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# The People Living with HIV StigmaSurvey UK 2015: HIV-related sexual rejection and other experiences of stigma and discrimination among gay and heterosexual men

We aim to understand the difference in stigma and discrimination, in particular sexual rejection, experienced between gay and heterosexual men living with HIV in the UK. The People Living with HIV StigmaSurvey UK 2015 recruited a convenience sample of persons with HIV through over 120 cross sector community organisations and 46 HIV clinics to complete an online survey. 1,162 men completed the survey, 969 (83%) gay men and 193 (17%) heterosexual men, 92% were on antiretroviral therapy. Compared to heterosexual men, gay men were significantly more likely to report worrying about workplace treatment in relation to their HIV (21% vs. 11%), worrying about HIV-related sexual rejection (42% vs 21%), avoiding sex because of their HIV status (37% vs. 23%), and experiencing HIV-related sexual rejection (27% vs. 9%) in the past 12 months. In a multivariate logistic regression controlling for other sociodemographic factors, being gay was a predictor of reporting HIV-related sexual rejection in the past 12 months (aOR 2.17, CI 1.16, 4.02). Both gay and heterosexual men living with HIV experienced stigma and discrimination in the past 12 months, and this was higher for gay men in terms of HIV-related sexual rejection. Due to the high proportion of men reporting sexual rejection, greater awareness and education of the low risk of transmission of HIV among people on effective treatment is needed to reduce stigma and sexual prejudice towards people living with HIV.

Word count: 232

Keywords: HIV/AIDS, stigma, discrimination, gay/MSM.

Word count: 2,881

#### Introduction

In the United Kingdom, 95% (37,301/39,185) of gay/bisexual men receiving ART were virally suppressed in 2015 (Kirwan, Chau, Brown, Gill, & Delpech, 2016). Having a suppressed viral load dramatically reduces the likelihood of onward transmission, and treatment as prevention has been effective at reducing the onward transmission of HIV among men who have sex with men (MSM) who are diagnosed in the UK (Brown, Gill, & Delpech, 2013) (Phillips et al., 2015). Furthermore, the PARTNER study found that there was zero within-couple HIV transmissions among MSM and heterosexual couples who were having condomless sex (Rodger et al., 2016).

To end the AIDS epidemic by 2030 UNAIDS called for an elimination of HIV-related stigma and discrimination by the year 2020 (Hollingdale, 2016). HIV stigma can be defined as labelling, stereotyping, segregating or discriminating against people living with HIV by social, political, or economic means (Mahajan et al., 2008). HIV stigma can be conceptualised as internalized stigma, anticipated stigma, and experienced stigma and/or discrimination (Earnshaw & Chaudoir, 2009). In a meta-analysis, experiencing HIV-stigma was significantly associated with higher rates of depression and lower social support (Rueda et al., 2016). In Canada, HIV stigma and specifically sexual rejection, was associated with increased risk of suicide among gay and bisexual men living with HIV (Ferlatte, Salway, Oliffe, & Trussler, 2017). In a nationally representative sample of people seen for HIV care in the UK, two in five MSM reported depression or anxiety (Carrion et al., 2015). Furthermore, the suicide rate among men diagnosed with HIV in the UK in the post ART era is twice that of the general population, and five times higher than the general population one year after diagnosis (Croxford et al., 2017).

An international literature review of HIV stigma within the gay community found living with HIV was associated with social exclusion, ageism, sexual rejection, and violence from other gay men (Smit et al., 2012). Qualitative interviews with gay men living with HIV in England found that men reported worrying and experiencing sexual rejection in relation to their HIV status (Bourne, Dodds, Keogh, Weatherburn, & Hammond, 2009). Almost two thirds of HIV-negative gay men who took part in the Gay Men's Sexual Health Survey in England in 2014 reported avoiding having sex with people who have HIV (Hickson, Reid, Hammond, & Weatherburn, 2016). Conversely, a European wide study of MSM in 2010 found that being aware that ART reduces HIV transmissibility was an independent predictor of engaging in unprotected anal intercourse (Kramer et al., 2016).

Research in Australia suggested that overall, heterosexuals were more likely to report negative HIV-experiences than gay participants, and that the two groups did not differ in the reporting of HIV-related sexual rejection (Brener, Wilson, Slavin, & de Wit, 2013). However, the heterosexual sample comprised of both men and woman, therefore not accounting higher reporting of HIV stigma among women in Australia (Tzemis et al., 2013). Although, research in Canada which controlled for gender and sexuality found that general HIV-related stigma was reported more among heterosexuals and women (Emlet et al., 2015).

Due to the high level of viral suppression among gay and bisexual men in the UK, and the very low risk of transmission of gay and bisexual men achieving viral suppression, rejecting someone on the basis of their HIV status can be considered outdated and discriminatory behaviour. The aim of this research is to better understand the extent to which people living with HIV in the UK, in particular men who have sex with men, experience stigma and sexual rejection compared to heterosexual men, despite current knowledge that undetectable viral load means that HIV is untransmissible.

#### Methods

#### **Participants**

*The People Living with HIV* StigmaSurvey UK 2015 was a convenience sample and recruited participants from 120 community organisations and 46 NHS clinics across the UK. Recruitment sites were selected through existing HIV networks in the first instance and expanded as others approached us to participate. Community organisations approached eligible clients during support groups or online via e-mail lists and social media platforms. Nurses and consultants in participating NHS clinic sites approached eligible patients during their HIV care appointments. We aimed to invite clinics and support organisations from all areas of the country as well as third sector organisations that serve clients outside the field of HIV. Ethical approval was gained from the Brighton and Sussex NHS Research Ethics Committee. Responses were stored securely and analysed at Public Health England in accordance with the Data Protection Act 1998.

The survey was either undertaken in the clinic using iPads, or the participants could choose to complete the survey online in their own time. Participants were informed that the survey would take approximately 20 to 40 minutes to complete and the median completion time was 28 minutes. Participants were also informed that the survey features some sensitive questions and therefore could complete it in the privacy of their own home online. Participants completed the survey independently and therefore the survey respondents were limited to those with a proficiency of the English language or who could source a formal or informal interpreter for assistance.

#### Procedure

The survey researched many aspects of HIV-related stigma, but this research will focus specifically on stigma in social settings and sexual rejection. For questions about stigma in social settings, participants were asked if they had worried about, avoided or experienced discrimination across various social settings in the past 12 months, and then asked to rate how much this was related to their HIV on a scale of 1-100. Worrying about, avoiding and experiencing discrimination were chosen to reflect internalised, anticipated, or experienced stigma. A score greater than or equal to 50 was considered to be HIV related. This was chosen because HIV was therefore the main factor contributing to the participants' experience of stigma and/or discrimination.

To control for internalized HIV-stigma, self-image in relation to participants' HIV status was measured. Participants were asked to rate nine statements about their HIV in the last 12 months (see Table 2), some of which overlap with the Beck Depression Inventory (Beck, Steer, & Brown, 1996), a widely used, 21-question multiple-choice, self-report inventory for measuring the severity of depression. An overall 'self-image' composite score was generated based on all nine questions: a "yes" answer to a question about positive feelings was given a value of -1 and a not sure -0.5, a "yes" answer to a question about negative feelings a value of 1, and a "not sure" of 0.5. Scores ranged from -4 to 5, where positive scores were related to poorer self-image. We used the mid-point score of 1 or below to indicate a poor self-image. Sensitivity analyses were conducted using different cut-offs.

Men who have sex with men were identified from participants who identified as male or trans male and selected men or trans men from the gender of their sexual partners, regardless of whether other genders were also selected. The vast majority (94%) of this group reported exclusively having sex with men, and are therefore referred to as 'gay men' in this

study. Heterosexual men were identified from participants who selected male or trans male from the gender identity question, and only selected women when asked the gender of their sexual partners.

Descriptive analyses of reported experiences in social settings were conducted using chi-square tests, and a multivariate logistic regression was used to explore the association of sociodemographic and well-being factors with reporting experiencing sexual rejection in relation to HIV status in the past 12 months.

#### Results

In total there were 1,908 responses to the survey, 273 were excluded as the respondent did not fulfil the entry criteria (e.g. did not consent, under the age of 18, not living with HIV, living outside of the UK or previously completed the survey). There were 59 respondents who were excluded from the survey as they did not answer any questions about experiences of stigma. In the final dataset there were 1,576 responses included in the survey analyses. Of these, 1,162 were from male respondents who were included in the analyses presented here.

The demographics for the 969 gay and 193 heterosexual men who took part in the study are displayed in Table 1. The mean age of gay men was 44 years old (range 18-78), 82% were of white ethnicity, had been diagnosed with HIV for a median of 9 years (95% CI 7-9 years), and 92% were currently on ART. This is compared to a mean age of 47 years (range 18-82) for heterosexual men, 32% of white ethnicity, diagnosed with HIV for a median of 8 years (95% CI 6-11 years), and 94% were currently on ART. Most other demographic details were similar for the two groups with notable exceptions being that gay men were more likely to report being single (50% vs. 31%), engaging in chemsex in the past 12 months (25% vs. 1%), and keeping up with bills (46% vs. 31%) compared to heterosexual men. Gay men were also more likely to have a poor self-image in relation to HIV compared

to heterosexual men (40% vs. 25%). A breakdown of the variables determining the selfimage score can be seen in Table 2. Over half of the participants were recruited through NHS clinics (52%) with fewer gay men reported being recruited through NHS clinics than heterosexual men (47% vs. 72%). Table 1. Demographic and social characteristics of participants.

	Gay mer	n (n=969)	Heterosexual men (n=193)		
Variable	N	%	Ν	%	
Age group***					
18-24	21	2%	6	3%	
25-34	171	18%	14	7%	
35-50	492	51%	89	46%	
>50	252	26%	63	33%	
missing	33	3%	21	11%	
Ethnicity***					
White	798	82%	62	32%	
Other ethnicity	170	18%	130	67%	
missing	1	0%	1	1%	
Relationship status***					
Living with a partner	350	36%	93	48%	
In a relationship, living separately	115	12%	38	20%	
Relationship with >1 partner	19	2%	2	1%	
No relationship/single	483	50%	59	31%	
missing	2	0%	1	1%	
Ever engaged in chemsex***	391	40%	23	12%	
In the past 12 months***	243	25%	7	1%	
Ever injected drug use**	177	18%	18	9%	
In past 12 months***	68	7%	1	1%	
Ever been paid for sex***	170	18%	6	3%	
In the last 12 months*	31	3%	1	1%	
Employment status***					
Full time	546	51%	87	42%	
Part time	100	9%	17	7%	
Retired	79	7%	10	7%	
Unemployed	92	9%	37	17%	
Sick/disabled	92	18%	16	14%	
Other	60	6%	26	13%	
Living locale size*					
Large town or city	723	75%	147	76%	
Town	200	21%	32	17%	
Rural area	45	5%	11	6%	
Missing	1	0%	3	2%	
Financial hardship***					
keeping up with bills	441	46%	60	31%	
keeping up but struggling	432	45%	101	52%	
fallen behind on some or many bills	93	10%	25	13%	
missing	3	0%	7	4%	
Going short of food**					
Never	703	73%	122	63%	
Sometimes	178	18%	58	30%	
Often	88	9%	13	7%	
Health					
Year diagnosed*					
In the last year	86	9%	16	8%	
2010-2014	254	26%	44	23%	
2005-2009	239	25%	44	23%	
2000-2004	155	16%	45	23%	
More than 15 years ago	225	23%	38	20%	
missing	10	1%	6	3%	
Ever diagnosed mental health condition***1					
Yes	499	52%	41	21%	
No	356	37%	127	66%	
missing	114	12%	25	13%	
Current disability <sup>2</sup>			-		
	010	220/	20	170/	
Yes	219	23%	32	17%	
No	717	74%	154	80%	
missing	33	3%	7	4%	

<sup>&</sup>lt;sup>1</sup> Depression, anxiety, bipolar-disorder, post-traumatic stress disorder, psychosis, or schizophrenia <sup>2</sup> Learning, behavioural, emotional, hearing, visual, speech, or mobility

In the last 12 months have you experienced any of the following feelings in relation to your	Gay men (n=969)		Heterosexual men (n=193)	
HIV status?	Yes	%	Yes	%
Shame***	489	50%	70	36%
Guilt	450	46%	82	42%
In control of your health***	560	58%	137	71%
Blaming yourself	469	48%	86	45%
Blaming others	203	21%	34	18%
Positive about the future	591	61%	129	67%
Positive about life	598	62%	131	68%
Low self-esteem***	512	53%	58	30%
As good as anyone else*	540	56%	129	67%
Overall poor self-image score***	386	40%	49	25%

Table 2. Reported feelings in relation to living with HIV among participants.

Statistical difference between gay and heterosexual men.

\*\*\*p<0.001

In the past 12 months, a high proportion of all men reported worrying about and experiencing HIV-related stigma and discrimination or avoiding situations because of fear of HIV stigma (Figure 1). Compared to heterosexual men, gay men were more likely to report worrying about workplace treatment in relation to their HIV (21% vs. 11%), worrying about HIV-related sexual rejection (42% vs 21%), avoiding sex because of their HIV status (37% vs. 23%), and experiencing HIV-related sexual rejection (27% vs. 9%). Additionally, other factors besides HIV status contributed to the difference in worrying about, avoiding and experiencing social situations, because overall gay men were more likely to report worrying about, avoiding or experiencing these social situations than heterosexual men.

<sup>\*</sup> p <0.05

<sup>\*\*</sup>p<0.01

Figure 1. Participants' HIV related and other experiences of stigma and discrimination in social settings in the past 12 months.

Statistical difference between gay and heterosexual men related to HIV status. p<0.01\*\*p<0.001

Due to the high proportion of men experiencing HIV-related sexual rejection in the past 12 months, a multivariate logistic regression analysis to investigate what sociodemographic factors contribute to reporting this experience in the past 12 months was conducted (Table 3). Being gay, not in a relationship, falling behind on some or many bills, and having a poor self-image in relation to HIV were independent predictors of men reporting HIV-related sexual rejection in the past 12 months. Being aged greater than 50 was a protective factor against reporting HIV-related sexual rejection in the past 12 months. This multivariate was repeated for reported sexual rejection, regardless of whether this was attributed to HIV status, with the same predictors and protective factors of sexual rejection, with the addition of being aged 18-24 as a protective factor (aOR 0.25, CI 0.08, 0.75) and engaging in chemsex in the past 12 months as an independent predictor (aOR 1.63, CI 1.11, 2.52).

Because 93% (258/276) of all men who experienced HIV-related sexual rejection in the past 12 months were gay, and being gay was associated with HIV-related sexual rejection, we conducted a multivariate logistic regression to identify predictors of HIV-related sexual rejection among gay men specifically. Again, this had the same predictors of HIV-related sexual rejection, with the addition of engaging in chemsex in the past 12 months (aOR 1.52, CI 1.03, 2.26), and having a poor self-image was no longer a predictor.

					Univariate	Adjusted model	
	Reported HIV-related sexual			-related sexual		<i>d</i>	
	Total (n=1,162)		rejection		OR (95% CI)	aOR (95% CI)	
	n	% <sup>3</sup>	n	% <sup>4</sup>			
Sexuality							
Gay men	969	83%	258	27%	3.53 (2.13, 5.85)***	2.17 (1.16, 4.02)*	
Heterosexual men	193	17%	18	9%	ref.	ref.	
Age group				2.10			
18-24	27	2%	4	15%	0.44 (0.15, 1.30)	0.34 (0.10, 1.12)	
25-34	185	16%	54	29%	1.05 (0.73, 1.51)	0.86 (0.56, 1.32)	
35-50	581	50%	164	28%	ref.	ref.	
>50	315	27%	47	15%	0.45 (0.31, 0.64)***	0.57 (0.37, 0.86)**	
Missing	54	5%	7	13%			
Ethnicity		*		- / -			
White British or Irish	860	74%	217	25%	ref.	ref.	
BAME	300	26%	59	20%	0.73 (0.52, 1.00)	0.93 (0.62, 1.40)	
Missing	2	0%	0	0%			
Relationship status							
Living with a husband, wife or partner	443	38%	68	15%	ref.	ref.	
In a relationship with a partner, not living together	153	13%	30	20%	1.35 (0.84, 2.16)	1.49 (0.87, 2.53)	
In relationships with more than one partner	21	2%	5	24%	1.72 (0.61, 4.86)	1.71 (0.53, 3.58)	
No relationship and/or single	542	47%	173	32%	2.59 (1.89, 3.54)***	2.24 (1.56, 3.21)***	
Missing	3	0%	0	0%			
Engaging in chemsex (past 12 months)							
Yes	250	22%	89	36%	2.14 (1.58, 2.91)***	1.47 (1.00, 2.17)	
No	912	78%	187	21%	ref.	ref.	
Injecting drug use (past 12 months)							
Yes	69	6%	25	36%	1.91 (1.14, 3.18)*	1.10 (0.59, 2.05)	
Not reported	1,093	94%	251	23%	ref.	ref.	
Been paid for sex (past 12 months)							
Yes	32	3%	13	41%	2.26 (1.10, 4.63)*	1.27 (0.54, 2.98)	
Not reported	1,130	97%	263	23%	ref.	ref.	
Employment status							
Full time	633	54%	158	25%	ref.	ref.	
Part time	117	10%	24	21%	0.78 (0.48, 1.26)	0.72 (0.41, 1.24)	
Casual	13	1%	1	8%	0.25 (0.03, 1.94)	0.20 (0.02, 1.76)	
Retired	89	8%	11	12%	0.43 (0.22, 0.82)*	0.67 (0.32, 1.41)	
Unemployed	129	11%	40	31%	1.35 (0.89, 2.04)	0.99 (0.60, 1.65)	
Sick or disabled	108	9%	30	28%	1.16 (0.73, 1.83)	0.86 (0.50, 1.64)	
Carer	4	0.3%	1	25%	1.00 (0.10, 9.70)	0.53 (0.04, 5.82)	
Student	15	1%	4	27%	1.09 (0.34, 3.48)	1.90 (0.49, 7.38)	
Volunteering	21	2%	4	19%	0.71 (0.23, 2.13)	0.46 (0.13, 1.55)	
Missing	33	3%	3	9%			

### Table 3. A multivariate analysis of predictors of reported HIV-related sexual rejection in the past 12 months.

<sup>3</sup> Column percentage <sup>4</sup> Row percentage

Living locale size						
Large town or city	870	75%	217	25%	ref.	-
Town	232	20%	47	20%	0.76 (0.54, 1.09)	-
Rural area	56	5%	12	21%	0.82 (0.43, 1.58)	-
Missing	4	0%	0	0%		
Financial commitments						
keeping up with bills	501	43%	97	19%	ref.	ref.
keeping up but struggling	533	46%	130	24%	1.34 (1.00, 1.81)	1.34 (0.94, 1.92)
fallen behind on some or many bills	118	10%	49	42%	2.96 (1.93, 4.54)***	2.75 (1.61, 4.68)***
missing	10	1%	0	0%		
Year diagnosed						
In the last year	102	9%	32	31%	1.50 (0.91, 2.48)	-
2010-2014	298	26%	74	25%	1.09 (0.74, 1.59)	-
2005-2009	283	24%	66	23%	ref.	-
2000-2004	200	17%	52	26%	1.16 (0.76, 1.76)	-
more than 15 years ago	263	23%	51	19%	0.79 (0.52, 1.19)	-
nissing	16	1%	1	6%		
Ever mental health condition						
Yes	540	46%	158	29%	1.16 (0.87, 1.55)	-
No	483	42%	96	20%	ref.	-
missing	139	12%	22	16%		
Ever physical health condition						
Yes	617	53%	160	26%	1.12 (0.86, 1.47)	-
No	406	35%	94	23%	ref.	-
missing	139	12%	22	16%		-
Disability						
Yes	251	22%	70	28%	1.31 (0.96, 1.81)	-
No	871	75%	198	23%	ref.	-
missing	40	3%	8	20%		
Poor self-image						
Yes	435	37%	137	32%	1.94 (1.48, 2.56)***	1.45 (1.05, 2.00)*
No	727	63%	139	19%	ref.	ref.

\*\*\*\*p<0.001

#### Discussion

This is the first study to compare experiences of stigma and discrimination between gay and heterosexual men living with HIV in the UK, and to distinguish HIV-related experiences from other types of stigma and discrimination. All men reported high levels of stigma and discrimination, but gay men were more likely to report worrying about, and experiencing stigma and discrimination across various social settings in the past 12 months, in particular HIV-related sexual rejection. They were also more likely to avoid sex because of their HIV status. Being gay was a strong predictor of reported HIV-related sexual rejection in the past 12 months which suggests greater levels of HIV stigma within the gay community. This is in line with previous research which examined HIV-related stigma within the gay community (Smit et al., 2012) (Bourne et al., 2009). Although this finding is contradictory to that found in Australia (Brener et al., 2013), this study did not control for higher reporting of HIV-stigma among women. In terms of general reporting of HIV stigma, our results contradict similar research in Canada, where stigma was reported more among heterosexuals even when controlling for gender (Emlet et al., 2015). However, the differences could be due to cultural differences between Canada and the UK, or due to the additional use of community organisations involved in our recruitment method, so participants did not necessarily have to be engaging in care to be involved.

An alternate explanation could be that, compared to heterosexual men, gay men have more tools at their disposal to meet potential sexual partners such as hook-up apps (Lehmiller & Ioerger, 2014) and to disclose their HIV status, and are therefore more likely to face rejection due to a greater frequency of meeting potential sexual partners. Number of sexual partners, or potential partners, in the past 12 months was not collected in this survey to control for this. However, the suggestion of negative attitudes among gay men towards other gay men living with HIV is in agreement with previous research (Hickson et al., 2016).

Age was a protective factor against reporting HIV-related sexual rejection for those aged over 50, which could be due to a lower frequency of potential sexual partners in this age group. Not being in a relationship was a predictor of reporting HIV-related sexual rejection, possibly because those that are in a relationship have a partner that is supportive and knowledgeable about their HIV status, but also because people not in a relationship are more likely to be meeting multiple sexual partners. Having a poor self-image in relation to HIV was a significant predictor of HIV-related sexual rejection, which could be related to internalized stigma, or having a poorer self-image could be due to sexual rejection experienced. Engaging in chemsex in the past 12 months was a significant predictor of HIV-related was conducted amongst gay men only, as those who reported engaging in chemsex were mostly gay men. Additionally, engaging in chemsex was a significant predictor for all men when conducting predictors of sexual rejection, regardless of attributing sexual rejection to HIV status, suggesting this is a further stigmatising behaviour in terms of sexual rejection.

A strength of this research is that the StigmaSurvey UK 2015 was conducted with community involvement, allowing people living with HIV to be involved with the design of the survey, collection, and dissemination of the results. Furthermore, the StigmaSurvey UK 2015 was demographically representative of people living with HIV in the UK (Crenna-Jennings et al., 2018).

A limitation of this research is that it did not collect data pertaining to the individual community organisations from which the participants were recruited. However, the demographic breakdown of men who took part in the study largely reflected the demographic of those attending for HIV care in the UK (Crenna-Jennings et al., 2018). Another limitation is that it is difficult to separate the interlinked stigmatising factors experienced by people living with HIV. In an attempt to overcome this, a multivariate analysis was conducted to

separate these factors. Additionally, when HIV was not the main contributing factor to reporting stigma, a list of other possible attributions such as sexuality, gender identity and race, were made available to participants. However, due to the complex nature of discrimination, and high association of gay men with HIV, it would be easy to misattribute the cause to be HIV-related when it could be homophobic and vice versa. Choosing sexual rejection as the main outcome variable helped overcome this as sexual rejection between two men is much more unlikely to be due to homophobia. Furthermore, our research could be subject to recall and selection bias due to the self-selected sample, and may not be truly representative of all men living with HIV. However, that should not diminish the finding that these experiences were still reported, and stigma still exists for these individuals, despite successful treatment and low probability of onward transmission.

In conclusion, Gay and heterosexual men living with HIV experience high levels of stigma and discrimination, especially in reference to sexual rejection by potential HIVnegative partners. Health outcomes for people living with HIV in the UK are excellent, and those who are on treatment and virally suppressed are at a very low risk of further transmission. However, stigma and discrimination can impact on mental health and wellbeing for people living with HIV, and our research suggests sexual prejudice towards men living HIV exists, particularly among gay men, despite there being a minimal risk of transmission. We suggest educating the general population, and in particular the gay community, about the clinical benefits of antiretroviral therapy and the low risk of transmission among those on treatment may help to reduce fear of transmission, and therefore sexual prejudice and stigma towards people living with HIV. Other strategies to reduce stigma in social and professional settings should also be developed and implemented.

#### **Disclosure statement**

No potential conflicts of interest.

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