they had difficulties in finding a dental practice but did not state where they were looking. Some said that the information on the NHS website was “outdated” and “misleading” and sometimes led to a wasted journey.

*“Missed appointment because I was not well. Now I cannot find a dentist. The NHS website is not good.”*

Others had enquired in person to the practice but were told they were not taking any new or NHS patients. A significant number reported that location and cost was also a factor.

*“Cannot find one in a 5 mile radius - ridiculous”.*

Recent research conducted by Healthwatch Kirklees, Healthwatch Bolton and Healthwatch Leicester have also found this to be to be a common problem. (2)

A significant number (17%) of the respondents were refused treatment or removed from a dental practice register after disclosing their status. It is clear in the General Dental Council Standards that all people should be treated as individuals without discrimination. (3)

Some respondents reported being taken off the practice register despite informing the dentist they were ill. It appears that dentists are not taking individual needs into consideration.



## Who we spoke to



*“I was in hospital due to illness at the time of an appointment so I couldn't attend, my husband rang them but I was deregistered.”*

*“I was taken off for missing my appointment when I was very ill, I asked them why and they said I'd missed too many which I do not remember - and I've not found another one yet.”*

Other reasons for not being registered with a dentist included negative previous experience, fear of stigma and leak of confidential information.

*“I was treated badly at my last dentist, they would not give me an*

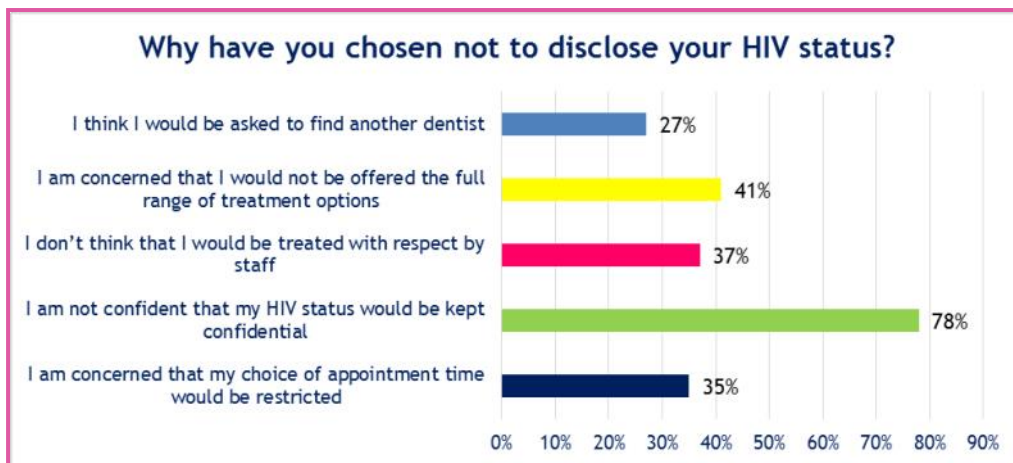
*appointment when they found out about my HIV.”*

### Disclosure of HIV status to the dental practice:

More respondents 56% said they disclosed their HIV status to their dentist compared to those who did not (44%).

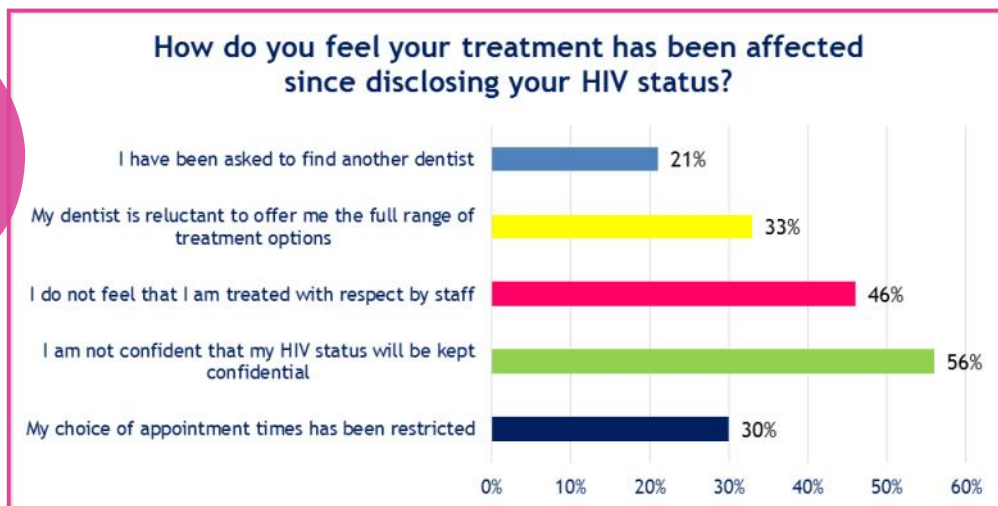
Those who did not disclose their status mentioned a number of reasons for this. The primary reason was fear that their status would not be kept confidential (78%). This was followed by fear of not being offered the full range of treatment (41%). About 37% thought they would not be treated with respect by staff and 35% feared

their choices of appointment times may be restricted. 27% of respondents said they didn't in case they would be asked to find another dentist.



Graph1: showing the reasons why respondents chose not to disclose their HIV status.





### Experience after disclosure:

Graph 2: Experience after disclosure of HIV status

A significant number (37%) said disclosure of their status affected their experience. Over half (56%) did not feel confident that their status would be kept confidential after disclosing it. 46% felt they were not treated with respect by staff after disclosure, whilst 33% felt they were not offered the full range of treatment options. 30% told us that their choices of appointment times were restricted and (21%) said they were asked to find another dentist.

We found that many people were treated differently and refused treatment after they disclosed their status. This is despite the fact that the Equality Act 2010 states that HIV is a registered disability and any discrimination of this disability is against the law.

“After disclosing my HIV status, the staff attitudes towards me changed totally.”

### Findings and discussion based on comments:

#### Discrimination and staff attitude:

Many comments from the survey highlighted respondents feeling disrespected by staff including receptionists and dentists. E.g. being asked to sit away from other patients or feeling they were being looked at with disgust. This behaviour from dental care staff can create HIV stigmatisation among people living with HIV and the community at large. It can also make people feel uncomfortable whilst waiting for treatment.

“In my previous place I did disclose, but each time I went in I felt I was being talked about. I felt really uncomfortable.”

## What we found

I was once told to sit away from the patient areas as I had a cough and possible infection in my mouth

*“The receptionist staff used to ignore me then wipe the pen after I used it or tell me to keep the pen.”*

This kind of behaviour can prevent people with HIV from accessing dental services and prevent them from disclosing their status. One of the respondents said,

*“I have no problem disclosing my status but I got annoyed when my dentist asked me how I got it.”*

Another said *“It’s hard being gay; I need to figure out how to disclose my status without being ostracised.”*

A significant number were concerned with their dentist’s lack of knowledge and awareness of HIV. One person stated their dental professional’s lack of knowledge about HIV affected their treatment.

*“The dentist is far behind and needs a refresher on what things to look for in my mouth.”*

Suggestions were made by

“I feel as though my dentist doesn’t know much about HIV”

respondents that reception staff should be appropriately trained.

*“Staff need customer service training on how to treat people with respect, especially the ones who answer the phone.”*

Other comments were related to previous negative experience.

“My previous dentist’s views were quite clear that there will be restricted treatment options due to the risk of passing on the disease.”

*“They come up with stupid reasons to refuse treatment once they become aware of your status.”*

### Restricted treatment options

Receiving appropriate treatment and difficulties with making appointments were mentioned by a number of respondents. Respondents

*“I was told to go private because treatment would be complicated at this practice.”*

were refused treatment because they were told their dentist did not have the right or specialist equipment to treat patients with HIV.

*“I was told my tooth extraction would be too difficult so needed specialist treatment, basically I should go elsewhere.”*

Some respondents were told to find another dentist or a specialist HIV dentist as their dentist was not trained to deal with HIV patients.

*“I was told they do not have the right equipment to treat someone with HIV”*

*“Dentist touches me with disgust and offers no advice told me to register with the Dental Hospital.”*

*“I was told I cannot get treated and to find a specialist HIV dentist.”*

Others said that their dentist did not offer them the full range of treatments. The most concerning case being that of a dentist performing half a treatment and telling the patient to go to a “more specialised dentist” for the remainder.

*“During a dentist check-up we got into a conversation with the dentist about HIV and her views were quite clear that there will be restricted treatment options due to the risk of passing on the disease.”*

### Restricted choice of appointment times and infection control

Many respondents complained about restricted appointments after disclosure, for example being given the last appointment of the day. Respondents were told that the dental practice needed to protect other patients by disinfecting all surfaces and taking extra precautions after a HIV patient.

*“I am always given the last appointment of the day. I have been told so that equipment can be properly disinfected to prevent the virus spreading to other patients.”*

*“I challenged why they are not taking HIV patients, the dentist told me it will take a long time and extra precautions. This meant longer waiting time.”*



## What we found:

Respondents felt that high standards of hygiene and infection control be consistent for all patients, and that this was prejudicial treatment.

Standard infection control procedures are designed to prevent transmission of HIV and other infectious diseases. According to the Department of Health and the British Dental Association: “The same procedure should be used for all patients, it is unethical as well as unlawful to refuse dental care to people with HIV and it is also illogical- lots of people (24%) have HIV without knowing it so dentists need to take the right precautions all the time”. (4)

### Confidentiality

The standards from the General Dental Council state that, confidentiality is central to the relationship and trust between a patient and dental practitioner. However, 56% of the respondents were concerned about disclosing their status and it being kept confidential. Some people commented that once they had disclosed their HIV status they noticed a label on their records that

identified that they were different.

*“On the screen my status was highlighted, I saw reception staff looking at each other and overheard them say HIV patient”.*

Some respondents reported were asked about their HIV medication whilst in the queue or the waiting area.

*“I was asked by a member of the reception staff in front of other patients what medication for HIV I was taking.”*

There was also concern that staff may share confidential information outside of the surgery impacting on those who live and use a dentist in the same area.

*“As there is still a stigma regarding HIV, I do not want to take the risk of being ostracized from my local community as I live in a small town and gossip travels.”*

Employees working in the NHS are bound by a legal duty of confidence to protect personal information. This





is not just a requirement of their contractual responsibilities but also within the common law.

### Recommendations

The report has highlighted some areas of concern and based upon these we are making the following recommendations and suggestions:

- As the commissioners of dentistry in the country, we recommend that NHS England review their current dental service commissioning plans and consider how they can improve practice and provision to reflect the concerns in this report.
- NHS England to review guidelines for patients and staff to feel safe to report incidents if they experience or witness discrimination of HIV patients in the ways outlined in this report.
- The Disability Discrimination Act makes it illegal to discriminate against people with HIV, whether that be in the workplace or through services. We strongly recommend in all dental practices all staff update their knowledge or undertake refresher Equality and Diversity and blood borne diseases training.
- Those staff who do not have the knowledge or skills to treat patients with blood borne diseases, should be provided with the appropriate training, so that they do not refer patients to another practice.
- Infection control procedure for all commissioned dental services should be sufficiently robust that different treatment is not required for people with HIV. The staff monitoring the performance of NHS dentists should ensure that appropriate infection control measures and training are in place, to ensure that HIV patients are not discriminated against.
- All practitioners and staff should respect and maintain patient confidentiality and adhere to their professional codes of conduct.
- Dental staff should have regular HIV awareness training e.g. HIV transmission, risks of exposure and







other care issues for patients living with HIV. Organisations such as BHA Leeds Skyline and the Leeds Centre for Sexual Health are willing to deliver such training.

- Practice staff should be aware of the negative effect that stigma can have on the quality of care patients receive. They should have accurate information about the risk of HIV.
- Dental practices should make waiting rooms more welcoming and inclusive. Posters and reading materials should reflect the diversity of people, raise awareness about HIV and reduce stigma. This will help to encourage patients to feel safe about disclosing their status.

## Conclusion

Overall, the study suggests that while the majority of people living with HIV in Leeds are registered with a dentist, a significant number are still not accessing dental care services. Feedback suggests that people living with HIV are still experiencing stigma and different forms of discrimination including gossip, being ostracised, being given restricted treatment options and appointment times, and in some cases refusal of treatment.

This report highlights that HIV related stigma and discrimination are very much evident in dental practices and still need to be addressed. Discrimination against people living with HIV can result in poor quality of care and can frighten patients in need of care. It is commendable that some dental practices in Leeds are making efforts to address concerns as evidenced by people who reported to have a positive experience. The level of discrimination and lack of knowledge highlighted in this report is not acceptable.



### Next steps

This report will be sent to NHS England and the West Yorkshire Area Dental Team for a response, as well as being published on the Healthwatch Leeds website. We will make copies available at SJUH, BHA Leeds Skyline and the Leeds Centre for Sexual Health to be shared with service users.

All responses will be available on our website and shared with SJUH, the Leeds Centre for Sexual Health and BHA Leeds Skyline.

### Acknowledgments

We would like to thank our volunteers Fateha Begum, Martin Gazimbi, Lydia Woellwarth, Rikki Banks, Conor Spencer, Lesley Thornton, and Daisy Cox for helping with inputting and analysing the survey data, and contributing towards writing the report. Thank you to BHA Leeds Skyline, SJUH and the Leeds Centre for Sexual Health for their support and guidance at various stages of this project and enabling us to reach out widely to this community.

### References

1. <https://www.gov.uk/government/collections/hiv-surveillance-data-and-management>
2. <http://www.healthwatch.co.uk/news/trouble-finding-nhs-dentist-youre-not-alone>
3. <http://www.gdc-uk.org/Newsandpublications/Publications/Publications/Standards%20for%20the%20Dental%20Team.pdf>
4. <http://www.tht.org.uk/myhiv/your-rights/equality-act-2010>



