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Experiences of stigma and discrimination in social and healthcare settings among trans people living with HIV in the UK

The People Living with HIV StigmaSurvey UK 2015 was a community led national survey investigating experiences of people living with HIV in the UK in the past 12 months. Participants aged 18 and over were recruited through over 120 cross-sector community organisations and 46 HIV clinics to complete an anonymous online survey. Trans is an umbrella term which refers to individuals whose current gender identity is different to the gender they were assigned at birth. Trans participants self-identified via gender identity and gender at birth questions. Descriptive analyses of reported experiences in social and health care settings were conducted and multivariate logistic regression analyses were used to identify sociodemographic predictors of reporting being treated differently to non-HIV patients, and being delayed or refused healthcare treatment in the past 12 months. 31 out of 1576 participants (2%) identified as trans (19 trans women, 5 trans men, 2 gender queer/non-binary, 5 other). High levels of social stigma were reported for all participants, with trans participants significantly more likely to report worrying about verbal harassment (39% vs. 23%), and exclusion from family gatherings (23% vs. 9%) in the last 12 months, compared to cisgender participants. Furthermore, 10% of trans participants reported physical assault in the last 12 months, compared to 4% of cisgender participants. Identifying as trans was a predictor of reporting being treated differently to non-HIV patients (48% vs. 30%; aOR 2.61, CI 1.06, 6.42) and being delayed or refused healthcare (41% vs. 16%; aOR 4.58, CI 1.83, 11.44). Trans people living with HIV in the UK experience high levels of stigma and discrimination, including within healthcare settings, which is likely to impact upon health outcomes. Trans-specific education and awareness within healthcare settings could help to improve service provision for this demographic.

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Introduction

Trans is an umbrella term that refers to people who do not identify with their assigned gender and/or traditional culturally bound male-female gender binary (e.g. transgender, trans male, trans female, gender queer/ non-binary)(Sevelius, Schelm, & Giambrone, 2015). The term 'cisgender' refers to people who identify with the gender they were assigned at birth. The prevalence of trans people in the UK remains unknown, but is likely to be similar to other high income countries such as the USA, where an estimate 0.6% of the population self-identifies as transgender (Flores, Herman, Gates, & Brown, 2016).

Globally, trans people face many forms of stigma and discrimination related to both gender identity and expression (T. Poteat et al., 2015), and as a result are at greater risk of mental health issues, physical abuse, social isolation and economic hardship (Herbst et al., 2008). Trans people, especially trans women, are also more vulnerable to HIV acquisition, although reliable data on the prevalence of HIV in this population is inconsistent (T. C. Poteat, Keatley, Wilcher, & Schwenke, 2016). However, a systematic review and meta-analysis estimated that the worldwide HIV prevalence among trans women was 19.1% (Baral et al., 2013). Research has suggested that over 60% of trans men identify as men who have sex with men (MSM) (Bauer, Redman, Bradley, & Scheim, 2013), but their inclusion in HIV epidemiology is relatively limited (T. Poteat, Scheim, Xavier, Reisner, & Baral, 2016).

In this study we report on the experiences of stigma and discrimination of people living with HIV in the UK in 2015 in a variety of social and healthcare settings.

Methods

The People Living with HIV StigmaSurvey UK 2015 recruited participants from over 120 community organisations and 46 NHS clinics across the UK. Participants were UK residents living with HIV, and aged 18 or older. 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 overall survey covered many aspects of HIV-related stigma, and detailed methodology has been previously reported (Crenna-Jennings et al., 2017) (Hibbert et al., 2017). Trans participants self-identified by utilising an adapted two-stage method of gender identity monitoring (Sausa, Sevelius, Keatley, Rouse Iñiguez, & Reyes, 2009) which included a question on current gender identity ("I am: male, female, trans male, trans female, gender queer/non-binary, Prefer not to say, Other") and a second question on gender at birth ("What sex were you assigned at birth? Male, Female, Prefer not to say"). Cisgender participants were those whose current gender identity was the same as their sex assigned at birth. Trans participants were those who had a different gender than their gender assigned at birth, or who identified as trans male, trans female, gender queer/non-binary, or other. Participants who responded 'prefer not to say' were not included.

Descriptive analyses of reported experiences in social and health care settings were conducted stratified by gender identity. Multivariate logistic regression analyses were performed to explore the association of sociodemographic factors with reporting being treated differently and feeling refused treatment in healthcare settings in the last 12 months. These analyses excluded the responses to 'worrying about being treated differently' and 'avoiding care when needed' due to their high correlation with the outcome variables. All statistical analysis was conducted in STATA 13.1 (StataCorp, Texas, USA).

Results

Of the 1,576 people who participated in the survey, 31 participants self-identified as trans (19 trans women, 5 trans men, 2 gender queer/non-binary, and 5 other). These 31 participants were grouped for these analyses and are referred to as 'trans'. Four participants did not disclose a gender, and were therefore not included in the analyses. Table 1 displays a breakdown of demographics for cisgender and trans participants. Notably, there were significant differences in injecting drug use and being paid for sex between trans and cisgender participants.

Table 1. Participant demographics.

	Cisgender (n=1,541)		Trans (n=31)	
Variable	**N**	**%**	**N**	**%**
Gender				
Women	359	23%	19	61%
Men	1,182	77%	5	16%
Gender queer / non-binary	-	-	2	6%
Other	-	-	5	16%
Age group				
18-24	37	2%	2	6%
25-34	237	15%	3	10%
35-50	782	51%	15	48%
>50	401	26%	6	20%
Missing	84	5%	5	16%
Ethnicity*				
White British or Irish	973	63%	15	48%
Other ethnicity	565	37%	15	48%
Missing	3	0%	1	3%
Sexuality***				
Men who have sex with men (MSM) / gay	966	63%	4	13%
Heterosexual	523	34%	14	45%
Other or preferred not to say	52	3%	13	42%
Relationship status***				
Living with a partner	554	36%	13	42%
In a relationship, living separately	240	16%	6	19%
Relationship with >1 partner	21	1%	5	16%
No relationship/single	723	47%	5	16%
Missing	3	0%	2	6%
Ever injected drug use*	207	13%	9	29%
in the past 12 months	*69*	*4%*	*2*	*6%*
Ever been paid for sex***	186	12%	12	39%
*in the last 12 months****	*31*	*2%*	*4*	*13%*
Financial hardship in the last 12 months**				

keeping up with bills	632	41%	10	32%
keeping up but struggling	714	46%	15	48%
fallen behind on some or many bills	182	12%	2	6%
Missing	13	1%	4	13%
Health				
Year diagnosed*				
In the last year	123	8%	0	0%
2010-2014	360	23%	7	23%
2005-2009	390	25%	10	32%
2000-2004	298	19%	4	13%
More than 15 years ago	340	22%	6	19%
Missing	30	2%	4	13%
Ever diagnosed mental health condition[1]				
Yes	691	45%	14	45%
No	676	44%	10	32%
Missing	174	11%	7	23%
Current disability[2]				
Yes	325	21%	5	16%
No	1,167	76%	24	77%
Missing	49	3%	2	6%
Poor self-image in relation to HIV				
Yes	565	37%	11	35%
No	976	63%	20	65%

Statistical difference between trans and cisgender people.

* p <0.05

**p<0.01

***p<0.001

Experiences of stigma and discrimination in social settings

Compared to cisgender people, trans participants were significantly more likely to report worrying about verbal harassment, having agreed a job change with their manager, and exclusion from family gatherings in the last 12 months (Figure 1).

[1] Depression, anxiety, bipolar-disorder, post-traumatic stress disorder, psychosis, or schizophrenia

[2] Learning, behavioural, emotional, hearing, visual, speech, or mobility

Notably, 10% of trans participants reported physical assault in the last 12 months, compared to 4% of cisgender participants.

Figure 1. Trans and cisgender participants' experiences of stigma and discrimination in social settings in the past 12 months.

Statistical difference between trans and cisgender people.

* p <0.05

**p<0.01

Experiences of stigma and discrimination in the healthcare setting

Compared to cisgender participants, trans participants were significantly more likely to avoid care, report being treated differently to non-HIV patients, and feeling delayed or refused treatment across healthcare settings in the past 12 months (Figure 2). In the past 12 months, trans participants were also significantly more likely to report; hearing negative comments about people living with HIV from healthcare workers; being given the last appointment of the day not by choice; and report disclosure of their HIV status without their consent from a health care worker to another healthcare worker (38% vs 16%, $p < 0.001$), or to a member of the public (21% vs 7%, $p < 0.01$).

Figure 2. Comparison of healthcare experiences in the last 12 months between trans and cisgender participants.

Statistical difference between trans and cisgender people.

* p <0.05

**p<0.01

***p<0.001

Multivariate analyses were conducted to determine sociodemographic predictors associated with reporting being treated differently to non-HIV patients, and feeling delayed or refused treatment in the past 12 months (Table 2). Identifying as trans, facing financial hardship, and having a negative self-image in relation to HIV were the strongest predictors of participants reporting being treated differently across healthcare settings. Additionally, identifying as trans, having another ethnicity, facing financial hardship, and having a negative self-image in relation to HIV were the strongest predictors of participants reporting feeling delayed or refused across healthcare setting.

Table 2. A multivariate analysis of predictors of participants reporting being treated differently or feeling refused treatment across healthcare settings in the last 12 months.

					Univariate	Adjusted model†			Univariate	Adjusted model†
	Total (n=1,528)		**Reported treated differently to non-HIV patients**		**OR (95% CI)**	**aOR (95% CI)**	**Felt refused treatment**		**OR (95% CI)**	**aOR (95% CI)**
	n	**%**	**n**	**%**			**n**	**%**		
Age group										
<=24	36	2%	8	22%	0.54 (0.24, 1.22)	0.52 (0.22, 1.22)	7	19%	1.11 (0.47, 2.61)	1.23 (0.49, 3.09)
25-34	229	15%	64	28%	0.69 (0.50, 0.96)*	0.73 (0.52, 1.05)	37	16%	0.84 (0.56, 1.24)	0.91 (0.59, 1.40)
35-50	785	51%	274	35%	ref.	ref.	143	18%	ref.	ref.
>50	401	26%	97	24%	0.58 (0.44, 0.76)***	0.56 (0.41, 0.76)***	54	13%	0.69 (0.49, 0.97)*	0.66 (0.44, 0.97)*
Missing	77	5%	24	31%	1.13 (0.66, 1.94)	0.88 (0.49, 1.59)	13	17%	1.25 (0.65, 2.39)	0.91 (0.45, 1.87)
Gender										
Cisgender	1,496	98%	453	30%	ref.	ref.	241	16%	ref.	ref.
Trans	29	2%	14	48%	2.95 (1.30, 6.69)**	2.61 (1.06, 6.42)*	12	41%	4.79 (2.13, 10.79)***	4.58 (1.83, 11.44)**
Missing	3	0%	0	0%			1	33%	2.39 (0.21, 26.50)	
Ethnicity										
White British or Irish	969	63%	268	28%	ref.	ref.	132	14%	ref.	ref.
Other ethnicity	555	36%	197	36%	1.58 (1.26, 1.98)***	1.27 (0.95, 1.68)	122	22%	1.98 (1.50, 2.60)***	1.90 (1.34, 2.68)***
Missing	4	0%	2	50%	4.92 (0.44, 54.46)	3.80 (0.32, 45.37)		0%		
Sexuality										
MSM/gay	952	62%	262	28%	ref.	ref.	143	15%	ref.	ref.
Heterosexual	513	34%	181	35%	1.51 (1.20, 1.91)**	1.29 (0.96, 1.74)	94	18%	1.36 (1.02, 1.81)*	0.92 (0.63, 1.34)
Other	63	4%	24	38%	1.78 (1.03, 3.07)*	1.47 (0.77, 2.81)	17	27%	2.38 (1.31, 4.33)**	1.36 (0.65, 2.81)
SES										
Employment status										
Full time	767	50%	216	28%	ref.	ref.	108	14%	ref.	ref.
Part time	183	12%	55	30%	1.05 (0.73, 1.49)	0.84 (0.57, 1.24)	33	18%	1.30 (0.84, 2.00)	0.98 (0.61, 1.56)
Retired	68	4%	15	22%	0.77 (0.42, 1.42)	1.14 (0.58, 2.24)	8	12%	0.89 (0.41, 1.94)	1.30 (0.56, 3.04)
Other (casual, unemployed, student)	510	33%	181	35%	1.52 (1.19, 1.94)**	0.96 (0.71, 1.30)	105	21%	1.68 (1.25, 2.27)**	0.91 (0.63, 1.31)
Living locale size										
Large town or city	1,143	75%	348	30%	ref.		195	17%	ref.	
Town	308	20%	94	31%	0.93 (0.71, 1.23)		45	15%	0.78 (0.55, 1.12)	
Rural area	71	5%	25	35%	1.16 (0.70, 1.93)		14	20%	1.12 (0.61, 2.05)	

Missing	6	0%	0	0%			0	0%		
Financial commitments										
keeping up with bills	627	41%	140	22%	ref.	ref.	65	10%	ref.	ref.
keeping up but struggling	711	47%	240	34%	1.77 (1.38, 2.26)***	1.50 (1.15, 1.96)**	133	19%	1.98 (1.44, 2.72)***	1.58 (1.12, 2.23)*
fallen behind on some or many bills	179	12%	85	47%	3.40 (2.37, 4.87)***	2.53 (1.70, 3.78)***	55	31%	4.10 (2.71, 6.22)***	2.85 (1.80, 4.53)***
missing	11	1%	2	18%	1.28 (0.25, 6.67)	0.77 (0.13, 4.67)	1	9%	1.60 (0.18, 13.88)	0.66 (0.05, 8.09)
Health										
Year diagnosed										
In the last year	121	8%	27	22%	0.60 (0.37, 0.97)*	0.57 (0.34, 0.95)*	13	11%	0.53 (0.28, 1.00)	0.50 (0.26, 0.98)*
2010-2014	360	24%	103	29%	0.85 (0.62, 1.16)	0.85 (0.60, 1.19)	55	15%	0.82 (0.55, 1.21)	0.82 (0.54, 1.25)
2005-2009	388	25%	122	31%	ref.	ref.	69	18%	ref.	ref.
2000-2004	297	19%	102	34%	1.17 (0.84, 1.42)	1.12 (0.79, 1.59)	52	18%	1.02 (0.68, 1.53)	1.00 (0.65, 1.54)
More than 15 years ago	343	22%	109	32%	1.00 (0.73, 1.38)	1.10 (0.77, 1.56)	63	18%	1.02 (0.70, 1.50)	1.07 (0.70, 1.63)
missing	19	1%	4	21%	1.13 (0.33, 3.95)	0.91 (0.24, 3.47)	2	11%	1.06 (0.22, 5.11)	0.78 (0.14, 4.21)
Ever mental health condition										
Yes	691	45%	229	33%	1.16 (0.92, 1.46)	0.86 (0.65, 1.13)	134	19%	1.35 (1.02, 1.80)*	0.97 (0.70, 1.37)
No	661	43%	197	30%	ref.	ref.	99	15%	ref.	ref.
missing	176	12%	41	23%	0.71 (0.48, 1.05)	0.67 (0.44, 1.02)	21	12%	0.77 (0.46, 1.27)	0.76 (0.44, 1.30)
Ever physical health condition										
Yes	782	51%	257	33%	1.17 (0.92, 1.49)		137	17%	1.03 (0.77, 1.37)	
No	570	37%	169	30%	ref.		96	18%	ref.	
missing	176	12%	41	23%	0.72 (0.48, 1.07)		21	12%	0.66 (0.40, 1.10)	
PHQ2										
Low	1,091	71%	300	28%	ref.	ref.	147	13%	ref.	ref.
High	416	27%	163	39%	1.82 (1.43, 2.32)***	1.14 (0.85, 1.54)	104	25%	2.23 (1.68, 2.97)***	1.40 (0.99, 1.99)
missing	21	1%	4	19%	1.41 (0.41, 4.84)	1.35 (0.36, 5.11)	3	14%	2.25 (0.59, 8.57)	2.37 (0.55, 10.12)
Disability										
Yes	323	21%	118	37%	1.39 (1.07, 1.81)*	1.27 (0.92, 1.75)	75	23%	1.70 (1.25, 2.30)**	1.48 (1.02, 2.15)*
No	1,156	76%	340	29%	ref.	ref.	176	15%	ref.	ref.
missing	49	3%	9	18%	0.58 (0.28, 1.23)	0.69 (0.32, 1.51)	3	6%	0.41 (0.12, 1.33)	0.46 (0.14, 1.57)
Poor self-image										
Yes	556	64%	222	40%	2.09 (1.67, 2.63)***	2.02 (1.54, 2.65)***	126	23%	1.99 (1.51, 2.61)***	1.62 (1.17, 2.26)**
No	972	36%	245	25%	ref.	ref.	128	13%	ref.	ref.
Injecting drug use past 12 months										
Yes	69	5%	21	30%	0.96 (0.57, 1.64)		11	16%	0.92 (0.47, 1.78)	

No / Not reported	1,459	95%	446	31%	ref.	243	17%	ref.
Been paid for sex past 12 months								
Yes	34	2%	15	44%	1.85 (0.92, 3.75)	8	24%	1.55 (0.69, 3.49)
No / Not reported	1,494	98%	452	30%	ref.	246	16%	ref.

* p <0.05

**p<0.01

***p<0.001

† including age, gender, ethnicity, sexuality, employment status, financial commitments, year diagnosed, ever mental health condition, PHQ2, disability, poor self-image

Discussion

The findings indicate that trans people perceive and experience different levels of stigma and discrimination compared to their cisgender counterparts. Within healthcare settings, compared to cisgender participants, trans participants were more likely to report incidences of discrimination in healthcare, and in the multivariate analyses, identifying as trans was a predictor of reporting being treated differently to non-HIV patients, and feeling delayed or refused treatment. Not all stigma and discrimination faced by trans people was identified as HIV related. These findings are in agreement with previous studies not specific to HIV which indicated that trans people in the UK experience high levels of silent harassment (e.g. being started at, whispered about etc.), verbal harassment, and physical violence (McNeil, Bailey, Ellis, Morton, & Regan, 2012; T. Poteat et al., 2015).

Our findings highlighted several risk factors among trans people that increase the likelihood of HIV acquisition, such as a history of transactional sex and injecting drug use. Future sexual health promotion messages need to be trans inclusive to target this often overlooked population. Four out of five trans men in our research identified as MSM, which highlights the importance of the inclusion of trans men in sexual health promotion messages targeted at MSM.

In Canada and the USA, barriers for accessing care for HIV-positive trans people include a lack of appropriate skill, knowledge and training of healthcare providers (Bauer et al., 2009; Thornhill & Klein, 2010; Wilson et al., 2009). This research would suggest a similar problem in the UK in terms of accessing services, as identifying as trans was a significant predictor of participants reporting being treated differently compared to non-HIV patients, as well as being delayed or refused treatment in the last 12 months.

The sample of trans people in our study was small, and comparisons within the trans community could not be investigated. The experiences of stigma and discrimination reported by participants were self-reported and may be subject to recall bias and/or selection bias. There was no attempt to validate participants' responses, however, the fact that these experiences are reported suggests that people living with HIV continue to face stigma, regardless of whether it was experienced or anticipated. Additionally, this is the first study to measure the experiences of trans people living with HIV in the UK, and the project had community involvement throughout the questionnaire development, analysis and dissemination of results, to ensure representation of the communities involved.

Our findings call for increased awareness and training of healthcare staff around trans issues, and the inclusion of trans/non-binary issues in clinical training programmes. The level of complexity and the high prevalence of additional risk behaviours (higher rates of injecting drug use, experiences of transactional sex etc.) also highlight the need for health services working with trans people living with HIV to be able to work address multiple and complex needs.

Future research could further explore the interlinked factors leading to stigma and discrimination for trans people. Such research should be trans inclusive, not only because of the increased risk of HIV and other sexual health issues within the community, but also to further advance trans rights and promote greater understanding and representation of trans people in the wider community. Trans people should be included in all areas of research where gender information is collected, so that trans experiences are acknowledged, and results can then be used to further structural changes which will result in greater societal inclusion.

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