



5 year review: Access to dental care for people living with HIV in Leeds



Introduction

Healthwatch Leeds produced a report in 2015 (*Access to dental care for people living with HIV in Leeds*). A factsheet was produced by Public Health England that is now used nationally and training modules have been introduced for dental students in the region.

In the summer of 2019, we learned that people living with HIV were still experiencing problems with access to dental care. We decided to re-visit the subject and seek views and experiences to help assess progress since 2015.

We worked with BHA Skyline and the Brotherton Wing HIV Outpatient Clinic at Leeds General Infirmary (LGI) to carry out a survey. The same questions were used as the previous survey and the project ran from October to mid-December 2019.

A total of 80 people completed the survey. However, it should be noted that not everyone who responded to the survey answered every question and, for some questions, respondents were allowed to provide more than one answer.

Key findings

- 4 out of every 10 people we spoke to aren't registered with a dentist. Most often, this was because they hadn't been able to find a practice which could offer them NHS treatment.
- 7 out of every 10 people who are registered have disclosed their HIV status to their dentist. In 93% of cases, disclosure hadn't led to them being treated any less well by their dentist.
- When people don't disclose their status, this is commonly because of fears of stigmatisation (specifically a concern that their status won't be kept confidential or they will not be treated respectfully).

What we did

We issued surveys to service users at BHA Skyline and to patients attending the Brotherton Wing Clinic at LGI between early October and mid-December 2019. All respondents were reassured about personal details being kept confidential and the content of their answers remaining anonymous.

We received a total of 80 responses

Of the 80 respondents, 44 (68%) were male, 17 female (26%), 4 (6%) identified as non-binary and 11 (13%) preferred not to say.

What we found

Registering with a dentist

The majority of respondents (47 people or 59%) told us they were registered with a dentist. It is worth bearing in mind, however, that in a small number of cases people told us that once they had registered, they then found it difficult to get an appointment to see the dentist (see the comments below).

We asked the 33 people (41%) who were not registered why this was the case. The most common answer was that they were unable to find an NHS dentist (19 people or 58%).

30% (10 people) said a fear of dental treatment prevented them from going to the dentist, while 24% (8 people) said it was too expensive. 3 respondents commented that they were unregistered specifically because of their HIV status or the requirement to disclose it.

What people told us about...

Trouble getting an appointment once they had registered

“A lot of my dental appointments are cancelled. It is really tough to see my dentist when I’m at work. I wonder if this will be made worse because of my HIV status.”

“The first dentist I saw would not take me on despite them being advertised as open to new NHS patients. I went again a few months later and saw a different dentist and he took me on.”

“Appointments not available for many months”

How stigma or dentists’ perceived lack of knowledge can discourage patients from registering

“Not with [a dentist] because of disclosure”

“There needs to be more training to help positive patients”

How other factors have influenced the decision not to register

“I have not been to a dentist for a long time, due to a bad experience. I felt like I was a burden and my appointment was rushed”.

“I do not go to the dentist as cannot afford to pay for visit or/and treatment despite having ongoing dental problems”

Disclosing HIV status

44 of the 47 people registered with a dentist told us whether they had disclosed their HIV status to their practice. 68% (30 people) said they had.

We asked these 30 people whether this had had a negative effect on their treatment or experience. 28 (93%) reported that disclosing had not had any adverse impact; 1 person said it had; and 1 was not sure.

The person who has had a bad experience of disclosing their status explained that they had been asked to find another practice.

What people told us about...

Their negative experiences of disclosing

“Since I disclosed I was not contacted ever again for an appointment”.

Their positive experiences of disclosing

“I have not been treated differently by my dentist.”

“My dentist took the time to sit and talk with me about how HIV and HIV medication might affect my dental health in the future. She was amazing and she went the extra mile to make me feel at ease.”

“The practice was very helpful and understanding from the start. No problems with treatment.”

“They never made me feel uncomfortable.”

Opting not to disclose

Of the 44 registered people who told us about disclosing their HIV status, 14 said they had not shared their status with their dentist.

Most commonly, this was because they were not confident that their status would be kept confidential (57% or 8 people). Further to this:

- 7 people (50%) said that they feared not being treated respectfully by staff;
- 4 (29%) are concerned they would not get a full range of treatment options;
- 4 (29%) don't think the dentist needs to know their status; and
- 3 (21%) worry that their choice of appointment times would be restricted.

“when they are aware of my health, they don't respect. Will be treated different from other patients”

Recommendations

1. Dental practices to enact a policy of actively encouraging patients to disclose a positive HIV status and communicating openly about how this will or won't affect their dental treatment.
2. Dental practices to assess whether their patients with HIV are less likely than others to be contacted for appointments and to put systems in place where appropriate to remedy any inequalities.
3. All dentists and practice staff to receive regular refresher training about the requirement to support people with HIV to access their services safely and comfortably and how best to do this. BHA Skyline have offered to provide this training.
4. Awareness raising to be carried out among people with HIV to reassure them about:
 - (a) How dentists keep their medical information confidential;
 - (b) How dentists and practice staff are trained to support people with HIV;
 - (c) Their right to a full range of dental treatments.