

# The *People Living with HIV* STIGMASurvey UK 2015: Stigmatising experiences and dental care

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Key points			
Over 95% of the 85,000 people living with diagnosed HIV in the UK are achieving and maintaining an undetectable viral load while on effective antiretroviral therapy – they can expect a normal life span and are protected from transmitting HIV.	Nevertheless people living with HIV reported high rates of stigma and discrimination when attending their dental practice in the previous 12 months.	These findings are a wakeup call to the dental team to ensure that care is delivered without discrimination and prejudice.	Greater awareness and training is required to ensure the dental team provides optimal care to people living with HIV in a supportive environment.

**Introduction** We report experiences of stigma and discrimination in the dental setting among people living with HIV in the UK and explore predictors of self-exclusion from dental care. **Methods** A convenience sample of people living with HIV recruited through community organisations and HIV clinics using an online anonymous survey. Analyses and writing of the findings were conducted with community engagement throughout. **Results** Fifty-three percent of 1,528 participants reported that their dental practice was aware of their HIV status, and among these 33% felt poorly supported upon disclosure. Over the previous 12 months, 40% had *worried* about being treated differently and 15% reported *being* treated differently to other people attending the dental practice; 5.4% felt their dental care was significantly delayed or refused and 14% had avoided their dental practice in relation to their HIV. Delayed or refused dental care was a strong predictor for self-exclusion (aOR = 6.41, 95% CI: 3.44, 11.95). **Conclusion** People living with HIV continue to report high levels of stigmatising and discriminatory attitudes and behaviour in the dental setting. These experiences were strongly associated with people avoiding dental care. Culturally sensitive awareness and educational tools targeting the dental team should be developed to address the stigma around HIV in this clinical setting.

## Introduction

Good oral health is important for overall health and wellbeing; particularly for those living with HIV. People living with HIV (PLHIV) have poorer oral health and greater dental care needs than the general population.<sup>1</sup> Oral conditions associated with HIV can impact on the ability to take medications, to maintain appropriate nutrition and subsequently lead

to diminished physical health.<sup>2–5</sup> Dentists and other oral healthcare professionals have a role to play in the detection of oral complications associated with HIV and the onward referral of these patients to appropriate sexual health services.<sup>6</sup> Additionally, there is emergent evidence in support of the dental setting as an appropriate site to screen for HIV using oral fluid or capillary blood point-of-care testing.<sup>6</sup>

The use of antiretroviral therapy (ART) has extended the life expectancy of PLHIV to the same level as the general population and HIV infection has moved from being considered as a deadly illness to a chronic disease.<sup>7,8</sup> Almost all (94%) of the 85,000 people living with diagnosed HIV in the UK are on ART – they can expect a normal life span and are protected from transmitting HIV.<sup>9</sup> However, despite these, the stigma around HIV remains a major challenge for some PLHIV, negatively impacting upon their lives, health and wellbeing.<sup>10–12</sup> Stigma has been defined as

beliefs and attitudes that lead people to fear, avoid or reject those they perceive as being different.<sup>13</sup> Perceptions of stigma have been linked to barriers to testing, disclosure of HIV status and delays in seeking care.<sup>10,12,14–16</sup> In 2008, PLHIV (N = 241) recruited at a London genitourinary medicine (GUM) clinic were significantly more likely to report difficulties when trying to register with a dentist compared to other patients (59% vs 18%); 35% reported that awareness of their HIV status in the dental setting had negatively impacted on the care received with 6.2% having been refused dental treatment.<sup>17</sup>

Over the last few decades changes in anti-discrimination laws have increased and protected the rights of PLHIV in the UK. Notably, the Equality Act 2010, which replaced the Disability Discrimination Act 1995, and other anti-discrimination legislations designed to protect PLHIV from discrimination in various settings including in healthcare services.<sup>18</sup>

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Furthermore, the Department of Health and the British Dental Association recommend that universal cross infection control precautions are used for all patients irrespective of their HIV status. Evidence from smaller studies suggests that in the ART era, HIV-related stigma and discrimination continue within healthcare services including in the dental setting.<sup>11,17,19,20</sup> We aimed to assess the current experiences of PLHIV when attending dental services in the UK, and to examine the factors associated with accessing dental care in this population.

## Methods

### Study population

The *People Living with HIV Stigma Survey UK 2015* was a convenience sample of PLHIV aged 18 or older recruited by community members from 120 community organisations and at 47 HIV clinics. Participants' responses were stored securely and analysed at Public Health England (PHE) in accordance with the Data Protection Act 1998 with community engagement throughout. The study was reviewed and approved by the Brighton and Sussex Research Ethics Committee (IRAS ID: 160361).

### Questionnaire data

The online anonymous survey contained questions about current feelings and experiences of HIV-related stigma in healthcare settings including dental practice, general practice (GP), GUM clinics, as well as inpatient and outpatient clinics. Respondents ranked the level of support that they received upon HIV disclosure between 0 and 100, and an arbitrary cut-off of 75 was used to distinguish between low and high level of support. Additionally, ten questions were included about positive and negative feelings related to HIV in the last 12 months including: having felt positive about the future, in control of health, shame, guilt, and self-blame, some of which overlap with the Beck Depression Inventory<sup>21</sup> (Fig. 1). A 'self-image' composite score was created based on nine statements (excluding suicidal ideation): a 'yes' or 'not sure' answer to a question about positive feelings was given a value of 1 and 0.5, respectively, and a 'yes' or 'not sure' answer to a question about negative feelings a value of -1 and -0.5, respectively. Composite scores ranged from -4 to 5 and a self-image score of -1 or less was assigned as 'poor' with sensitivity analyses performed using different cut-offs.

### Statistical analysis

Descriptive and analytical analyses were performed in StataV13 (StataCorp LLC, USA). The chi-squared test was used to compare the experiences of participants by sociodemographic characteristics. Univariate and multivariate logistic regression analyses were conducted to determine the factors associated with self-exclusion of dental care.

## Results

### Sociodemographic data

Sociodemographic and clinical characteristics of the 1,528 (97%) participants who completed the healthcare setting are presented in Table 1. Three quarters were men and almost two thirds were men who have sex with men (MSM). The mean age was 44 years (95% CI 43.7–44.8 years) with a 9-year median time since diagnosis (IQR = 15–4 years). The majority of respondents were of White British ethnicity (60.4%), followed by Black or Black British ethnicity (20.9%). Financial hardship was common among respondents with 58.2% 'struggling' or 'falling behind' with their bills. In line with the national average of the UK population living with HIV (94%, PHE, 2016), 94.3% of respondents were receiving ART. Just under half (45.2%) of individuals had been diagnosed with a mental health condition; mainly depression (89%) and a third (36.4%) had a poor self-image in relation to their HIV (Table 1, supplemental image S1).

### Disclosure of HIV status

About half (53%) of participants reported that their dental practice was aware of their HIV status (53.3%) and this proportion increased with both the respondent's age and time since HIV diagnosis. Participants of Asian and Black ethnicity were less likely to have made their dental practice aware about their HIV status compared to those of White British ethnicity (27.0% and 40.1% respectively, vs 56.6%, both  $P < 0.001$ ); as were those not on ART (33.6% vs 55.0% for those on ART  $P < 0.001$ ). Dental practices were more likely to be aware of the HIV status of respondents who had a disability than those without (69.3% vs 48.5%,  $P < 0.001$ ). Following HIV disclosure, a third of participants (32.8%) did not feel well supported by dental staff. Notably, respondents from a non-white ethnic group were significantly less likely to feel supported than those of White British ethnicity (42.5% vs 27.5%,  $P < 0.001$ ), those who identified as transgender (47.1% vs 30.5%  $P < 0.001$ );

heterosexual women compared to MSM (41.4% vs 30.5%,  $P = 0.002$ ) and respondents who reported that they were struggling with their bills (38.3% vs 25.5%,  $P < 0.001$ ).

In the past 12 months, 39.9% of participants had worried about being treated differently to other patients in dental practices and 14.6% reported that they had actually been treated differently. Respondents with a poor self-image were more likely to report having been treated differently to other patients in dental practices (20% vs 11.5%,  $P < 0.001$ ).

Over one in twenty (5.5%) respondents reported that they felt they had been refused dental care or that it had been significantly delayed (Table 1). Markedly, participants from Black or Black British ethnic backgrounds were more likely to report this experience compared to White British respondents (7.8% vs 4.7%,  $P = 0.016$ ) as did those who reported falling behind with their bills (11.7% vs 3.0%,  $P < 0.001$ ) and those who identified as transgender (21.9% vs 5.0,  $P < 0.001$ ). Almost all participants (96.4%) who had felt refused or significantly delayed care by dental staff, reported that they worried about being treated differently in dental practices, compared to 38.1% who did not report this experience ( $P < 0.001$ ). Furthermore, participants who had made dental staff aware of their HIV status were more than twice as likely to report being treated differently and feeling refused or significantly delayed dental care than those who had not disclosed their HIV status (19.5% vs 10.9% and 6.8% vs 3.2%, respectively) (both,  $P < 0.001$ ).

### Factors associated with self-exclusion from dental practices among people living with HIV

Of the 1,528 participants, 1,431 (93.7%) indicated whether they had avoided seeking dental care when needed over the past 12 months (Table 2). In a multivariate model with adjustment for age, year of diagnosis, gender, financial commitments, self-image, feeling supported upon disclosure, worry about being treated differently, reported being treated differently and feeling refused or significantly delayed care; two factors stand out as being associated with self-exclusion from dental care. Participants who reported worry about being treated differently were nearly eight times (adjusted odds ratio (aOR) = 7.52, 95% CI: 4.80–11.76) more likely to avoid seeking dental care and those who felt refused or significantly delayed dental care were six times (aOR = 6.41, 95% CI: 3.44–11.95) more likely

**Table 1 Experiences of stigma and discrimination in dental practice by sociodemographic characteristics (cont. on pg 146)**

	Total (N = 1528)	Dental staff aware of HIV status		Worry about being treated differently		Reported being treated differently		Felt refused or significantly delayed	
		n (%)	814 (53.3)	P-value	610 (39.9)	P-value	223 (14.6)	P-value	83 (5.4)
<b>Demographic</b>									
<b>Gender*</b>			0.286		0.193		0.214		<0.001
Male	1152 (75.4)	627 (54.4)		471 (40.9)		162 (14.1)		58 (5.0)	
Female	344 (22.5)	170 (49.4)		124 (36.0)		54 (15.7)		18 (5.2)	
Transgender or GQNB*	29 (1.9)	14 (48.3)		12 (41.4)		7 (24.1)		7 (29.2)	
<b>Age group</b>			<0.001		0.092		0.043		0.601
<25	36 (2.4)	18 (50.0)		13 (36.1)		4 (11.1)		2 (5.6)	
25–34	229 (15.0)	80 (34.9)		94 (41.0)		24 (10.5)		12 (5.2)	
35–49	734 (48.0)	393 (53.5)		319 (43.5)		129 (17.6)		47 (6.4)	
50–64	409 (26.8)	256 (62.6)		147 (35.9)		51 (12.5)		16 (3.9)	
65+	43 (2.8)	34 (79.1)		13 (30.2)		7 (16.3)		2 (4.7)	
Not stated	77 (5.0)	33 (42.9)		24 (31.2)		8 (10.4)		4 (5.2)	
<b>Ethnicity*</b>			<0.001		0.015		0.740		0.601
White British	902 (59.0)	527 (58.4)		361 (40.0)		125 (13.9)		39 (4.3)	
White Irish	46 (3.0)	23 (50.0)		25 (54.3)		7 (15.2)		3 (6.5)	
Any other White background	133 (8.7)	75 (56.4)		69 (51.9)		24 (18.0)		12 (9.0)	
Black or Black British	319 (20.9)	128 (40.1)		111 (34.8)		48 (15.0)		25 (7.8)	
Asian of Asian British	24 (1.6)	7 (29.2)		10 (41.7)		3 (12.5)		1 (4.2)	
Other ethnic groups	100 (6.5)	54 (54.0)		34 (34.0)		16 (16.0)		3 (3.0)	
<b>Sexuality</b>			0.002		0.225		0.139		0.006
MSM	952 (62.3)	534 (56.1)		399 (41.9)		137 (14.4)		47 (4.9)	
Heterosexual men	184 (12.0)	79 (42.9)		64 (34.8)		21 (11.4)		8 (4.3)	
Heterosexual women	329 (21.5)	162 (49.2)		120 (36.5)		51 (15.5)		19 (5.8)	
Other sexuality	63 (4.1)	39 (61.9)		27 (42.9)		14 (22.2)		9 (14.3)	
<b>Ever injecting drug use</b>			0.314		0.05		0.957		0.462
No or not reported	1318 (86.3)	695 (52.7)		513 (38.9)		192 (14.6)		69 (5.2)	
Yes	210 (13.7)	119 (56.7)		97 (46.2)		31 (14.8)		14 (6.7)	
<b>Socioeconomic status</b>									
<b>Educational level</b>			0.036		0.013		0.825		0.567
College or university	1174 (76.8)	617 (52.6)		494 (42.1)		170 (14.5)		60 (5.1)	
Secondary school	322 (21.1)	186 (57.8)		103 (32.0)		50 (15.5)		22 (6.8)	
Up to primary school	25 (1.6)	8 (32.0)		11 (44.0)		2 (8.0)		1 (4.0)	
Not reported	7 (0.5)	3 (42.9)		2 (28.6)		1 (14.3)		0 (0.0)	
<b>Employment status</b>			<0.001		0.12		0.242		0.189
Full time	767 (50.2)	384 (50.1)		323 (42.1)		102 (13.3)		37 (4.8)	
Part time/casual	243 (15.9)	107 (44.0)		101 (41.6)		36 (14.8)		11 (4.5)	
Retired	68 (4.5)	49 (72.1)		18 (26.5)		7 (10.3)		3 (4.4)	
Unemployed	209 (13.7)	117 (56.0)		80 (38.3)		33 (15.8)		17 (8.1)	

**Table 1 Experiences of stigma and discrimination in dental practice by sociodemographic characteristics (cont. from pg 145)**

	Total (N = 1528) n (%)	Dental staff aware of HIV status		Worry about being treated differently		Reported being treated differently		Felt refused or significantly delayed	
		814 (53.3)	P-value	610 (39.9)	P-value	223 (14.6)	P-value	83 (5.4)	P-value
Sick or disabled	135 (8.8)	95 (70.4)		54 (40.0)		27 (20.0)		11 (8.1)	
Other	106 (6.9)	62 (58.5)		34 (32.1)		18 (17.0)		4 (3.8)	
<b>Financial commitments</b>			0.247		0.306		<0.001		<0.001
Keeping up with bills	627 (41.0)	333 (53.1)		233 (37.2)		62 (9.9)		19 (3.0)	
Struggling with bills	711 (46.5)	376 (52.9)		300 (42.2)		123 (17.3)		42 (5.9)	
Have fallen behind bills	179 (11.7)	82 (45.8)		73 (40.8)		38 (21.2)		21 (11.7)	
Not stated	11 (0.7)	3 (27.3)		4 (36.4)		0 (0.0)		1 (9.1)	
<b>Health and wellbeing</b>									
<b>Year diagnosed</b>			<0.001		0.376		0.288		0.221
In the last year	121 (7.9)	29 (24.0)		53 (43.8)		13 (10.7)		1 (0.8)	
2010–2013	360 (23.6)	158 (43.9)		158 (43.9)		45 (12.5)		21 (5.8)	
2005–2009	388 (25.4)	199 (51.3)		160 (41.2)		62 (16.0)		25 (6.4)	
2000–2004	297 (19.4)	171 (57.6)		110 (37.0)		41 (13.8)		18 (6.1)	
<2000	343 (22.4)	253 (73.8)		123 (35.9)		60 (17.5)		17 (5.0)	
Not stated	19 (1.2)	4 (21.1)		6 (31.6)		2 (10.5)		1 (5.3)	
<b>On ART</b>			<0.001		0.216		0.621		0.742
Yes	1411 (92.3)	776 (55.0)		559 (39.6)		208 (14.7)		76 (5.4)	
No	110 (7.2)	37 (33.6)		51 (46.4)		15 (13.6)		7 (6.4)	
Not stated	7 (0.5)	1 (14.3)		1 (14.3)		0 (0.0)		0 (0.0)	
<b>Poor self-image</b>			0.012		<0.001		<0.001		0.096
No	972 (63.6)	542 (55.8)		325 (33.4)		112 (11.5)		46 (4.7)	
Yes	556 (36.4)	272 (48.9)		285 (51.3)		111 (20.0)		37 (6.7)	

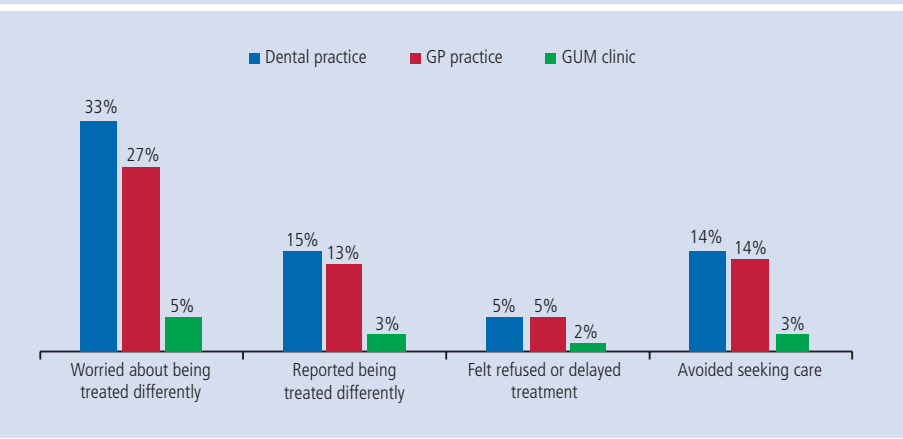
P-value, chi(2) P-value, \*Missing value below 5 are not indicated in the table  
 \*Adjusting for year of diagnosis as an *a priori* factor, gender, age, employment status.  
 OR, odds ratio; aOR, adjusted odds ratio; CI, confidence interval, P, Chi(2) P-value.  
 GQNB - Genderqueer and non-binary

of having avoided seeking dental care within the past 12 months. Reports of being treated differently (aOR = 2.89, 95% CI: 1.86–4.47) and having a poor self-image (aOR = 1.65, 95% CI: 1.14–2.40) also remained independently associated with dental practice self-exclusion in the past 12 months (Table 2).

**Perceptions of stigma in general and other healthcare settings**

The study also explored experiences of stigma and discrimination in any healthcare setting as well as other specific settings. Overall 21% of respondents felt that excessive barrier protection was used in a healthcare settings over the past year, 12% had experienced their appointments being booked for the last slot in the day and 13% had experienced negative comments

**Fig. 1 Stigma and discrimination experiences of people living with HIV in the previous 12 months in dental practice and other healthcare settings. Histogram presenting the experiences of stigma and discrimination of people living with HIV in dental practices, general practitioners (GP) practices and genitourinary medicine (GUM) clinic (N=1528). Percentages presented include missing values (all <7%)**



**Table 2** Descriptive, univariate and multivariate analyses of avoidance of dental care in the previous 12 months among people living with HIV in the UK (cont. on pg 148)

n (%)	N (%) Univariate model				Multivariate model*		
	217 (14.2)	OR	95% CI	P	aOR	95% CI	P
<b>Demographic</b>							
<b>Gender</b>				0.049			
Male	156 (13.5)	1					
Female	53 (15.4)	1.2	(0.861.69)				
Transgender or GQNB	7 (29.2)	2.46	(1.006.03)				
<b>Age group</b>				0.046			
<25	7 (19.4)	1.27	(0.542.98)				
25–34	34 (14.8)	0.86	(0.571.30)				
35–49	121 (16.5)	1					
50–64	43 (10.5)	0.58	(0.400.84)				
65+	3 (7.0)	0.39	(0.121.29)				
Not stated	9 (11.7)	0.86	(0.411.81)				
<b>Ethnicity</b>				0.98			
White British	132 (14.6)	1					
White Irish	5 (10.9)	0.68	(0.261.74)				
Any other white background	18 (13.5)	0.96	(0.561.64)				
Black or Black British	45 (14.1)	1.01	(0.701.47)				
Asian of Asian British	3 (12.5)	0.98	(0.283.31)				
Other ethnic groups	14 (14.0)	1.06	(0.581.94)				
<b>Sexuality</b>				0.469			
MSM	134 (14.1)	1					
Heterosexual men	21 (11.4)	0.81	(0.501.33)				
Heterosexual women	52 (15.8)	1.21	(0.851.71)				
Other sexuality	10 (15.9)	1.25	(0.622.54)				
<b>Ever injecting drug use</b>				0.578			
No or Not reported	189 (14.3)	1					
Yes	28 (13.3)	0.89	(0.581.36)				
<b>Socioeconomic status</b>							
<b>Educational level</b>				0.972			
College or university	169 (14.4)	1					
Secondary school	45 (14.0)	0.98	(0.691.40)				
Up to primary school	3 (12.0)	0.87	(0.262.98)				
<b>Employment status</b>				0.209			
Full time	108 (14.1)	1					
Part time/casual	36 (14.8)	1.06	(0.701.59)				
Retired	3 (4.4)	0.3	(0.090.98)				
Unemployed	30 (14.4)	1.08	(0.701.68)				
Sick or disabled	26 (19.3)	1.47	(0.912.37)				
Other	14 (13.2)	0.95	(0.521.74)				

**Table 2** Descriptive, univariate and multivariate analyses of avoidance of dental care in the previous 12 months among people living with HIV in the UK (cont. from pg 147)

n (%)	N (%) Univariate model				Multivariate model*		
	217 (14.2)	OR	95% CI	P	aOR	95% CI	P
Keeping up with bills	65 (10.4)	0.59	(0.430.82)		0.68	(0.451.03)	
Struggling with bills	116 (16.3)	1			1		
Have fallen behind bills	35 (19.6)	1.29	(0.841.96)		0.79	(0.451.39)	
Not stated	1 (9.1)	0.8	(0.096.67)		1.31	(0.1214.7)	
<b>Health and wellbeing</b>							
<b>Year diagnosed</b>				0.372			
In the last year	21 (17.4)	1.09	(0.631.88)				
2010–2013	58 (16.1)	1.02	(0.691.51)				
2005–2009	61 (15.7)	1					
2000–2004	35 (11.8)	0.74	(0.471.15)				
<2000	41 (12.0)	0.72	(0.471.11)				
Not stated	1 (5.3)	0.45	0.063.57)				
<b>On ART</b>				0.154			
Yes	197 (14.0)	1					
No	20 (18.2)	0.69	(0.411.15)				
<b>Poor self-image</b>				<0.001			0.008
No	100 (10.3)	1			1		
Yes	117 (21.0)	2.7	(1.773.18)		1.65	(1.142.40)	
<b>Experiences in relation to HIV status</b>							
<b>Dental staff aware of HIV status</b>				0.743			
Yes	113 (13.9)	1					
No	103 (14.5)	0.92	(0.691.23)				
Not reported	1 (20.0)	1.79	(0.1817.4)				
<b>Felt supported upon disclosure</b>				<0.001			0.142
Dental staff not aware of HIV status	104 (14.6)	1			1		
Felt not supported upon disclosure	68 (25.5)	1.98	(1.42.8)		1.46	(0.892.30)	
Felt supported upon disclosure	41 (8.1)	0.5	(0.340.73)		0.85	(0.491.48)	
Not reported	4 (10.0)	0.72	(0.252.08)		1.44	(0.346.08)	
<b>Worry about being treated differently</b>				<0.001			<0.001
No	34 (3.6)	1					
Yes	182 (35.7)	15.11	(10.322.3)		7.52	(4.811.8)	
Not reported	1 (1.3)	13.16	(1.16149)		0.13	(0.0044.2)	
<b>Reported being treated differently</b>				<0.001			<0.001
No	100 (8.3)	1			1		
Yes	233 (49.8)	11.33	(8.1015.8)		2.89	(1.864.47)	
Not reported	6 (6.4)	16.53	(4.5954.6)		13.91	(0.87221)	
<b>Felt refused or significantly delayed care</b>				<0.001			<0.001
No	151 (11.3)	1			1		
Yes	60 (72.3)	20.51	(12.334.1)		6.41	(3.4411.9)	
Not reported	6 (5.7)	11.79	(3.2942.3)		8.63	(0.70107)	

about their HIV in a healthcare setting. Figure 1 shows those respondents who had attended for care in general practice, general dental practice or at a GUM clinic. The report found that of those who provided responses about their experiences of stigma in dental practice, one third (33%) worried about being treated differently, in general practice, the number reporting the same concern was over one quarter (27%) of respondents and for those who received care in GUM clinics the figure was 1 in 20 (5%). When asked about being treated differently in healthcare settings as a result of their HIV status, 15% of respondents agreed that this occurred in dental settings and 13% felt that this occurred in GP practices, contrastingly, only 3% felt treated differently in the GUM setting. One in 20 (5%) of the respondents felt that their treatment was refused or delayed as a result of their HIV status in dental and GP settings, whereas this figure was only 2% in a GUM clinic setting. In dental and general practice settings 14% of respondents had avoided seeking care as a result of perceptions of stigma related to their HIV status, almost five times more likely than avoiding care at a GUM clinic. Both dental settings and general practice showed considerably higher numbers of patients worried about being treated differently, reported being treated differently, felt refused or delayed treatment and avoided seeking care when compared with their experiences in a GUM clinic setting.

## Discussion

The findings of this cross-sectional study indicate that in 2015, PLHIV continued to experience high levels of HIV-related stigma and discrimination when attending dental services in the UK, and that these experiences were strongly associated with self-exclusion from dental practices. Fear of being discriminated against in dental practices was strongly related to the actual experience of discrimination and 1 in 20 participants felt refused or significantly delayed dental care (in line with the findings from a smaller London study in 2008<sup>17</sup>). Seven out of ten respondents who reported feeling refused or significantly delayed dental care indicated that they have avoided seeking care when needed in dental practices in the past year. Together, these findings suggest that stigma and discrimination experiences in dental practices are a source of anxiety for PLHIV and can directly impact on their oral and general health, through the refusal or delayed by dental staff

in providing dental care for HIV patients. These discriminatory experiences may prevent PLHIV from seeking necessary dental care and thereby reduce their chance of achieving better oral and general health outcomes in addition to negative impacts on their mental health and wellbeing.

Similar to previous studies,<sup>17,22</sup> about half of participants had made their dental practice aware of their HIV status. A third of those who had disclosed their HIV status felt poorly supported, and in particular, people from ethnic minority groups, transgender people, and those who struggle with their bills. Moreover, PLHIV were more likely to report being treated differently and feeling refused or significantly delayed dental care compared to those who did not discuss their HIV status. This indicates that lack of good support may discourage PLHIV from discussing their HIV status in the dental setting.<sup>23</sup> And as with previous studies, our study indicates that HIV-related stigma and discrimination in dental practices, is embedded with issues related to gender, ethnicity, sexual orientation, and socioeconomic inequalities.<sup>15,23,24</sup>

Practices such as 'double-gloving' and scheduling dental appointments for the end of a treatment session for HIV patients are now considered archaic with universal precaution advice and guidance now accepted and applied routinely in dental practice.<sup>25,26</sup> However, the qualitative study of the *People Living with HIV STIGMA Survey UK 2010* in which 61 people were interviewed indicated that PLHIV continue to experience such practices. Some of the participants explained that other people's negative experiences had made them anxious about disclosing their HIV in dental practices.<sup>27</sup> Furthermore, although the survey questions in our study did not specify the ways in which PLHIV felt that they had been treated differently in dental settings; a considerable proportion of participants felt that excessive barrier protection was used, had experienced their appointments being booked for the last slot in the day, and reported experiences of negative comments about their HIV in a healthcare setting. These findings are echoed in the dental literature by a qualitative study undertaken in the United States which interviewed 66 PLHIV who revealed a variety of concerns related to receiving care in a dental setting.<sup>11</sup> Some of the participants were anxious that dentists would overreact to their condition by wearing double gloves or masks or that the dentist may be nervous to treat them or may discriminate against them. Despite

double-gloving being described as an unnecessary practice when providing dental treatment almost two decades ago, dishearteningly these practices may still persist in general dental practice. For those who have been living with HIV for many years it is likely that they will have experienced attending dental settings during a time when such infection control practices were commonplace.<sup>28</sup> This may provide some explanation for the *People Living with HIV STIGMA Survey UK 2015*; results showed that respondents aged 35–49 were nearly twice as likely to report being treated differently to other patients in dental practices compared to those aged 25–34. This could be interpreted as a reflection of the changing attitudes of dental professionals and as a result, reduced experiences of stigma by those who are more recently diagnosed. It may also suggest that the respondents have reported an event experienced more than 12 months ago (recall bias) and this would skew the results toward a higher proportion of event being reported with increasing time to diagnosis (and potentially age).

In addition to the stigmatising clinical practices described above, perceptions of HIV stigma may be enhanced by the cost of dental care. In this study, 58.2% of respondents stated that they had difficulty keeping up with or were falling behind with paying bills. This may have been a prohibitive factor in accessing additional dental services such as attending a hygienist for private dental care or may have created an uneasy relationship with a dental practice if payment for dental care was delayed or outstanding. In general dental practice this could have had the potential to contribute to feelings of being treated differently due to HIV status. In the group of 217 respondents who reported having avoided the dentist in the past year, 33.6% were not in full-time or part-time employment and 68.2% were struggling with or had fallen behind with bills.

Consistent with previous studies, the findings of this survey indicate that stigma around HIV in the dental setting continues to affect a significant proportion of people living with HIV.

## Strengths and weaknesses of the study

This study was supported by an advisory group of academics, oral health experts including dentists, HIV experts and representatives of the HIV community. Nearly 2% of all the people living with HIV in the UK were enrolled across the country from 120 community organisations and 47 HIV clinics. The survey

population was relatively representative of the population of PLHIV in the UK although the study aimed to include more participants from ethnic minority groups. The information was anonymous and securely collected online which provided an efficient platform for the disclosure of sensitive information. However, the experiences of stigma and discrimination were self-reported and may be biased by self-perception of stigma and discrimination, cultural differences between the different ethnic groups and other sociodemographic differences. Because this is a convenience sample, people with strong opinions about HIV stigma may have been more likely to respond to the survey, thus giving a more marked perception of stigma in dental settings than truly exists. Furthermore, as it is a cross-sectional survey, direct cause and effect relationship between experiences of stigma and discrimination in the dental setting and self-exclusion from seeking dental care could not be established but strong associations could be determined.

The findings of this study suggest that persisting perceptions of stigma and discrimination within the dental setting are significantly associated with self-exclusion from dental services and failure to receive dental treatment. The implications of such self-exclusion may be the unnecessary experience of preventable dental pain, a lack of opportunity for the delivery of oral health promotional education in a cohort known to have poorer oral health and potentially oral conditions that may be indicative of advancing HIV. Additionally, the findings have implications for the way in which dental care professionals provide services and treatment for PLHIV. Further undergraduate and postgraduate dental education may be of benefit, both to increase knowledge of blood borne viruses (BBV) including HIV and to better prepare dental staff to manage disclosures of HIV status. Inclusion of cultural competency training may also serve to provide the next generation of dental staff with the tools to provide inclusive care to all vulnerable communities. Additional training and targeted Personal Development Plans may support dental staff to ensure that the care provided post-disclosure mirrors that provided for a patient who is not known to have HIV and that stigmatising clinical practices are made a thing of the past. Training for dental staff might include ways to support patients post-disclosure of their HIV status including: ensuring confidentiality, using non-discriminatory language, booking appointments at any time

of day, having up-to-date knowledge of current ART, treatment outcomes for PLHIV and comorbidities likely to affect patients who have been living with HIV for a number of years and who have been on long-term ART. There are also implications for wider engagement of the dental profession, public health and health promotion to reach out to people living with HIV to demonstrate that dental community are listening and changing to ensure they feel and are fully supported in accessing and receiving dental care. Further studies to better the HIV knowledge, perceptions and attitudes of dentists towards people living with HIV would be welcomed in this field.

## Conclusion

In conclusion, this study shows that despite knowledge from the dental and medical profession that HIV is a chronic, manageable disease, stigma toward people living with HIV persists in dental practices. The dental team would benefit from targeted training to improve their ability to support PLHIV when receiving dental services and treatment. Targeted under- and post-graduate education in an accessible format such as an e-learning package could support dentists in developing supportive non-discriminatory approaches when working with people living with HIV. The findings highlight that there may be benefit to undertaking qualitative research to further explore which behaviours or practices may lead participants to feel stigmatised and discriminated in the dental settings.

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- Burger-Calderon R, Smith J S, Ramsey K J *et al*. The association between the history of HIV diagnosis and oral health. *J Dent Res* 2016; **95**: 1366–1374.
- Dobalian A, Andersen R M, Stein J A *et al*. The impact of HIV on oral health and subsequent use of dental services. *J Public Health Dent* 2003; **63**: 78–85.
- Soares G B, Garbin C A S, Roviata T A S *et al*. Oral health associated with quality of life of people living with HIV/AIDS in Brazil. *Health Qual Life Outcomes* 2014; **12**: 28.
- Benjamin R M. Oral health care for people living with HIV/AIDS. *Public Health Rep* 2012; **127**(Suppl 2): 1–2.

- Rajabiun S, Fox J E, McCluskey A *et al*. Patient perspectives on improving oral health-care practices among people living with HIV/AIDS. *Public Health Rep* 2012; **127**(Suppl 2): 73–81.
- Santella A J, Conway D I, Watt R G. The potential role of dentists in HIV screening. *Br Dent J* 2016; **220**: 229–233.
- Deeks S G, Lewin S R, Havlir D V. The end of AIDS: HIV infection as a chronic disease. *Lancet* 2013; **382**: 1525–1533.
- May M T, Gompels M, Delpuch V *et al*. Impact on life expectancy of HIV1 positive individuals of CD4+ cell count and viral load response to antiretroviral therapy. *Aids* 2014; **28**: 1193–1202.
- Kirwan P D, Chau C, Brown A E *et al*. *HIV in the UK – 2016 report. December 2016*. Public Health England, London: 2016. Available online at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/574667/HIV\\_in\\_the\\_UK\\_2016.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/574667/HIV_in_the_UK_2016.pdf) (accepted 2 May 2018).
- Rueda S, Mitra S, Chen S *et al*. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open* 2016; **6**: e011453. DOI: 10.1136/bmjopen-2016-011453.
- Patel N, Furin J J, Willenberg D J *et al*. HIV-related stigma in the dental setting: A qualitative study. *Spec Care Dentist* 2015; **35**: 22–28. DOI: 10.1111/scd.12078.
- Mahajan A P, Sayles J N, Patel V A *et al*. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS* 2008; **22**(Suppl 2): S67–79. DOI: 10.1097/01.aids.0000327438.13291.62.
- Goffman E. *Stigma: Notes on the management of spoiled identity*. Penguin, 1963.
- Pulerwitz J, Michaelis A, Weiss E *et al*. Reducing HIV-related stigma: lessons learned from horizons research and programs. *Public Health Rep* 2010; **125**: 272–281.
- Ekstrand M L, Ramakrishna J, Bharat S *et al*. Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *J Int AIDS Soc* 2013; **16**(3 Suppl 2): 18717. DOI: 10.7448/ias.16.3.18717.
- Shiboski C H, Cohen M, Weber K *et al*. Factors associated with use of dental services among HIV-infected and high-risk uninfected women. *J Am Dent Assoc* 2005; **136**: 1242–1255.
- Levett T, Slide C, Mallick F *et al*. Access to dental care for HIV patients: does it matter and does discrimination exist? *Int J STD AIDS* 2009; **20**: 782–784. DOI: 10.1258/ijisa.2009.009182.
- McGoldrick C. HIV and employment. *Occup Med (Lond)* 2012; **62**: 242–253. DOI: 10.1093/occmed/kqs051.
- Williams M. The HIV positive dentist in the United Kingdom: a legal perspective. *Br Dent J* 2009; **207**: 77–81. DOI: 10.1038/sj.bdj.2009.608.
- Elford J, Ibrahim F, Bukutu C *et al*. HIV-related discrimination reported by people living with HIV in London UK. *AIDS Behav* 2008; **12**: 255–264. DOI: 10.1007/s10461-007-934434-2.
- Beck A T, Epstein N, Brown G *et al*. An inventory for measuring clinical anxiety: psychometric properties. *J Consult Clin Psychol* 1988; **56**: 893–897.
- Reznik DA. Oral manifestations of HIV disease. *Top HIV Med* 2005; **13**: 143–148.
- Arnold E A, Rebchook G M, Kegeles SM. "Triply cursed": Racism, homophobia, and HIV-related stigma are barriers to regular HIV testing, treatment adherence, and disclosure among young Black gay men. *Cult Health Sex* 2014; **16**: 710–722. DOI: 10.1080/13691058.2014.905706.
- Feyissa G T, Abebe L, Girma E *et al*. Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health* 2012; **12**: 522. DOI: 10.1186/1471-2458-12-522.
- Croser D. Written off. *Br Dent J* 2006; **201**: 497–499. DOI: 10.1038/sj.bdj.4814168.
- NHS. Standard Infection Control Precautions, 2010.
- Sharp L. The People Living with HIV Stigma Index qualitative data: Findings of the qualitative work undertaken to complement the people living with HIV stigma index. 2010. Available online at [http://www.stigmaindexuk.org/reports/final\\_qualitative\\_report\\_nov\\_2010.pdf](http://www.stigmaindexuk.org/reports/final_qualitative_report_nov_2010.pdf) (accessed 2 May 2018).
- Avery C M E, Gallagher P, Birnbaum W. cross-infection control: Double gloving and a glove perforation indication system during the dental treatment of HIV-positive patients: are they necessary? *Br Dent J* 1999; **186**: 27–29. DOI: 10.1038/sj.bdj.4800009.